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Pepperdine University  
Graduate School of Education and Psychology

FAMILY EXPERIENCES WITH ACCESSING INFORMATION, SOCIAL, AND  
RESOURCE SUPPORTS AS PARTICIPANTS IN SERVICES FOR THEIR SPECIAL  
NEEDS CHILD OVER THREE YEARS OF AGE

A dissertation submitted in partial satisfaction  
of the requirements for the degree of  
Doctor of Education in Organizational Leadership

by

Joannie Busillo-Aguayo

July 2010

Doug Leigh, Ph.D. – Dissertation Chairperson

This dissertation, written by

Joannie Busillo-Aguayo

under the guidance of a Faculty Committee and approved by its members, has been submitted to and accepted by the Graduate Faculty in partial fulfillment of the requirements for the degree of

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## TABLE OF CONTENTS

	Page
LIST OF TABLES.....	ix
LIST OF FIGURES .....	x
DEDICATION.....	xi
ACKNOWLEDGEMENTS.....	xii
VITA.....	xiv
ABSTRACT.....	xvi
CHAPTER 1: INTRODUCTION.....	1
Background .....	1
Effects of Child Disability on Family .....	3
Family Stress .....	4
Family Coping and Adaptation .....	5
Family Support Needs.....	8
Barriers to Support .....	9
Information Support .....	11
Social Support .....	11
Resources Support.....	13
Family-Centered Practices .....	13
Systems Perspective of Development .....	16
Investigated Program.....	19
Family and Parent Support Services .....	21
Assessing Family Needs.....	22
Statement of Problem .....	23
Purpose of Study .....	25
Research Questions and Objectives .....	27
Operational Definitions .....	28
Importance of Study .....	32
Assumptions of the Study.....	33
Limitations of the Study.....	34
Summary .....	35
CHAPTER 2: REVIEW OF LITERATURE.....	36
Historical Overview and Background .....	38
Compensatory Education Programs .....	38

	Page
Head Start .....	39
Perry Preschool Project .....	41
Chicago Child-Parent Centers .....	42
Carolina Abecedarian Project.....	42
Policies Regarding Special Needs Children and Families .....	44
Individuals with Disabilities Education Act.....	46
California Lanterman Act.....	47
Empirical Research: Early Intervention/Education.....	48
Theoretical and Conceptual Framework .....	51
Normative Development .....	53
Child Development.....	53
Role of Family .....	55
Systems Perspectives of Development.....	58
Developmental Systems Model.....	59
Family Systems Perspectives .....	63
Social Systems Perspectives.....	65
Ecological Systems Perspectives.....	67
Effects of Child's Special Needs on the Family .....	70
Stress.....	72
Coping and Adaptation.....	75
Family Support Needs.....	78
Information .....	79
Social Support .....	79
Resources.....	81
Family-Centered Practice.....	81
Desired Family Support Outcomes .....	84
Implications of Study .....	86
Summary .....	87
 CHAPTER 3: METHODS.....	 89
Research Design.....	93
Philosophical Perspectives .....	94
Constructivist.....	94
Advocacy/Participatory .....	95
Pragmatic.....	95
Phenomenological Approach .....	96
Population.....	98
Sampling Methods.....	98
Sample and Analysis Unit.....	99
Human Subjects.....	99
Respect .....	100

	Page
Beneficence .....	101
Justice .....	101
Informed Consent .....	101
Risk Minimization and Benefit Maximization .....	102
Anonymity .....	102
Confidentiality .....	103
Institutional Approvals .....	103
Data Collection Procedures .....	105
Participant Recruitment .....	105
Initial Screening .....	106
Instrument .....	107
Phase 1: Focus Group Interview Protocol .....	107
Empirical Support for Interview Protocol .....	109
Phase 2: Family Support Survey Protocol .....	113
Empirical Support for the Family Support Survey Tool .....	116
Expert Review and Field Testing of Instruments .....	118
Focus Group Interview Protocol Review .....	119
Family Support Survey Protocol Review .....	119
In-Depth Data Collection Process .....	120
Phase 1: Qualitative Data .....	121
Open-Ended Focus Group Interview .....	121
IE <sup>2</sup> SWOT Analysis: Steps One Through Three .....	122
Phase 2: Quantitative Data Collection .....	127
IE <sup>2</sup> SWOT Analysis: Step Four .....	127
Trustworthiness .....	129
Analytical Techniques .....	131
Data Analysis .....	132
Phase 1: Qualitative Data .....	132
Data Reduction .....	132
Analysis .....	132
Phase 2: Quantitative Data .....	133
IE <sup>2</sup> SWOT Analysis: Step Five .....	134
IE <sup>2</sup> SWOT Analysis Step Six .....	135
Summary .....	138
 CHAPTER 4: FINDINGS .....	 139
Introduction .....	139
Research Questions .....	139
Procedures .....	140
Participant Characteristics .....	141
Data Collection .....	143

	Page
Phase 1: Qualitative Data .....	144
Focus Group Interview .....	144
Phase 2: Quantitative Data Collection .....	146
IE <sup>2</sup> SWOT Matrix Analysis .....	146
Data Analysis .....	148
Transcription and Analysis of Qualitative Data .....	150
Clusters and Themes for Research Question 1 .....	150
Meanings of Parent’s Lived Experiences .....	150
Summary of Clusters and Themes for Research Question 1 .....	156
Clusters and Themes for Research Question 2 .....	158
Experiences with Accessing and Utilizing Information .....	159
Experiences with Accessing and Utilizing Social Support .....	162
Experiences with Accessing and Utilizing Resources .....	166
Summary of Clusters and Themes for Research Question 2 .....	168
Analysis of Quantitative Data .....	169
Research Question 3 .....	170
Research Question 4 .....	171
Strengths .....	172
Information Strengths .....	172
Social Support Strengths .....	173
Resources Strengths .....	174
Summary of Strengths .....	175
Weaknesses .....	177
Information Weaknesses .....	178
Social Support Weaknesses .....	179
Resources Weaknesses .....	180
Summary of Weaknesses .....	181
Opportunities .....	184
Information Opportunities .....	184
Social Support Opportunities .....	186
Resources Opportunities .....	187
Summary of Opportunities .....	188
Threats .....	191
Information Threats .....	192
Social Support Threats .....	193
Resources Threats .....	194
Summary of Threats .....	196
Summary for Research Question 3 and 4 .....	197
Research Question 5 .....	198
Hierarchical Cluster Analysis Results .....	198
Cluster Analysis Results: Strengths .....	199
Cluster Analysis Results: Weaknesses .....	203
Cluster Analysis Results: Opportunities .....	207

	Page
Cluster Analysis Results: Threats.....	212
Hierarchical Cluster Analysis Summary .....	216
IE <sup>2</sup> SWOT Matrix Analysis.....	217
Strengths Clusters.....	219
Weaknesses Clusters .....	222
Opportunities Clusters.....	227
Threats Clusters.....	234
Summary of IE <sup>2</sup> SWOT Matrix Analysis.....	238
 CHAPTER 5: DISCUSSION.....	 239
Findings.....	239
Findings for Research Question 1 .....	241
Period of Diagnosis .....	241
Effects on Marriage .....	242
Community Experiences .....	243
Empowerment.....	244
Interpersonal Well-Being .....	244
Adaptation, Benefit, Hopefulness.....	245
Future Needs.....	245
Conclusions and Implications for Research Question 1.....	246
Findings for Research Question 2 .....	247
Information .....	247
Social Support .....	250
Resources.....	251
Conclusions and Implications for Research Question 2.....	252
Findings for Research Question 3 and 4 .....	255
Strengths.....	256
Weaknesses.....	258
Opportunities.....	259
Threats .....	260
Conclusions and Implications for Research Questions 3 and 4 .....	261
Findings for Research Question 5 .....	262
Cluster Analysis and IE <sup>2</sup> Matrix.....	263
Strengths.....	264
Weaknesses.....	265
Opportunities.....	266
Threats .....	268
Conclusions and Implications for Research Question 5.....	269
Findings About the Utility of the IE <sup>2</sup> SWOT Matrix Analysis.....	270
Findings About Implications for Family Support .....	272
Meanings of Lived Experiences.....	272



	Page
Access and Utilization of Information .....	274
Access and Utilization of Social Support.....	276
Access and Utilization of Resources .....	277
Limitations.....	278
Contributions .....	280
Early Intervention/Education Field .....	280
Investigated Program.....	282
Family Support.....	283
Recommendations .....	284
Concluding Comments .....	286
REFERENCES .....	289
APPENDIX A: Research Questions .....	316
APPENDIX B: Informed Consent.....	317
APPENDIX C: Site Consent.....	320
APPENDIX D: Institutional Review Board (IRB) Approval.....	321
APPENDIX E: Recruitment Procedures.....	323
APPENDIX F: Phone Interview Script .....	325
APPENDIX G: Focus Group Interview Protocol.....	326
APPENDIX H: Family Support Survey Protocol.....	329
APPENDIX I: Expert Panel Review Procedures.....	332
APPENDIX J: Focus Group Interview Question and Administration .....	336
APPENDIX K: Family Support Survey Administration .....	338
APPENDIX L: Child Characteristics Questionnaire .....	339
APPENDIX M: Family Support Survey.....	340
APPENDIX N: Additional Dendrograms.....	370

## LIST OF TABLES

	Page
Table 1. Mixed Methods Data Collection .....	108
Table 2. Relationship Between Research Questions and Focus Group Interview Questions .....	109
Table 3. Focus Group Questions, Conceptualization, and Literature Source .....	113
Table 4. Relationship Between Research Questions and Family Support Survey .....	116
Table 5. Family Support Survey Theoretical and Conceptual Foundations .....	118
Table 6. Relationship Between IE2 SWOT Procedure and Data Collection and Analysis .....	123
Table 7. Research Questions and Analytical Techniques .....	131
Table 8. Child Characteristics .....	143
Table 9. RQ1: Meanings of Parents' Lived Experiences .....	157
Table 10. RQ 2: Experiences with Accessing and Utilizing Information, Social Support, and Resources .....	168
Table 11. Family Support Survey Results: SWOT Strengths .....	177
Table 12. Family Support Survey Results: SWOT Weaknesses .....	182
Table 13. Family Support Survey Results: SWOT Opportunities .....	189
Table 14. Family Support Survey Results: SWOT Threats .....	195
Table 15. Cluster Membership and Agglomeration Schedule: Strengths .....	202
Table 16. Cluster Membership and Agglomeration Schedule: Weaknesses .....	205
Table 17. Cluster Membership and Agglomeration Schedule: Opportunities .....	210
Table 18. Cluster Membership and Agglomeration Schedule: Threats .....	215

## LIST OF FIGURES

	Page
Figure 1. Sample of conventional SWOT matrix .....	127
Figure 2. Sample of IE2 SWOT matrix .....	136
Figure 3. Sample of IE2 SWOT matrix for family support .....	138
Figure 4. Cluster analysis dendrogram: Strengths .....	203
Figure 5. Cluster analysis dendrogram: Weaknesses.....	207
Figure 6. Cluster analysis dendrogram: Opportunities .....	212
Figure 7. Cluster analysis dendrogram: Threats .....	216
Figure 8. IE2 matrix grid and plotted SWOT factors .....	220

## DEDICATION

To my son Anthony, who has shown me the true meaning of the word *courage*. Many years ago, when he was still in high school, he had an assignment to write about someone who was his hero. He wrote that I was his hero because I stood up for him and made sure that he got all the support and help he needed. He was 16 years old at the time. However, like most parents of children with special needs, I have never thought of myself as anyone other than a parent who would do anything I could to help my son have the most satisfying quality of life that he desires and deserves.

Now that my son is almost 30 years old, I can say that he is *my* hero. He is my inspiration and the reason for my passion. He has brought meaning to my life and has led me to what has become my career and purpose in life: namely, to help individuals like my son and their families attain those resources and supports that will empower and enhance their lives.

With deep appreciation, I wish to thank all of the families who openly and honestly shared their stories. To all those families raising children with special needs, I hope others are inspired by your unwavering courage and stamina. It has been a privilege to share your experiences.

## ACKNOWLEDGEMENTS

So many individuals have made it possible for me to write this paper. My journey toward higher education started late in life, long after I was married with children. What started out as a few college classes soon became the goal of a Bachelor's degree, then a Masters, and ultimately my Doctorate; that was over 20 years ago. Although I may be the first in my family to achieve this level of formal education, I hope that I am not the last.

First, I want to thank my family, whose sacrifices, though I am sure not always willing, nonetheless made this achievement possible. My youngest son, Thomas has shared this journey of mine his entire life and I am grateful for his support and sacrifice. His father, Tom, was the first person who encouraged me to go back to school, and for that, I am forever indebted. My son Anthony, without you, this would never have been written. Many thanks to his father, Joe, for helping to keep my home in order so I could finish. My two daughters, Alisa and Adrienne grew up, became young women, and married during this period. From the time I began my doctorate program until now, my family has grown by three beautiful grandchildren, Kinslee, Madeline, and Beckham. Thank you for sharing your "Nana" and I am looking forward to having more time to just sit and enjoy you!

Dad, thank you for showing me that what we dream we can do. You have shown me that working hard does lead to success. Thank you for teaching me the lesson in life, that if it is worth doing at all, it is worth doing well.

Two people sadly, are not here to see this day. My mother, whose life was cut short, was the spark that started me on this journey. She always said, "Life is not a dress rehearsal, this is it." Thank you mom for this constant reminder to keep reaching for my

dreams. My husband, Ric, although he is not here physically, I feel his presence every day. I can still hear him say, “Get back to work distractoid.” Well I finally finished!

Thank you for your support and encouragement, then and now.

To my dissertation committee, words alone cannot express my deepest appreciation for your support and assistance. Thank you Kathy Church for your thoughtful comments and feedback. Your input and encouragement have been invaluable. Thank you Doug Leigh for taking me under your wing and being willing to chair my dissertation. From our first class together, you inspired me. You introduced me to a new way of thinking about education and work, which has become deeply ingrained in my own practice. I look forward to future collaborations with you.

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My deep and sincere appreciation and gratitude to each of you for helping me to achieve this monumental goal. I could not have done this without every one of you.

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## PUBLICATIONS

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Busillo-Aguayo, J. (2005). *Play with Purpose*. The Autism Perspective. No.1, Vol. 1. Spring 2005.

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## ABSTRACT

Families of children with special needs often experience substantial stress and an increased need for informational, social, or resource support throughout their child's growth and development. However, supports for families of children older than three often report a severe shortage of supports and difficulty accessing and utilizing them. Using purposive sampling techniques, this phenomenological and mixed methods study recruited 6 mothers of children over the age of 3 years diagnosed with autism spectrum disorder to participate in a single 2-hour focus group. Qualitative data was collected using open-ended and semi-structured questions to gain a deeper understanding of parent's lived experiences with obtaining supports and the meanings they make of these experiences. A content analysis of qualitative data identified 7 categories and themes: the period of diagnosis, effects on marriage, community experiences, feelings of empowerment, interpersonal well-being, adaptation, benefit, hopefulness, and child and family future needs. Families' statements were further categorized around four areas of influence referred to as SWOTs (strengths, weaknesses, opportunities, threats) and used to create a Likert-type Parent Support Survey questionnaire developed to quantitatively measure and compare participants' perceptions of experiences. Analysis and comparison of participants' group means ratings identified factors they perceived as helping or hindering their access to information, social support, and resources, as well as their attributions of control (internal or external) over these experiences. Analysis of similarities and differences among participants' responses using a Ward Hierarchical Analysis method identified those factors that "hang" together. Bivariate data of participants' group means ratings was plotted onto one of four SWOT quadrants of the

IE<sup>2</sup> SWOT Matrix Grid to visually illustrate factors perceived by parents as being strengths (internally controlled and enhancing), weaknesses (internally controlled and inhibiting), opportunities (externally controlled and enhancing), and threats (externally controlled and inhibiting). Multiple methods of collection and analysis (content analysis, numerical analysis, and graphical depiction) of participant responses provided a deeper understanding of those factors that are most helpful to families and therefore should be leveraged or exploited and those factors that act as barriers to family access to supports and should be confronted, mitigated or reduced.

## CHAPTER 1: INTRODUCTION

### Background

There are over 1million children in the United States under 5 years of age identified as having a disability, developmental delay, or a risk factor with a high probability of delay (U. S. Department of Education, 2006). In California there are over 36,000 children under 3 years of age receiving early intervention supports for developmental delays, disabilities, or risk factors associated with developmental delays (California Department of Developmental Services, 2008). The U.S. Department of Education, Office of Special Education Programs, reports that over 67,000 children between 3 and 5 years of age are currently receiving preschool special education services in California – a 70% increase from 1993 to 2006 (U.S. General Accounting Office, 2002).

It is estimated that 17% of all children have a special need associated with learning, developmental, or behavioral challenges that substantially affects their ability to engage in age appropriate activities (Centers for Disease Control and Prevention, 2006). While the prevalence rate of disabilities such as cerebral palsy, mental retardation, or seizure disorder have remained relatively stable, the rate of Autism Spectrum Disorder (ASD) is rapidly rising and is now the second most common developmental disability affecting children after mental retardation (Prevention, 2008). In California, the prevalence rate for autism spectrum disorders has grown over 400% from 1996 to 2006 (DDS Information Services Division, 2008). The Center for Disease Control reports a prevalence rate of 1 in 150 individuals as having some form of autism spectrum disorder (Centers for Disease Control and Prevention, 2008).

As the number of children with special needs, and their families increase, there is a greater need to understand how families make meaning of their experiences and the factors that help or hinder their ability to cope and adapt. The term special needs is used interchangeably throughout this study to include developmental disability, social-emotional difficulty, behavioral challenge, medical condition, or other risk factor that, without intervention, are likely to result in disability.

According to the Individuals with Disabilities Education Act (IDEA), enacted by Congress in 1975 and most recently re-authorized in 2004, all children with disabilities from birth through age 21 are entitled to special education services (Individuals with Disabilities Education Act (2004)). Infants and toddlers under 3 years of age are served under Part C of IDEA, while children three through 5 years are served under Part B. Under Part C, families are viewed as a unit of service delivery, that is the needs of the family are targets for services, in addition to specific interventions for the child (Dunst & Deal, 1994).

Once children turn 3 years old, they are required to transition from Part C early intervention services to special education services under Part B, at which time the parent's role changes considerably (Connelly, 2007). Services for children under Part B are not specifically targeted towards families; however, states are encouraged to develop practices that support and collaborate with families as partners throughout the planning and provision of services at the preschool level, the emphasis is not on the direct enhancement of family capacities (NECTAC, 2010).

Both Part C and Part B of IDEA require that families are provided with supports that promote informed consent, enable them to participate in making decisions on behalf

of their child, ensures access to their children's records, and protects their rights through procedural safeguards (Bailey & Bruder, 2005). A primary difference between services provided under IDEA Part C and IDEA Part B is that, under Part C services, there is an explicit emphasis on the support and enhancement of family capacities as a means to promote optimal child outcomes (Connelly, 2007). Family supports under Part B focus on strengthening family involvement, not as a target of intervention, but as a means to facilitate parent/family involvement in their child's educational program planning according to Bailey and Bruder.

Whereas obtaining family support, education, and training was embedded in services for children prior to age three, comprehensive services that integrate family support are difficult to obtain or are nonexistent for families of children over three (Connelly, 2007). At the very time that families need critical information, a strong network of social support, and adequate resources and services for their children, many families find that parent support services in particular are often unavailable.

#### *Effects of Child Disability on Family*

Parenting a child with special needs can be a devastating experience for a family. However, not all families perceive their child's developmental challenge as a "tragedy that hangs over the family" (Summers, Behr, & Turnbull, 1988, p. 27), and in fact many families are able to accept the reality of their child's disability and use their energies to organize a system of supports. Some studies show that many parents in fact perceive their child's special need as making a positive contribution to the family (e.g., closer and stronger family) or to themselves personally (e.g., more patience, compassion, and

unselfishness) as shown by some studies (Abbott & Meredith, 1986; Summers et al., 1988).

### *Family Stress*

Although, many families adapt and cope with little effort, for others the experience may compromise their capacity to meet their child's physical, developmental, social, and emotional needs (Hanson & Lynch, 2004). Naseef (1997), a parent of a child with special needs, and author of *Special Children, Challenged Parents*, captures the experience expressed by some parents who are raising children with developmental disabilities when commenting, "The dream of a perfect child can die a painful death" (p. 11). Later he states, "The impact of the lost dream upon a family is lifelong" (Naseef, 1997, p. 49). For some families, learning that a child has a lifelong disability can emotionally feel similar to experiencing the death of a loved one; not an actual death, but a real loss nonetheless, of the dreams and hopes for the child they anticipated.

It is well-documented that stress is strongly correlated with parenting a child with special needs. (Bailey, 1988; Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Bernheimer & Weisner, 2007; Dunst & Deal, 1994; Guralnick, 2006; Hill, 1949; McCubbin & McCubbin, 1987; Moes, 1996; Seligman & Darling, 2007). Upon learning that a child has a disability or special need, families often experience a number of stressors that vary in terms of severity and duration, and may include, interpersonal distress, depression, marital difficulties, anxiety, fatigue, low self-esteem, and loss of control (Weiss, 2002). Additionally, parents may experience feelings of isolation as their prior social network of family and friends withdraw due to stigmas attached to individuals with special needs, and/or their lack of knowing how to support parents

(Orsmond, 2005). When families experience their child's disability or special need as an overwhelming stress, or if there is interpersonal distress in either parent, or if marital difficulties are present in the family, then the family's capacity to effectively cope with, and adapt to, parenting a child with special needs may be threatened (Weiss, 2002).

Families with a restricted range of interpersonal resources or limited informational, material, and social support are at increased risk of experiencing substantial challenges with providing optimal parent-child interactions (Dunst & Deal, 1994). If a stressor results in demands that exceed the family's capacity to successfully cope and adapt, or if the family *perceives* that they are not competent or capable of managing these demands, the resulting crisis may adversely affect the family's capacity to provide optimal experiences and interactions for their child (Kelly, Booth-LaForce, & Spieker, 2005; McCubbin & McCubbin, 1987). In contrast, if families have adequate existing resources or access to needed resources, *and* if families are able to define their situation as manageable, then the presence of a child with disability may never result in a crisis event (Seligman & Darling, 2007).

#### *Family Coping and Adaptation*

While most early research on parenting a child with disabilities viewed family adaptation from a perspective of pathology, current research shows that families are highly capable of achieving successful adaptation, and many adjust to their responsibilities with minimal disruption (Hassall, 2005). This later assumption is derived from a family strengths perspective and is at the core of why family support is included as a principle function of early intervention/education services to families of children with developmental challenges. According to Bernheimer & Weisner (2007), all families,

regardless of whether or not they have a child with disabilities, seek to give meaning and direction in their lives by building and organizing their family's routines around the circumstances in which they live. However, families of children with special needs face additional challenges in adapting and accommodating their child's special needs within the context of daily routines that are embedded within the family's ecological-cultural system and natural environments (Bailey et al., 2006; Bernheimer & Weisner, 2007).

Webster's New World Dictionary (2002), defines adaptation as meaning, "to adjust oneself" ( p. 8). As applied to families of children with disabilities, Barnett et al. (2003) define adaptation as "an *ongoing process* [italics added] whereby parents are able to sensitively read and respond to their child's signals in a manner conducive to healthy development" (p. 184).

As an ongoing process, successful adaptation is influenced by many factors, both within and outside of the immediate family, including the interpersonal characteristics of individual family members (Guralnick, 2005a); the integrity of the marital relationship (Osofsky & Thompson, 2000); the child's individual characteristics and needs (Shonkoff & Marshall, 2000) and the influence of external or environmental factors (Garbarino & Ganzel, 2000). Furthermore, there appears to be a positive relationship between parental level of stress, severity of the child's disability, and the extent to which the child has challenging behaviors (Baker, Blacher, Crnic, & Edelbrock, 2002; Erickson & Upshur, 1989).

Research related to parental coping and adaptation is largely derived from Taylor's theory of cognitive adaptation (Taylor, 1983). According to Taylor, parents are more likely to experience positive adjustment to parenting a child with disability if they



are able to find meaning in the event, gain a sense of mastery or control, and re-frame the event as having a positive interpersonal or familial benefit. Many theorists have built upon Taylor's work and have conceptualized models to depict the relationship between parent cognitive beliefs and adaptation (Barnett et al., 2003; Boyd, 2002; Desjardin, 2005; Hassall, 2005; Judge, 1997; McCubbin & Patterson, 1983; Taylor, 1983).

Current literature related to parenting children with disabilities identifies several factors as predictive of successful parental coping and adaptation: parental self-esteem, or in other words a sense of competence and efficacy (Desjardin, 2005); parental attributions of cause, or in other words the perception of cause and origin of child's behavior (Hassall, 2005); parental perceptions of meaning, or in other words the perception of having resources to manage event (McCubbin & McCubbin, 1987); and parental locus of control, or in other words the beliefs about ability to maintain control (Judge, 1997; Smith, Oliver, Boyce, & Innocenti, 2000).

Parents that perceive a high level of internal control are more likely to feel capable, confident, and empowered. As such they are likely to be more involved in their child's intervention and education and to follow through on the type of parenting practices related to positive child outcomes (Desjardin, 2005; Dunst, Hamby, & Brookfield, 2007; Smith et al., 2000). Conversely, when families see control as being in the hands of others (e.g., service provider or so-called powerful others) there is a greater probability that families will not achieve a sense of confidence or competence in their capacities, which in turn may negatively impact their interactions with their child (Judge, 1997).

Parent beliefs about the cause of their child's behavior, or whether they perceive themselves as having internal or external control, are important variables that are known to relate to the quality of parent-child interactions they are able to establish and maintain (Dunst et al., 2007). Knowing how families perceive their experiences and the meanings they make about parenting a child with a special needs has important implications for understanding the type of supports that would meet an individual child and families' needs.

The following section discusses the type of family supports that families frequently need, the importance of family-centered practices for providing support services, and the nature of the type of parent-professional relationship that is seen by parents as being supportive (Dunst & Trivette, 2005).

#### *Family Support Needs*

In order for family support programs to be of value to parents, it is important that support services are based on their identified needs according to the expressed concerns, resources, and priorities of parents, not according to what professionals think families *should or might* need (Dunst & Deal, 1994). According to Dunst, Trivette and Deal (1988) a need is something that is valued or desired by an individual, but is lacking. They further define a need as “the discrepancy between actual states or conditions and what is considered normative, desired, or valued from a help seekers and not a help giver's perspective” (p.13). One important implication of understanding family needs from this perspective is that unless intervention services explicitly address the needs and priorities valued and desired by the family, then the effectiveness of such services are likely to be diminished substantially (Hassall, 2005).

Family needs for support is a dynamic process that varies according to several factors. For example, normative family transitions, such as a change in family member's composition, number, or status, are transitions that most families experience over the course of the family life cycle (Connelly, 2007; Roth, 1996). Childhood transitions can be either normative, as in the case of a child moving from infancy to preschool to elementary school, and to high school; or non-normative, such as when a child is diagnosed with a disability or transitions from early intervention to special education preschool (Seligman & Darling, 2007).

Family adaptation to normative transitions is relatively seamless and usually not perceived by parents as being a crisis. However, when a child has special needs the traditional rite of passage for which most parents look forward may be disrupted. Additionally, families of special needs children often experience normative life cycle events with heightened levels of stress or return to earlier stages of the grieving process, such as shock, denial, bargaining, anger, depression, before ultimately experiencing acceptance (Kubler-Ross, 1969; Marshak, Siligman, & Prezant, 1999; Whitaker, 2002). The early childhood period in particular can be challenging for parents as families strive to gain information on the nature of their child's disability, when their child fails to reach developmental milestones, or when faced with concerns about their child's future development and needs (Barnett et al., 2003).

### *Barriers to Support*

As the child approaches entry to preschool and later to kindergarten, some families experience a further sense of loss, especially if their child is placed in special education classes. Up to this point, many families hold out hope that their child's

disability will have diminished and that they will be fully integrated into regular education classes (Marshak et al., 1999). Frequently, families experience a disruption in their sense of competence, confidence, and sense of control over circumstances that affect their child and family (Bailey, 1988). It is at this time that many families seek information about their rights and how to advocate effectively for the services their child needs (Seligman & Darling, 2007).

Unfortunately, these families frequently discover that information, social support, and resources are limited or lacking altogether (Connelly, 2007). Several qualitative studies have explored the subjective experiences of families with special needs children and have identified several factors that families perceive as being barriers to accessing services and supports for their child and family (Allen, 2007; Freedman & Boyer, 2000; Shannon, 2004). The most consistent barrier identified by families is a lack of information related to their child's disability, lack of social supports, and lack of services, according to Allen. Others perceive the service delivery system to be inflexible and inaccessible, as well as not meeting needs for socialization, community inclusion, or education and advocacy supports, according to Freedman and Boyer. Many families describe relational factors such as not feeling respected or valued by the service provider, or a perception of being labeled as unmotivated or inept if they do not participate in services according to the provider's expectations, according to Shannon. This latter issue is strongly related to the effects of culture, values, and beliefs that exist among and between families and services providers (Seligman & Darling, 2007).

Having a child with special needs provides additional challenges and therefore a need for additional support to help families adapt successfully to these challenges

(Barnett et al., 2003). The three primary support categories that are frequently described as needed by families of children with special needs are: (a) information support, (b) social support, and (c) resource support (Guralnick, 2005a).

### *Information Support*

The 16<sup>th</sup> Century English philosopher, Sir Francis Bacon, is attributed with the familiar phrase “knowledge is power” (BrainyQuote.com, 2010, para. 1), and this is certainly true for parents of children with special needs. As previously stated, a primary purpose of family support is to provide opportunities for parents to experience a sense of empowerment so they can make informed decisions about their child’s current and future needs (Dunst et al., 1988). Thus, one of the most consistent findings in studies of families with special needs children is the strong desire for information about their child’s development, disability, or services available (Bailey & Powell, 2005; Davis & Gettinger, 1995). According to Guralnick (2001), these “information needs are paramount for families” (p. 12) and include information related to the child’s current developmental status, future development expectations, and the type of intervention/education programs that are available. In particular, families indicate needs for information about helping their child grow and learn, handling their child’s behavior, getting information about their child’s specific disability, and accessing services, according to Bailey and Powell.

### *Social Support*

In addition to parent’s expressed need for information about their child’s disability or for strategies to parent their child effectively, parents also identify formal and informal social support as essential to their family and child’s well-being (Mahoney, Kaiser, & Girolametto, 1999). As discussed in previous sections of this chapter, parents

of children with disabilities or special needs commonly experience varying degrees of stress related to their caregiving demands (Weiss, 2002). Mothers in particular are vulnerable to the effects of stress that may result in extreme fatigue and depression (Weiss, 2002). Additionally, many families report feeling socially isolated, especially during the period when a child is getting diagnosed (Orsmond, 2005).

In order to alleviate the heightened level of stress that parents experience, families express a need for social support from their family, friends, neighbors, and community (Whitaker, 2002). Social support has been found to be especially important during critical periods such as at the time of diagnosis or during transitions (Seligman & Darling, 2007; Turnbull et al., 2007). Social support can be either formal, such as a structured parent support group, or informal, such as friends and family (Dunst, Trivette, & Jodry, 1997).

When families receive adequate or desired social support they demonstrate lower levels of stress, depression, and maladaptive parenting strategies; and an increase in parent self-efficacy, empowerment, and sense of mastery and control (Summers et al., 1988). On the other hand, low levels of social support, or social support that does not meet the individual needs of the family, are correlated with increased maternal depression, external locus of control, poor parenting practices, and lack of competent parenting practices (Spiker, Hebbeler, & Mallik, 2005).

Parent support groups in particular have been found to be helpful in providing families a place to connect with other families in order to give and share information and to provide emotional and social support for one another (Marshak et al., 1999). Support groups may be especially helpful during the first few years following diagnosis and may alleviate loneliness and isolation and provide information for parents (Seligman &

Darling, 2007). Furthermore, participation in social support groups have been found to increase parent coping strategies, help parents regain a sense of mastery and control, and promote healthy adaptation (Weiss, 2002).

### *Resources Support*

Professionals are more than “providers of services;” but are also seen as “helpers that link families to community resources” (Spiker et al., 2005, p. 323). According to McWilliam (2005), resources are more than services that a child or family receives; they also include emotional support, such as responsiveness and sensitivity from service providers; material support which includes tangible objects or financial resources that help families function effectively; and informational support related to child’s development, disability, or available resources. One of the most important goals of family support is to help parents identify and access the resources they need to establish and maintain family routines and continued participation in community activities that they value (Bernheimer & Weisner, 2007; Guralnick, 2005b). The family-centered model is discussed in the next section as an approach for working with families that is based on recognition of the family as the primary social-ecological context within which children develop.

### *Family-Centered Practices*

Zigler and Berman (1983) state that the purpose of family support is to “enhance parent empowerment – to enable families to help themselves and their children” (p. 901). Weissbourd and Kagan (1989) state that “family support programs provide services to families that empower and strengthen adults in their roles as parents, nurturers, and providers” (p. 21). Dunst, Trivette, and Deal (1994) provide the most widely accepted

definition of family support in the statement that “the aims of family support programs are to enable and empower people by enhancing and promoting individual and family capabilities that support and strengthen family functioning” (p. 31).

The family-centered, strengths based approach—which sees the family as being capable and competent—is in sharp contrast to the deficit approach. From a strengths based perspective, the professional does not *give* a family a sense of empowerment, but rather creates the opportunities by which families can further develop their existing capacities.

A central principle guiding programs serving young children with and without disabilities is the belief that one cannot address the developmental, educational, or social-emotional needs of children without also addressing the needs of their families (Atkins-Burnett & Allen-Meares, 2000; Bruder, 2000; Dunst, 2002; Dunst & Deal, 1994; Guralnick, 2006; Warren, Denham, & Bassett, 2008). Increased understanding and emphasis on the family as a key influence and moderator for child outcomes (Bronfenbrenner, 1979; Guralnick, 2005a) has lead the early intervention/special education field towards the use of family-centered approaches (Pearl, 1993).

Family-centered early intervention is conceptualized around several key beliefs and principles (Bailey & Powell, 2005; Bruder, 2000; Dunst & Deal, 1994; Turnbull, Blue-Banning, & Turbiville, 1999). These beliefs and principles include an understanding of the family as the constant in the child’s life, and as such should be an active, senior partner with professionals (Trute & Hiebert-Murphy, 2007). Families are the ultimate decision makers (Bailey et al., 1998), and their concerns, needs, and priorities should direct intervention planning and services (Bernheimer & Weisner, 2007). Services should



build on family strengths (Bromwich, 1997), support family values and cultural preferences (Krauss, 1997), and provide information, resources and supports so families can parent their child in a manner that promotes optimal child outcomes (Dunst, 2002; McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1994). Perhaps most importantly, family-centered practices exist within the context of relationships, and that ultimate child and family outcomes depend on the extent to which professional-parent relationships are nonjudgmental, empathetic, and characterized by mutual trust, respect, collaborative rapport, and clear communication (Trute & Hiebert-Murphy, 2007).

Families who perceive their services as being family-centered, and as meeting the needs of their child and family, are more likely to establish adaptive and supportive family interaction patterns (Bromwich, 1997; Bruder, 2000; Dunst et al., 1988; Trivette & Dunst, 2000; Turnbull et al., 2007; Whitaker, 2002). In turn, these interactions are more likely to promote responsive parent-child interactions that provide optimal learning experiences, and that meet the health and safety needs of their child and family (Atkins-Burnett & Allen-Meares, 2000; Bailey & Bruder, 2005; Bernheimer & Weisner, 2007; Bromwich, 1997; Bruder, 2000; Dunst, 2002; Mahoney & Perales, 2003; Whitaker, 2002). These enhanced family interaction patterns in turn enhance child outcomes, ultimately leading to the family's achievement of a satisfying quality of life for the child and family (Turnbull et al., 2007).

A key goal of family support is to enable and empower parents by providing opportunities for parents to develop a sense of competency and confidence in their capacity to provide developmentally supportive learning experiences that will promote optimal developmental outcomes in their child with disabilities (Dunst, 2002). Parents

who are empowered and enabled are more likely to be competent and confidence in accessing and using the services and supports needed to provide responsive, developmentally supportive parent-child interactions; ultimately resulting in improved outcomes for their child as well as a more satisfying family quality of life (Bailey et al., 2006; Dunst et al., 2007).

In order to understand the role of support in family adaptation and coping with parenting a child with special needs, it is important to place this life cycle event within a conceptual framework that explains (a) *why* families should be supported, (b) *what* type of supports families need, and (c) *how* family supports should be provided.

#### *Systems Perspective of Development*

This study is grounded in the conceptual and theoretical frameworks of systems perspectives of development. The constructs of family, social, ecological, and developmental systems perspectives of development provide a comprehensive conceptual framework for understanding the rationale for family support and the type of supports families need.

Guralnick's Developmental Systems Model (2001) is particularly useful for conceptualizing early childhood development, including children with and without disabilities. The developmental systems perspective (Guralnick, 1997) is best understood as an overarching system that encompasses other systems perspectives that includes, family systems theory (Minuchin, 1985), social systems perspectives (Dunst et al., 1994), and ecological systems perspectives of development (Bronfenbrenner, 1979). Each of these systems perspectives share similar beliefs that view the family as the most proximal and stable influence that affects children's developmental outcomes (Shonkoff &

Phillips, 2000). Additionally, the child's biological makeup, social contexts, relationships, parent-child interactions, and the environment are viewed as factors that influence development in a transactional and dynamic pattern in which one factor or individual within the system influences the other (Bromwich, 1997; Gilkerson & Stott, 2000; Sameroff & Fiese, 2000).

While family, social, ecological, and developmental systems perspectives share similar beliefs, they each emphasize distinct aspects of the family life cycle and child development process. Family systems focus primarily on relationships that occur within the child's immediate family unit (Bromwich, 1997; Minuchin, 1985). Social systems perspectives, on the other hand, expand the sphere of influence to include extended family, friends, and formal networks of support and provides a lens for understanding the critical role of a supportive social network in helping families effectively manage their parenting responsibilities (Dunst et al., 1988). The ecological systems perspectives further builds on family and social systems, which includes a broader range of influencing factors that exist both within and outside the family structure, and includes various environments within which the child and family interact and socio-cultural factors (Bronfenbrenner, 1979).

As an overarching conceptual model, Guralnick's Developmental Systems Model encompasses elements of family, social, and ecological systems. Furthermore, Guralnick's model explicitly illustrates the connection between family, child, and environmental risk and how these relate to ultimate outcomes for children and families. Finally, the developmental systems perspective provides a conceptual framework for understanding the pathways of influence of child disability on the family, and the factors

that mediate or moderate the family's capacity to cope and achieve successful adaptation. Critical to family adaptation is the family's perception of support and their ability to access and utilize the supports needed for their child and family.

Family support is not a one-size-fits-all proposition. Without a full understanding of how an individual family is affected by their child's developmental challenge, there is a risk of providing family supports that do not match the family's information, social, or resource needs. For example, it is conceivable that a program might offer a support group to a family that might not need this service because of already having a strong network of social support (e.g., family and friends). Not only would the above service be unwanted, but the program may actually fail to provide the family with a desperately needed service they do need, such as information to help guide parents through their child's upcoming transition from preschool to elementary school. In either case, the service provider has failed to understand accurately the families' needs, resulting in a mismatch between the family needs and the supports available. Not only is this not advantageous for the family, but it is not an efficient use of limited program resources.

According to Dunst, Trivette, and Deal (1988) a need is something that is valued or desired by an individual, but is lacking. They further define a need as "the discrepancy between actual states or conditions and what is considered normative, desired, or valued from a help seekers and not a help giver's perspective" (p. 13). From this perspective, the actual discrepancy is not in of itself a problem or need, unless the individual perceives the gap as having the potential for an undesirable effect (Dunst et al., 1988). One important implication of understanding family needs from this perspective is that unless intervention services explicitly address the needs and priorities valued and desired by the

family, then the effectiveness of such services are likely to be diminished substantially (Hassall, 2005).

Thus, it is paramount that the type of support provided to families is based on the families' perceived needs, otherwise support via early intervention, parent education or parent support may be viewed as another burden or task that is added to the families list of responsibilities (Koegel & Koegel, 1996).

In summary, most families of children with developmental disabilities or other special needs experience some level of stress associated with the parenting demands associated with their child's care. While many families are able to successfully adapt to their circumstances with minimal supports, other families are at risk for experiencing prolonged family instability and stress resulting in decreased caregiver locus of control, greater family dependency on external supports, less family involvement, and diminished child outcomes (Bailey et al., 2006; Bromwich, 1997). For these families, it is essential that they have access to and are able to utilize sufficient social, informational, and resource support in order to provide optimal parent-child interaction patterns (Crnic & Stormshak, 1997; Dunst & Deal, 1994; Guralnick, 2006). Furthermore, it is important that family supports offered by early intervention/ special education service providers match the expressed concerns, needs, and priorities of families. In addition to identifying the type of services desired, it is also important to understand factors that enhance or inhibit family experiences as well as their appraisals of control over these experiences.

#### Investigated Program

The program investigated in this study is a non-profit organization located in an ethnically, culturally, linguistically, and socio-economically diverse suburban community

of the City of Los Angeles. The Center for Family and Child Development (CFCD) was established to address the social-emotional, relational, and environmental challenges that affect young children with disabilities, developmental delays, and risk factors; as well as to provide support to families. (The name CFCD is a pseudonym developed for the purpose of this study to maintain the organization's anonymity.) The program receives funding from a combination of sources including, private pay, public agencies, grants, and fundraising. The current annual revenue and budget for the CFCD is over \$4 million dollars.

CFCD serves nearly 300 children from birth through 8 years of age who have disabilities, developmental delays, or risk factors that have a high probability of leading to delay without intervention. The majority of children are from Caucasian, middle to upper class two-parent English speaking families. Reflecting the diversity of the broader geographical context, approximately 20% of families are represented by diverse racial, cultural, ethnic, and lingual backgrounds (e.g., Spanish, Russian, Armenian, and Persian).

The Program has two center-based facilities that together provide over 10,000 square feet of individual therapy rooms, small group and large group spaces. CFCD employs over 100 individuals from psychology, speech pathology, occupational therapy, physical therapy, early childhood education, marriage and family therapy, as well as administrative support staff and management. As a training institute, CFCD provides internships to students working towards licensing in psychology, marriage and family therapy, speech and occupational therapy, and fieldwork for early childhood development students. Services currently offered include a wide range of therapeutic intervention, education, occupational, physical, and speech therapy. Family and parent support and

mental health support for families of young children is a core service that is embedded in all therapeutic and educational activities.

### *Family and Parent Support Services*

Traditionally, CFCD's family/parent support services have been oriented to the needs of families with children birth until the child's third birthday at which time they transition to preschool educational services related to their special needs. As described earlier in this chapter, the time surrounding this transition period can create new stressors for parents, or can trigger the re-surfacing of stressors to which a family may have already adapted. Unfortunately, once children transition from early intervention services at age three, family supports dramatically decrease, leaving most families without a strong network of social support. Up to this point, formal parent supports have not been offered for parents of children participating in CFCD's programs for children over 3 years of age.

However, recently many parents have expressed a desire for parent support that includes a combination of formal and informal social support opportunities. In response to family and community needs, CFCD has gradually developed family and parent support services in multiple ways. Parent education and training is provided formally through parent-child dyad therapy in center-based, home, or community based settings. Several mothers have successfully established informal social supports through a "Mom's Club" and a Parent Advisory Committee which plans informational and fundraising events offered to all CFCD parents of children who participate in programs at CFCD.

### *Assessing Family Needs*

Prior to developing new programs or expanding existing programs, CFCD wants to ensure that services offered match the expressed desires and needs of the families who will be using these services. In order to gain a better understanding of families' lived experiences related to accessing and utilizing information, social, and resource support, CFCD conducted a focus group of parents whose special needs children are 3 years and older and are currently participating in early intervention/special education services. The families selected for the focus group were chosen because their children are over 3 years of age and because they have experienced transitioning from early start to preschool education and/or to kindergarten. The information obtained from parents who have already had the lived experience of parenting a child with special needs over 3 years of age informed CFCD about practices that enhance or hinder parent's experiences with accessing and using information, social, and resource supports. The insights obtained from their stories informed the investigated program of the type of supports families value and the methods they prefer for receiving supports.

Furthermore, the study shed light on the experiences that families perceive as working or not working and should be monitored, leveraged, exploited, confronted, or mitigated (Leigh, 2004, 2005b). Most importantly, the information obtained helped CFCD plan future programs to meet family information, social, and resource support needs. One benefit of including parents in the process of further developing family support programs is that they can be active participants in the design and development of family support services (Fetterman, 2003). Furthermore, the process of working together in deciding ultimate outcomes can be unifying, as well as increasing both the family and



program's commitment to what and how supports are provided (Chen, 2005; Patton, 1997).

### Statement of Problem

While many families accept and adapt to having a child with developmental challenges with minimal disruption to family functioning, most families experience some degree of stress that triggers a need for information, social support, and additional resources to achieve successful family adaptation (Guralnick, 2006). These areas of support, in particular, have been found to be important in promoting the families capacity to meet the developmental needs for their child, and to effectively cope with depression, anxiety, anger, interpersonal distress, and marital discord that often occur in families raising children with special needs (Seligman & Darling, 2007). If a parent or family perceives the presence of a child with special needs as a crisis event, then the parent or family's capacity to provide optimal family interaction patterns may be substantially compromised (McCubbin & McCubbin, 1987).

As demonstrated by a system's perspective of development, poor parent-child interactions, inadequate learning opportunities, or lack of meeting the child's health and safety needs can negatively influence a child's social and intellectual development (Guralnick, 2006). Conversely, when parents have access to and utilize the supports needed and desired to meet their family and child's needs, they are more likely to successfully cope with and adapt to their child's developmental challenges or special needs (Dunst et al., 1997).

There is wide acceptance that most families benefit from some level of informational, social, or resource support, although the type of support families' desire,

the intensity of supports needed, and the preferred method for receiving supports varies between families depending on multiple child and family factors. Furthermore, the need for information, social, and resource support is an ongoing process that continues throughout the child's growth and development (Barnett et al., 2003), and is commonly intensified during critical periods, such as when receiving a diagnosis or when transitioning from one service system to another (Marshak et al., 1999). While family supports are readily accessible for parents of children under 3 years of age, as children grow older, there remains considerable gaps in what supports are provided and how these supports are delivered (Connelly, 2007).

Because the family is the primary context within which children develop, family support is an essential component of working with young children with special needs (Guralnick, 2005b; Guralnick & Bennett, 1987). However, the type, intensity level, and methods through which family supports are provided must be based on those areas that families value, desire, and need. The most important consideration when developing and implementing family supports is to ensure that they are based on practices that are family-centered and which will result in measurable benefits that enable and empower parents to competently and confidently provide optimal parent-child interactions and developmentally supportive learning experiences (Bailey & Powell, 2005; Gilliam & Leiter, 2003; Hebbler, Barton, & Mallik, 2007; Leigh, 2004).

The type of supports families' desire at a given time and the means by which families prefer access to these supports are highly individualistic and dynamic. In order to gain a deeper understanding of families' experiences with accessing and utilizing informational, social, and resource supports, and their perceptions of factors that enhance

or inhibit these experiences, it is important to get this information directly from the families being served. To date, there has been minimal research combining both qualitative and quantitative measures to explore families' lived experiences with accessing and using information, social, and resource supports, and their perceptions of factors that enhance or inhibit their experiences, as well as their perception of control.

Furthermore, one critique of research in the field of early childhood intervention and family support is the predominate use of survey methods to determine parent satisfaction with services rather than the use of methods that would uncover the deeper meanings that families relate to their experiences in getting desired family support (Wesley, Buysee, & Tyndall, 1997). Finally, although many researchers have recommended increased use of focus groups to obtain parent perceptions of experiences, to the best of this researcher's knowledge, few mixed-methods studies using focus groups of parents whose children have special needs have been conducted (Allen, 2007; Freedman & Boyer, 2000; Wesley et al., 1997).

### Purpose of Study

The purpose of this phenomenological and mixed-methods study was to gain a deeper understanding of the lived experiences of families whose children with special needs over 3 years of age participating in early intervention or special education services and the meanings they make of these experiences. The study explored the lived experiences of parents with accessing and using family support related to caring for a child with special needs, and the meanings they make of these experiences. Specifically, the study aimed to understand family perceptions about experiences that either enhance or inhibit their ability to access informational, social, and resource supports and how they

perceive control over these experiences. Additionally, the study sought recommendations from families on what and how the investigated program can provide the type and method of support that they perceive as being beneficial and desired.

Researchers describe the need for a new generation of research that focuses on identifying specific program components that are most effective, and that mediate or moderate factors that relate to program outcomes (Donaldson, 2003; Guralnick, 1997). There is a need to not only determine program practices that are effective in providing family support, but more importantly, evaluation research should seek to investigate those factors related to why a program works or fails to work, for whom it works best, and what is needed to make program practices more effective (Donaldson, 2003; Leigh, 2004).

The researcher employed a mixed methods sequential exploratory approach, using qualitative methods to explore family experiences and the meanings they make of these experiences, and quantitative methods to examine parent ratings of the value and priority of responses obtained from qualitative data. Qualitative data increased understanding of the type of experiences that families perceive as either enhancing or inhibiting their attainment of information, social support, and resources and their appraisals of control over these experiences. The addition of quantitative methods enhanced the reliability of responses and provided further explanation of the extent to which there is agreement among participants about which experiences they perceived as enhancing or inhibiting, as well as the extent to which parents expressed high/low internal or external appraisal of control.

The results from this study provided a greater understanding of program practices that work and therefore should be leveraged or exploited and those practices that do not work and should be confronted or mitigated (Leigh, 2005b). Finally, the information obtained from families provided the investigated program with valuable information it could use to make decisions about the appropriate action to take related to family support services and where to allocate resources.

### Research Questions and Objectives

The phenomenological mixed methods research design using data collected from families participating in a focus group will address the following research questions:

Research question 1: What are the lived experiences of families whose children with special needs participate in early intervention or special education services and what meanings to they make of these experiences?

Research question 2: What are families' perceived experiences with obtaining informational, social, and resource support?

Research question 3: What are families' perceptions of the type of experiences that enhance or inhibit their ability to obtain information, social support, and resources?

Research question 4: What are families' appraisals of control over their experiences with obtaining information, social support, and resources?

Research question 5: To what extent, if any, is there agreement within families' ratings of the value of enhancing or inhibiting experiences, and appraisal of control over these experiences?

## Operational Definitions

Definition of variables used in the research questions:

- Appraisal of control: Appraisal of control is a construct that refers to the extent to which an individual perceives control over life events as being internal (self) or external (others). Rotter (1966), who is credited with the coining the concept, locus of control, offers the definition of control as being related to an individual's perception of control as being either internal (control by oneself), or external (control by others). Appraisal of control is used in this study as meaning parent perception of control over issues related to their child's disability, including accessing and utilizing supports.
- Disability: Disability is defined by *Webster's New World Dictionary and Thesaurus* as "a disabled condition . . . that which disables, as an illness or physical limitation" (Agnes, 2002, p. 176). The term disabilities used in this study will reflect the definition set forth by the American's with Disabilities Act of 1990 (ADA) that defines disability as a "physical or mental impairment that substantially limits one or more of the major life activities" (p. 176) of an individual.
- Early intervention services: Early intervention services are provided in accordance with the Individuals with Disabilities Education Act, Part C and includes, but are not limited to, family training, special instruction, speech, occupational, and physical therapy, counseling and social work services. Early intervention services provided to infants and toddlers from birth through age 2 years as discussed in this study are in accordance with federal law (Individual

with Disabilities Education Act, 1999). The term early intervention will be used to refer to programs for children under 3 years of age and their families.

- Enhance: The *Webster's New World Dictionary and Thesaurus* defines enhance as "to make greater, better, etc." (Agnes, 2002, p. 211). As used in the context of this study the meaning of the term(s) enhance or enhancer refers to those strengths, opportunities, actions, circumstances, or beliefs that lead to a desired outcome or opportunity (Leigh, 2005b).
- Family: Family includes extended, nuclear, multigenerational, one or two parents who may or may not live together. Family can be temporary or permanent and includes becoming a family by birth, adoption, marriage. Family has its own culture with different values (California Interagency Coordinating Council on Early Intervention: Family Support Services Committee, 2003).
- Family outcomes: According to Bailey et al. (2006), a family outcome is defined as "a *benefit* experienced by families as a result of services received" or "what happens as a consequence of providing services or supports," not the receipt of services (p. 228). A family outcome relates to whether or not families benefited from early intervention services, and how they benefited.
- Information supports: Information supports relate to families' needs for knowledge that help them "make informed decisions and ... learning about their child's condition, gaining access to available services, teaching their child, or dealing with a developmental or behavioral issue" (Bailey & Powell, 2005, p. 158). In this study, information supports refers to any activity that

strengthens parent's understanding of their child's disability, educates or trains parents in the use of strategies that increase their sense of confidence or competency in meeting their child's needs, or assists parents in knowing their rights and how to advocate effectively for their child.

- **Inhibit:** The term inhibit is defined by the Webster's New World Dictionary (2002) as "to check or repress" (p. 329). As used in the context of this study the meaning of the term(s) inhibit or inhibitor refers to those weaknesses, threats, actions, circumstances, or beliefs that hinder a desired outcome or opportunity (Leigh, 2005b).
- **Lived experiences:** According to Creswell (1998) the term lived experiences as used in phenomenological studies refers to the everyday experiences of individuals. As used in this study, the term lived experiences refers to the actual events that participants have experienced in relation to their child's special needs. Specifically, this study is concerned with those lived experiences related to accessing and utilizing informational, social, and resource support.
- **Meaning:** Refers to how an individual interprets their experience. According to Schultz (as cited in Creswell, 1998), the term meaning refers to how individuals develop meaning out of their experiences or social interactions. Moustakas (1994) defines meaning as "to determine what an experience means for the persons who have had the experience and are able to provide a comprehensive description of it" (p. 13). In this study, the term "meaning" is used to describe how parents make sense of their child's special needs and



their related experiences with accessing and utilizing information, social, and resource supports.

- Obtain and/or attain supports: As defined in this study, obtain and/or attain refers to the act of being able to access and use information, social, and resource supports.
- Parent: As defined in this study, parent refers to the following definition in accordance with IDEA, Sec. 300.30 in which the term parents means a biological or adoptive parents, a foster parent, a legal guardian, an individual who is acting on behalf of the child, and surrogate parent.
- Resource support: Resource supports includes family assets (e.g., financial assistance, and potential places, activities, and settings for intervention). As used within the context of family supports, resources go beyond services, to include community activities, places, and events (McWilliam, 2005). The term resource support is used in this study to mean those resources related to parent's material needs, including, but not limited to, financial, housing, recreational activities, transportation, medical/dental care, child care, employment.
- Early childhood special education services: Services that preschool aged children are eligible for under the Individuals with Disabilities Education Act (IDEA) as per Sec. 300.34 , In addition to classroom support, children are entitled to so-called related services, which includes transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education, and includes

speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, early identification and assessment of disabilities in children, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services for diagnostic or evaluation purposes. Related services also include school health services and school nurse services, social work services in schools, and parent counseling and training.

- **Special needs:** The term special need(s) is used in this study to mean both a variety of and a continuum of developmental challenges that includes but is not limited to difficulties in learning, developmental, mental, emotional, social, behavioral, physical, sensory, or communication abilities.
- **Social support:** Social support is a multidimensional construct that includes instrumental assistance, information, emotional empathy and understanding, and “financial and tangible aid” (Crnic & Stormshak, 1997, p. 210). Gottlieb (1983) defines social support as “verbal and non-verbal information or advise, tangible aid, or action that is proffered by social intimates or inferred by their presence and has beneficial emotional or behavioral effects on the recipients” (p. 28).

### Importance of Study

The information gained from this phenomenological mixed-methods study will provide a deeper understanding of the lived experiences of families who have children with special needs participating in early intervention and special education services.

Specifically, the study will illuminate families' experiences with accessing and utilizing information, social, and resource supports, and the meanings that families make of these experiences. Additionally, the study will provide a greater understanding of the various psychological and environmental factors that either enhance or inhibit their access and utilization of supports. The insights gained from examining family appraisals of control as being either high/low internal (self) or high/low external (professional) control can identify factors that may promote or interfere with how families access and utilize information, social, and resource supports.

Furthermore, the findings from the study can help the investigated program eliminate blockages of service delivery pathways that either enhance or inhibit families' capacity to successfully adapt to their role of parenting a child with special needs. Finally, the value of this information is to identify those practices that families perceive as being enabling and empowering, that support their sense of confidence and competency in providing optimal parent-child interactions and developmentally supportive learning experiences, and that lead to positive developmental outcomes in their child, and ultimately promote enhanced family-wellbeing.

#### Assumptions of the Study

The study was predicated on the following assumptions:

1. Parents answered focus group questions honestly.
2. Families value information, social supports, and resources available from family/parent support services
3. Participation in program services is presumed to have a positive effect on children with disabilities and families.

4. Parent appraisal of control is positively correlated with parental behaviors associated with accessing and using informational, social, and resource support and successful adaptation.

#### Limitations of the Study

Limitations of this study include the following:

1. The study is limited to a small number of participants ( $N = 6$ ) from one early intervention program located in a single geographical area and does not encompass practices at other early intervention programs.
2. Only families who participated in a single program for children over 3 years of age at this single location are included in this study and therefore results cannot be generalized outside of this sample.
3. The amount of time for the study was 9 months. During this time the interview protocol was field tested, administered, analyzed and interpreted by the researcher.
4. The researcher is employed by the investigated program and is a parent of a child with a disability. This could pose a threat to maintaining a non-biased position and interpretation of results. Although every effort was made to avoid these biases, they are a potential threat to the study's validity.
5. Additionally, knowing that I am employed by the agency, it is possible that family responses could be less forthcoming for fear of how their responses might affect their child's intervention. Every effort was made to develop rapport with families and to ensure participants that individual

family responses are kept confidential and are not accessible to other members in the organization.

### Summary

Having a child with special needs presents an unexpected and unique challenge for parents. In order to adapt to this unexpected parenting role, families typically express an intense need for information, social support, and resources to help them learn about their child's developmental needs, to develop effective parenting strategies so they can provide developmentally supportive learning experiences, and to access services and other resources needed for their child and family. Additionally, the type of support families' desire is highly individualistic and needs to be tailored to the specific desires of each family and child. Therefore, programs providing services for children with special needs and their families need to engage parents in the process of developing the form and function of what and how parent support services should be offered.

The purpose of this phenomenological study was to gain a deeper understanding of family experiences with accessing and using family supports and the meanings they make from these experiences. The information gathered from families informed the investigated program about the type of experiences that families perceive as enhancing or inhibiting their access and utilization of family support as well as whether they attribute control over these experiences to self or professionals. The results provided a greater understanding of practices that are working and should be leveraged or exploited and those practices that are not working and should be confronted or mitigated.

## CHAPTER 2: REVIEW OF LITERATURE

Parenthood represents a major transition in the family life cycle and most families look forward to the birth of a child with high levels of excitement and anticipation. However, when a family learns that their young child has a special need, parents must quickly adjust and adapt to their new set of responsibilities. For many families this unexpected event may trigger several stressors that can substantially undermine their capacity to provide the quality of parent-child interactions and developmentally supportive experiences that children need to reach their fullest developmental potential (Guralnick, 2006). Research on the effects of children with special needs on their families, consistently demonstrates that parents experience a heightened need for information and services, social support, and access to financial and material resources (Guralnick, 2005b). Furthermore, the need for support, especially social support, remains constant throughout the child's development. In order to meet the support needs of families, it is important to gain a better understanding of their experiences with parenting a child with special needs.

A primary purpose of this phenomenological and mixed methods study is to examine family experiences with accessing and using information, social support, and resources as well as the meanings they make of these experiences. In particular, the study seeks to understand family perceptions of factors that either enhance or inhibit their experiences, as well as their attributions of control. It is presumed that a better understanding of families' lived experiences and the meanings they make from these experiences will help identify the type of parent support services and practices that

families perceive as helping them to more effectively parent their child with special needs. Furthermore, the information gathered from parents can reveal the extent to which families perceive a gap, if any, between the current supports available and the type of supports that they desire. It is expected that the results from the study will help to identify what families perceive as working and not working with respect to obtaining desired information, social support, and resources. Ultimately, understanding family perspectives of their experiences, the type of supports they desire, as well as the extent to which supports are currently meeting their needs is useful in guiding early intervention/early childhood special education programs in making decisions about those family support practices that should be maintained, improved, reduced or extinguished, as well as developed.

The study is grounded in the literature related to family experiences with parenting young children who have developmental challenges and family support. The chapter begins with a brief historical overview of compensatory and early intervention/special education programs for young children and the expanding focus on including families as a unit of service delivery. The literature related to normative, atypical, and systems perspective of development and the central role of families in shaping development are discussed as providing a conceptual and contextual framework for explaining the importance of family support services. Additionally, the chapter investigates how families are affected by their child's special needs and the various factors that either enhance or inhibit parental coping and adaptation. Finally, the theoretical and empirical findings from the literature are summarized and discussed as a

foundation for developing family-centered programs for families of children with special needs.

### Historical Overview and Background

The legislative and philosophical foundation for family support programs can be traced to the early 1900s when the federal government recognized the need to support poor and disadvantaged mothers in order to prevent or ameliorate negative consequences associated with poverty (Guralnick, 1997). While initially concerned primarily with disadvantaged mothers, gradually these programs began to include children with disabilities and placed a greater emphasis on the importance of supporting families, in particular mothers, as fundamental to a child's well-being (Meisels & Shonkoff, 2000). The success of these programs laid the foundation for future programs aimed at intervening early for children at risk for health and developmental challenges as well as the importance of supporting families (Bryant & Maxwell, 1997; Halpern, 2000).

### *Compensatory Education Programs*

Longitudinal studies conducted for the past 40 years provide mixed results for the benefits and effectiveness of early childhood compensatory programs for disadvantaged and at-risk children and their families (Farran, 1990, 2000). Key variables identified as influencing the effectiveness of early childhood intervention programs include: parent involvement and the provision of parent support, education, and training (Bailey, 1988; Barnard, 1998; Bruder et al., 2005; Dunst & Deal, 1994; Dunst et al., 1988; Halpern, 2000; Hebbler, Barton et al., 2007; Hubbell, 1983; Isaacs, 2007; Karoly, Kilburn, & Cannon, 2005; Mahoney & Perales, 2003; Olds et al., 1999; Snyder & Sheehan, 1993; Werner, 1984; West et al., 2007; Zigler & Valentine, 1979). The assumption of these



early programs was that changing the primary caregiver's interactions with their child (usually the mother) through targeted parent education would result in more developmentally supportive parent-child interactions, which in turn would lead to more optimal child development outcomes (Bryant & Maxwell, 1997).

The most well known early childhood compensatory program for children is the federally funded Head Start program. Three other programs for young children at risk for delayed intellectual development due to environmental disadvantage, with strong emphasis on family involvement, have been reported on extensively in the literature. These are the High/Scope Perry Preschool Project, the Chicago Child-Parent Centers (CPC), and the Carolina Abecedarian Project (Isaacs, 2007; Karoly et al., 2005; Masse & Barnett, 2002; Parks, 2000; Reynolds, Temple, Robertson, & Mann, 2001; Schweinhart et al., 2005).

### *Head Start*

Established in 1965, Head Start provides high quality pre-kindergarten education, health, and social services to children between the ages of three and five who are at-risk for poor developmental outcomes (Guralnick, 1997; Shonkoff & Marshall, 2000). Additionally, Head Start programs are federally mandated to enroll 10% of their spaces to children with disabilities. From the beginning, involvement of parents and families has been seen as essential to children's developmental outcomes; thus a key feature of Head Start, then and now, is the emphasis placed on family involvement and supporting parents in their ability to make informed and appropriate decisions on behalf of their children, according to Meisels and Shonkoff. The ultimate goal of Head Start is to ensure that children develop social competence and readiness for entry into kindergarten, to

encourage family involvement in their child's activities at home and school; and to promote family economic and social self-sufficiency (Connell & O'Brien, 2002).

Although Head Start has traditionally recognized the importance of parent support and family involvement, research documenting the impact of these programs on parenting behaviors is limited (Bryant & Maxwell, 1997). One early study of 80 Head Start mothers showed a correlation between moderate to high levels of parent involvement and parent report of greater psychological well-being and higher levels of satisfaction after participation in Head Start (Parker, Piotrkowski, & Peay, 1987). However, this study lacked random assignment and control of variables, this study's results are limited.

Beginning in 1997, the Head Start Family and Child Experiences Survey (FACES) launched the first of several periodic longitudinal studies of program performance (Administration for Children and Families, 2007; West et al., 2007). The Head Start Family and Child Experiences Survey (FACES) is a large longitudinal, cross-sectional descriptive study of a sample of over 3,200 ethnically, culturally, linguistically, socially, and economically diverse families randomly selected from 40 Head Start programs that are distributed throughout the United States. The FACES study began collecting data during Fall 1997 through Spring 2001 to determine Head Start's performance in promoting social competence and school readiness in low-income children as well as helping families attain their "educational, economic, and child rearing goals" (Connell & O'Brien, 2002, p. 6).

The FACES report published in January 2002, *A Descriptive Study of Head Start Families: FACES Technical Report I*, found that high levels of parent involvement were a strong predictor of a number of factors. Parents who were more involved in Head Start

activities had higher levels of social support, more internal locus of control, increased engagement with their child, and decreased maternal depression (O'Brien et al., 2002). Even with controlling for extraneous variables, parent involvement was a significant predictor of positive social behavior, decreased aggression, and increased literacy in child participants. Of particular importance to this study is that mothers of children with disabilities reported that Head Start was helpful or very helpful in providing social support (91%); assisting them with other agencies, schools, and resources (75%); and helping them meet their child's special needs (73%), according to O'Brien et al.

The findings from the FACES study demonstrate that family involvement is not only an important predictor of child outcomes, but also predicts significant benefits to parents (typically mothers) that improve their well-being and ability to provide nurturing, developmentally supportive experiences for their child.

Although the Head Start program is perhaps the most well-recognized program serving low-income, disadvantaged children and families, other early childhood programs aimed at the same population have likewise conducted longitudinal studies demonstrating the long-term positive influence of parent participation on child outcomes (Bryant & Maxwell, 1997; Karoly et al., 2005).

#### *Perry Preschool Project*

The High/Scope Perry Preschool Project was a single site demonstration program that operated from 1962 to 1967 for children ages 3 and 4 years from low-income high-risk families and/or environments in Ypsilanti, Michigan (Schweinhart et al., 2005). The primary goal of the Perry Preschool Project was to prevent school failure and associated problems through high quality preschool education for preschool-aged children, and

weekly home visits to parents that supported them in providing enhanced learning experiences for their child (Károly et al., 2005). The randomly controlled experimental design has followed participants for the past 40 years and has found that a substantial factor in the Perry Preschool Project outcomes related to a strong parent support and education component that resulted in increased parental involvement and use of improved parenting practices (Károly et al., 2005; Parks, 2000; Schweinhart et al., 2005).

#### *Chicago Child-Parent Centers*

The Chicago Child-Parent Centers is an ongoing multi-site public preschool program for children 3 years of age through third grade in Chicago (Reynolds et al., 2001). A key feature of the Chicago Child-Parent Centers (CPC) is a strong emphasis on parent involvement and the explicit belief that enhancing parent-child interactions, parent and child attachment to school, and social support among parents will have a direct effect on promoting children's school readiness and social adjustment (Reynolds, Temple, Robertson, & Mann, 2002). Follow-up studies at 20 years of a cohort of participants who entered the preschool program between 1979 and 1980 found that parents whose children participated in the program experienced benefits such as higher educational attainment, lower rates of reliance on disability or public assistance, and higher rates of employment (Reynolds et al., 2001).

#### *Carolina Abecedarian Project*

The Carolina Abecedarian Project, started in 1972 is an intensive preschool program for children (birth to 5 years of age) from low-income, high-risk families (Masse & Barnett, 2002). A 20-year follow-up of 104 children who participated in the program between 1972 and 1977 found that teenage mothers (under 18 years of age) whose

children who attended the program during the study had higher rates of high-school graduation and were more likely to have some post-secondary education and less reliance on public assistance. Furthermore, these mothers were less likely to have had additional children as teens (Masse & Barnett, 2002).

Similar to Head Start, all of these programs have conducted longitudinal studies of participants and continue to report statistically significant outcomes for children related to increased academic achievement, positive behaviors, less special education and grade retention, and enhanced life-long benefits that extend into adulthood more than 35 years later, as well as benefits to parents (Karoly et al., 2005). Each of the programs were high-quality model programs that provided center-based programs for preschool-aged and had strong parent involvement components to promote parenting practices associated with positive child outcomes (Isaacs, 2007). Direct benefits to mothers included increased completion of high school and greater economic self-sufficiency, and delayed birth of subsequent children.

Not only are there substantial direct and indirect benefits to children and their families, there are substantial economic and societal benefits. For example, Isaacs (2007), from The Brookings Institution, analyzed the cost-effectiveness of early childhood education programs for young children. Her study suggested that high quality early education in combination with family support has the potential to save taxpayers over \$25 billion dollars a year in the form of reduced academic failure, special education, juvenile and adult crime, teen pregnancy, underemployment, and inadequate parenting practices, according to Isaacs. Her findings are based on the premise that high quality programs can mediate the negative impacts associated with poverty, low parental

education, poor parenting skills, and insufficient early learning experiences by increasing children's social, cognitive, and academic skills that are essential for school readiness, academic success, and workforce development. In contrast, provision of direct supports to families led to improved parent-child interactions and learning experiences for their child.

Longitudinal studies from other authors documenting the cost-benefit of the Abecedarian Project, the Perry Preschool Project and the Chicago Child-Parent Centers show that these programs are not only cost-effective at a benefit-cost ratio of over \$17 for every dollar spent, but also provide substantial social capital benefits to children, parents, and society that far exceeds the cost of funding these programs (Heckman & Masterov, 2004; Karoly et al., 2005; Masse & Barnett, 2002; Reynolds et al., 2002; Rolnick & Grunewald, 2003, 2007; Schweinhart et al., 2005).

Current programs developed for children with special needs are based on the successes experienced from these early compensatory programs. In addition to the economic and social benefits to children and families directly, there are substantial benefits to society as a whole. In recognition of this benefit, federal and state public policy promotes the importance of providing early intervention/early childhood special education programs for children with special needs and their families.

#### *Policies Regarding Special Needs Children and Families*

Historically, because families were encouraged to place their children with disabilities in institutions, support for families was nonexistent during the first half of the 20<sup>th</sup> Century (Meisels & Shonkoff, 2000). The movement towards education for individuals with disabilities, as well as support for families, has evolved gradually and

has been described by Caldwell (1973) as occurring in three major historical periods. The first period, identified by Caldwell as “Forget and Hide,” occurred during the first half of the 1900s and was characterized by the exclusion of children with substantial physical or intellectual disabilities from public view through institutionalization or being hidden away by families with no public support. The second period, referred to as *screen and segregate*, was characteristic of the *separate but equal* socio-political attitudes of the 1950s and 1960s during which children were identified, only to be labeled and then isolated away from society in specialized settings under the assumption that families should be spared the burden of caring for their child. Caldwell’s third period of *identify and help* occurring during the 1970s, is reflected in the passage of early federal special education programs for individuals with disabilities mandating that children have opportunities to participate in mainstream educational settings (Caldwell, 1973).

More recently, other researchers have expanded Caldwell’s earlier descriptions to add a fourth period that places greater emphasis on full inclusion (Meisels & Shonkoff, 2000) and family empowerment (Turnbull et al., 1999). This movement places a greater emphasis on early identification and family support, largely due to increased scientific understandings about the importance of the first few years of life and the critical role of families in shaping early development (Shonkoff & Phillips, 2000). In spite of this recognition, current service delivery systems continue to leave many children and their families without the support needed to ensure that inclusion in the community not only happens, but that the experience is beneficial and meaningful children with and without special needs.

### *Individuals with Disabilities Education Act*

In 1975 Congress enacted federal legislation authorizing special education services for children with disabilities from three to 21 years of age under the Education for All Handicapped Children Act of 1975. Re-authorizations in 1986 expanded services to infants and toddlers from birth through age two, and in 1991 was re-named the Individuals with Disabilities Education Act (IDEA). Since 1997, IDEA services for children birth through age two have been referred to as Part C and services for children 3 to 5 years as Part B.

*Part C of IDEA.* An important purpose of IDEA Part C services is supporting the family's ability to provide interactions and experiences that nurture optimal developmental outcomes (Atkins-Burnett & Allen-Meares, 2000; Bromwich, 1997; Pearl, 1993). Under Part C, families are viewed as a unit of service delivery – in that the needs of the family are targets for services, in addition to specific interventions for the child (Dunst & Deal, 1994). Early intervention services that families are entitled to under Part C include assessment of family strengths, concerns, priorities, and resources; and the provision of family training, counseling, and home visits (Bailey & Bruder, 2005).

*Part B of IDEA.* At age three, IDEA requires that children transition from Part C early intervention services to special education services under Part B, at which time the parent's role changes considerably (Connelly, 2007). Even though states are encouraged to develop practices that support and collaborate with families as partners throughout their joint planning and provision of services at the preschool level, the emphasis is not on the direct enhancement of family capacities (NECTAC, 2002). Family supports under Part B focus on strengthening family involvement, not as a target of intervention, but as a



means to facilitate parent/family involvement in their child's educational program planning (Bailey & Bruder, 2005).

A primary difference between services provided under IDEA Part C and IDEA Part B is that Part C services emphasize the support and enhancement of family capacities as a means to promote optimal child outcomes (Connelly, 2007). Both Part C and Part B of IDEA require that families are provided with supports that promote informed consent, enable them to participate in making decisions on behalf of their child, access to their children's records, and protection of rights through procedural safeguards (Bailey & Bruder, 2005).

#### *California Lanterman Act*

In California, individuals with severe, lifelong developmental disabilities, such as autism, cerebral palsy, mental retardation, seizure disorder, or any condition that will likely impair independent functioning in adulthood are also entitled to services under California legislation referred to as the Lanterman Act (Lanterman Developmental Disabilities Services Act, 1977b).

A key purpose of the Lanterman Developmental Disabilities Services Act (1977a) is providing opportunities for children with developmental disabilities to live with their families, to provide family support services, to focus on the entire family, and to promote the inclusion of children with disabilities in all aspects of school and community. Services under the Lanterman Act and the California Early Intervention Services Act (CEISA) are provided through the regional center, a statewide system of 21 private nonprofit agencies that coordinate and purchase individual and family supports. Whereas the CEISA is responsible for services pertaining to children with developmental delays,

disabilities, or risk factors for children under 3 years of age, families of children with moderate to severe lifelong disabilities after age 3 years are guaranteed access to family support services through the Lanterman Act. However, families of children with less severe special needs, while they may be eligible for educational supports under IDEA, usually do not qualify for family support services, thus leaving many parents without access to essential social support opportunities.

*Empirical Research: Early Intervention/Education*

There is wide acceptance and consensus among early intervention researchers and practitioners that families play a central role in young children's development (Bailey et al., 2006). Additionally there is agreement, at least philosophically and theoretically, about the value and benefit to families as participants in early intervention services for their children with special needs (Affleck, Tennen, Rowe, Roscher, & Walker, 1989; Bailey, 1988; Bromwich, 1997; Bruder, 2000; Bryant & Maxwell, 1997; Guralnick, 1998; Meisels & Shonkoff, 2000; Shonkoff & Phillips, 2000). While there is a considerable body of research demonstrating the effects of early intervention/education on child outcomes, the quality and quantity of research on family benefits is minimal (Bailey et al., 2006).

Most empirical research in the field of early intervention/education is focused on child outcomes (Bailey et al., 1998), although parents have been included in such studies to the extent that parental or family characteristics are viewed as having a mediating or moderating effect on their child's development (Dunst, 1999; Mahoney et al., 1999). In their comprehensive review of studies related to measuring the effects of early intervention with children who have Down syndrome, Spiker and Hopmann (1997) found

that results of most studies are mixed and because of methods-related weaknesses, causal attributions cannot be determined. However, a few studies have shown short-term improvements in fine motor and adaptive skills (Harris, 1988) and that child improvements which were sustained beyond the intervention treatment were associated with corresponding improvements in the quality of mother-child interactions (Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992).

Dawson and Osterling (1997) in their review of factors associated with effective autism intervention treatment, found that programs with the strongest effects all recognized parents as a critical component in the treatment. Furthermore, successful programs emphasized parent training and expected parents to implement specific strategies to improve their child's skills, because they spent the most amount of time with their child and therefore could have a greater impact on their child's outcomes (Schopler & Reichler, 1971). Dawson et al. concluded that inclusion of parents as active partners lead to greater maintenance and generalization of skills, increased parental feeling of relatedness with their child, and an enhanced sense of competence in their role as parents (Dawson & Osterling, 1997). These benefits are of particular importance as they have been found to be strongly correlated with successful family coping and adaptation in families of children with special needs (Dunst et al., 1988; Seligman & Darling, 2007).

As the first and largest longitudinal study of a nationally representative sample of 3,338 children who entered early intervention in 1997 and 1998 under IDEA Part C, The National Early Intervention Longitudinal Study (NEILS) investigated the long-term effects of early intervention on child outcomes and parent perceptions of well-being (Hebbler et al., 2007). The final report completed in January 2007 showed that children

made significant progress in their developmental skills and that most (96%) of parents felt that early intervention services helped them to help their child develop and learn and that their family was much better (59%) or somewhat (23%) better off because of their participation. The majority of parents strongly agreed (62%) or agreed (27%) that they had an adequate informal social support network of friends or relatives that they could rely on for help when needed. However, over one third of the families reported that they did not have as many opportunities as desired to participate in community activities. Overall, the NEILS findings demonstrated that early intervention not only benefited children, but also provided insight as to how families perceive their experiences as participants in early intervention services (Hebbler, Spiker, Bailey, Scarborough, Malik et al., 2007). Furthermore, these results demonstrate that comprehensive supports for both families and children yield positive outcomes for both.

As a result of increased understandings about the important role of families as exerting a substantial influence on their child's development, it is increasingly important to give greater attention to measuring how families are benefiting from their participation in early intervention/education programs with their children (Bailey et al., 2006; Buysse & Wesley, 2006). Furthermore, recent federal requirements require that programs operating under IDEA Part C and Part B will need to not only demonstrate positive effects for child outcomes, but will also be responsible for showing how families are benefiting as well (Bailey & Bruder, 2005).

Because parents are critical to their child's development, it is important to identify the type of early intervention/education experiences that provide the support they need to meet their child's needs. Today, most (95%) children with disabilities are raised at home

by their families, and as such a primary focus of intervention services is to ensure that families are receive the support they need to care for their children (DDS Information Services Division, 2008).

### Theoretical and Conceptual Framework

This study is grounded in the theoretical and empirical literature related to families of children with disabilities and the influence of several constructs in shaping how and what families supports are provided. The literature related to each of the following constructs will be explored in this section:

1. Normative and atypical child development and the role of family (Guralnick, 2005b; Shonkoff & Phillips, 2000)
2. Systems perspectives of family functioning (Bromwich, 1997; Bronfenbrenner, 1992; Guralnick, 2001; Minuchin, 1985; Shonkoff & Phillips, 2000)
3. Models of stress, coping, and adaptation (McCubbin & Patterson, 1983) and;
4. Family-centered practices (Dunst & Deal, 1994).

As a comprehensive conceptual framework that integrates the theoretical and empirical literature related to normative and atypical development, Guralnick's Developmental Systems Model is used in this study as the overarching theoretical and conceptual foundation for understanding the critical role of families in shaping children's development (Guralnick, 2005a).

Embedded in the developmental systems model is the recognition that children and families exist within the broader social, ecological, and cultural contexts within which children develop. Three systems perspectives in particular are discussed in the

child disabilities literature and includes: the family systems perspective (Bromwich, 1997; Gilkerson & Stott, 2000; Greenspan & Wieder, 2006; Hanson & Lynch, 2004; Minuchin, 1985), the social systems perspective (Affleck et al., 1989; Dunst & Trivette, 2005; Dunst et al., 1997; Sameroff, 1987; Turnbull et al., 2007; Weissbourd & Kagan, 1989; Whitaker, 2002), and the ecological systems perspective (Bronfenbrenner, 1979, 1992; Garbarino & Ganzel, 2000; Shonkoff & Phillips, 2000).

One advantage of conceptualizing the developmental systems model as an overarching framework, is that it also provides a pathway for understanding how stressors, such as having a child with special needs, affect family functioning, as well as, the means by which families are able to cope with and adapt to their child's special needs (Guralnick, 2001, 2005a, 2006, 2005b). In particular, the Double ABCX model of stress, coping, and adaptation provides a theoretical foundation for understanding how family support is essential to successful family adaptation (Barnett et al., 2003; Hill, 1949; Marshak et al., 1999; McCubbin & McCubbin, 1987; Seligman & Darling, 2007; Summers et al., 1988; Werner, 2000).

In order to facilitate family coping and adaptation, a family-centered model is recognized as recommended practice for providing services to young children and their families (Bickman, 1987; Bromwich, 1997; Bruder, 2000; Dunst, 2002; Dunst, Boyd, Trivette, & Hamby, 2002; Sandall, Mclean, Santos, & Smith, 2000; Turnbull et al., 1999). Furthermore, because empowerment of parents is viewed as a principle goal of family support, help-giving models emphasizing parent empowerment provide an important context for developing desired outcomes for families (Bailey et al., 2006; Dunst et al., 1988; Dunst et al., 1994; Mahoney & Perales, 2003; Summers et al., 2005).

The theoretical and empirical literature on (a) normative development and the role of family, (b) developmental, family, social, and ecological systems perspectives, (c) the ABCX model of stress, coping, and adaptation, as well as the (d) family-centered approach are discussed in the following sections.

### *Normative Development*

#### *Child Development*

Modern theories of child development recognize that the family plays a central and critical role in determining whether a child achieves positive developmental outcomes (Shonkoff & Phillips, 2000). One of the most important contributions of normative developmental research is increased understanding of the various factors that influence the child's developmental trajectory, including characteristics within the child, the family unit, individual family members, and the environment (Guralnick, 2001). Insights gained from this body of research is increasingly being applied within the disabilities field as a framework for understanding the impact of child disability or developmental challenges on the family as well as the various elements that can support or hinder child development outcomes and family well-being (Guralnick, 2005a; Marshak et al., 1999; Seligman & Darling, 2007).

The theoretical frameworks upon which normative development are founded have developed over the past 30 years from the cumulative understandings gained from the developmental, educational, biological, psychological, neurological, and sociological fields of study and research (Bronfenbrenner, 1992; Gallagher, 2005; Guralnick, 2005a; Knudsen, Heckman, Cameron, & Shonkoff, 2006; Ludwig & Sawhill, 2007; Rolnick & Grunewald, 2003; Shonkoff & Phillips, 2000). An important advancement of this

research is a greater understanding that brain growth and social-emotional development are particularly vulnerable to the quality of relationships, environments, and early experiences (Garbarino & Ganzel, 2000; Osofsky & Thompson, 2000). This is especially true for children with identified risk factors such as disabilities, developmental delay, regulatory, or social-emotional challenges (Shonkoff & Marshall, 2000; Spiker et al., 2005).

Babies enter the world wired and ready to learn and it is during these first few years of rapid growth and development when the quality of early experiences and interactions with primary caregivers has the greatest impact on the infant's developmental trajectory (Shonkoff & Phillips, 2000). Furthermore, these early relationships and experiences form the foundation for all future growth and development that extends throughout the lifespan, according to Shonkoff and Phillips. Because neurons are rapidly developing crucial connections during the first few years of life, the quality of experiences and interactions that parents provide during early childhood has an enormous impact on brain growth and development. According to Hawley and Gunner (2000) in Zero to Three's report *Smart Start: How Early Experiences Affect Brain Development*, early interactions with people and objects are just as important as other essential nutrients, such as fats, vitamins, and proteins on the child's developing brain. Most importantly, it is the quality of these experiences and interactions that matters most (Shonkoff & Marshall, 2000). Although all children require responsive, nurturing relationships, supportive environments, and high quality learning experiences, children with developmental delays, disabilities, or other risk factors are at greater risk for poor



outcomes when these experiences are inadequate or lacking (Guralnick, 2005b; Hawley & Gunner, 2000; Shonkoff & Marshall, 2000; Shonkoff & Phillips, 2000).

### *Role of Family*

Current understandings of human development indicate that it is relationships that shape the child's development of self-awareness, social competence, conscience, emotional growth, emotion regulation, learning, and cognitive growth (Shonkoff & Phillips, 2000). Normative and atypical child development, according to Gilkerson and Stott (2000), is significantly enhanced when family members feel more connected to each other, and when mothers engage in more supportive and contingently responsive and growth promoting interactions. Other factors associated with optimal parent-child relationships is sensitivity, love, availability, and commitment to the child's well-being (Shonkoff & Phillips, 2000).

Numerous studies have been conducted that support the critical role of parents, especially mothers as central to children's development (Hauser-Cram et al., 2001; Jeong-Mee & Mahoney, 2004; Mahoney & Perales, 2003; McCollum & Hemmeter, 1997). McCollum and Hemmeter's review of 10 studies investigating parent and child interaction behaviors revealed that higher levels of parental responsiveness, positive emotional affect, and lower levels of directedness and stimulation were positively related to children's improved cognitive and language development. Additionally, children demonstrated increased interaction skills, engagement, and toy play.

Hauser-Cram et al. (2001) found similar results in their longitudinal study of child development and parent well-being conducted over a 10 year period with 183 children with Down syndrome, motor impairment, developmental delay and their families. Their

results demonstrated that mother-child interactions predicted changes in child's communication and social skills and that the quality of family relations predicted changes in social skills (Hauser-Cram et al., 2001). Furthermore, children of mothers with higher scores on measures of mother child interaction had higher mental age scores, whereas parent perception of family relations predicted positive changes in social skills.

Jeong-Mee and Mahoney (2004) compared the interaction engagement of two matched two groups of Korean mother-child dyads, with and without disabilities to determine if the child's level of engagement was related to their developmental status or to how their mothers interacted with them. Similar to previously discussed studies, substantial group differences were found and showed that maternal responsiveness accounted for 33% and maternal affect accounted for 30% of the variance in children's total engagement scores. Although the study involved a homogenous group and small sample size ( $N = 30$ ), Jeong-Mee and Mahoney's results further support the important role of mothers in shaping their child's developmental potential.

Beckwith (1988) and Spiker, Ferguson, and Brooks-Gunn (1993) studied the effects of providing support to mothers of high risk pre-term infants on maternal-child interactions. Beckwith's study of 92 families found to have increased involvement and reciprocal interactions between the mother and child in comparison to the control group. Spiker et al. examined the effects of a comprehensive intervention program, the Infant Health and Development Program (IHDP) which consisted of weekly home visits with parents of pre-term infants for 1 year following hospital discharge. Their results indicated that program participants demonstrated higher levels of supportive presence, such as

affective involvement and warmth; as well as higher quality assistance in the form of developmentally appropriate learning experiences (Beckwith, 1988; Spiker et al., 1993).

In comparison, Lawhorn's (1994) study involving a small sample of parent-child dyads, developed an intervention design that explicitly focused on developing a "therapeutic alliance" with parents based on the assumption that the parent-therapist relationship is an important element of effective intervention (Barnard, 1997, p. 259). The results of Lawhorn's study showed that her approach resulted in improved maternal responsiveness to their child when they are able to control the amount and timing of intervention and when they are treated as equal partners (Barnard, 1997; Lawhorn, 1994). Studies conducted by others support Lawhorn's findings on the benefits of a relationship based approach when working with families of children with special needs (Bromwich, 1997; Bruder, 2000; Dunst & Deal, 1994; Greenspan & Wieder, 2006; Kelly & Barnard, 1999; Mahoney & Perales, 2003; Turnbull et al., 1999).

In summary, it is readily accepted that early learning experiences and family-child interaction patterns influence the child's developmental trajectory (Bronfenbrenner, 1979; Harbin & Salisbury, 2000), and are key predictors of positive outcomes for children with special needs (Mahoney, Spiker, & Boyce, 1996). In order to better understand how these early parent-child transactions, and later transactions outside of the family influence a child's development, the following section describes four systems perspectives of development. First, the developmental system model is discussed as an overarching framework within which the other system's perspectives are conceptualized as being embedded. The remaining three system models that will be described include the family systems, social systems, and ecological systems perspectives.

### *Systems Perspectives of Development*

Understandings derived from the contribution of normative developmental processes for understanding the importance of early learning experiences (Bronfenbrenner, 1979; Gallagher, 2005; Greenspan & Wieder, 2006; Guralnick, 2005b; Shonkoff & Marshall, 2000), and the role of parents in ensuring quality parent-child interactions (Bromwich, 1997; Dunst, Johanson, Trivette, & Hamby, 1991; Gilkerson & Stott, 2000; Guralnick, 2006; Minuchin, 1985; Trivette & Dunst, 2000), guide modern day early intervention services for children with special needs. Additionally, family and socio-ecological systems theories help inform beliefs about what, why, and how modern early intervention and support practices should be provided to families (Bromwich, 1997; Bronfenbrenner, 1979; Greenspan & Wieder, 2006; Guralnick, 2006; Shonkoff & Phillips, 2000).

One of the most influential contributions shaping current practices within the field of early intervention is the application of a developmental systems perspective proposed by Guralnick (2001). Guralnick's developmental systems model has been shown to provide a useful comprehensive conceptual framework for understanding how early development unfolds through a series of multidirectional transactions between a child and his parents. During the early childhood period of development, these transactions occur initially and predominately within the context of the child's family system (Guralnick, 2006). Gradually, the child's world and its influences on development expand outside of the immediate family to the broader social systems and ecological context of the child's environments, including the influences of culture and other socio-political factors

(Beckwith, 2000; Guralnick, 2005a; Harbin, McWilliam, & Gallagher, 2000; Werner, 2000).

The following section further describes the unique, as well as overlapping, features of the developmental, family, social, and ecological systems perspectives and their respective contributions in providing the conceptual framework that underlies early intervention services for children with special needs.

### *Developmental Systems Model*

Guralnick's Developmental Systems Model provides a comprehensive model for understanding the relationship between family interaction patterns and child developmental outcomes that is inclusive of each of the above systems perspectives and normative theories of child development (Guralnick, 1997, 2005a). As such, it provides an overarching framework for understanding the type of interactions and experiences that all children need for optimal growth and development. Furthermore, it explicitly describes the pathways of influence and the various mediating or moderating factors that influence development and family functioning (Guralnick, 2006). This includes an understanding of the central role of families as the most proximal influence on a child's development, and the many contextual variables that either moderate or mediate the family's capacity to provide responsive, developmentally appropriate interactions and experiences (Bruder, 2000; Guralnick, 1997).

These factors include the quality of family social supports (Minuchin, 1985), availability or lack of financial and material resources, the degree of family coherence, level of marital stress (Bromwich, 1997), and personal and cultural beliefs about parenting practices and expectations (Guralnick, 1997). Additional factors that affect the

family's capacity to meet their child's needs reside within the child in the form of his or her individual traits such as temperament, biological risk, or disability (Guralnick, 1997).

All children, regardless of the presence of a special need or developmental challenge, require family interaction patterns that support optimal parent-child interactions in order to achieve positive developmental outcomes (Comfort, 1988). Guralnick identifies three types of family interaction patterns that are critical for optimal developmental outcomes in all children with or without risk or disability (Guralnick, 2005a). These three family patterns include (a) high-quality parent-child interactions, (b) family-orchestrated child experiences, and (c) family provision of a healthy and safe environment (Guralnick, 1997).

*Parent-child interactions.* Guralnick's first family pattern, high-quality parent-child interactions, is supported by normative child development theories which posit that all children require parenting practices that are sensitive, responsive, non-intrusive, and affectively warm (Guralnick, 2001). Previously described in this chapter, theories of normative development provide a frame for understanding the type of interactions that all children need, but especially for children with special needs (Shonkoff & Phillips, 2000). Barnard's (1997) exhaustive review of empirical research related to the influence of parent-child interactions on child outcomes, demonstrates a strong link between positive parent-child interactions and children's later cognitive and language development. Other researchers note the importance of parental awareness of the characteristics related to optimal parent-child interactions and the capacity to provide responsive, sensitive, nurturing caregiving for their child (VanHooste & Maes, 2003). The family support literature consistently identifies information about their child's disability and strategies

for managing child behaviors as an area of primary concern for parents of special needs children (Bailey & Powell, 2005).

*Family-orchestrated experiences.* In addition to quality parent-child interactions, all children require opportunities to learn about their world and to interact with age appropriate toys and other materials (Guralnick, 2006). These developmentally supportive, stimulating learning experiences are essential in promoting optimal development for all children, but especially for children with special needs (Spiker et al., 2005). These experiences include, parent-initiated activities such as arranging for therapeutic, educational, recreational and community activities that match the child's interests and special needs (Guralnick, 2001). Unfortunately, accessing community services, such as childcare, recreational, or social supports is a persistent challenge for families of children with special needs (Hebbler et al., 2007).

Hebbler et al.'s, (2007) National Early Intervention Longitudinal Study (NEILS) of 3,338 special needs children and their families participating in early intervention, found that the services most needed by families were those that enhanced their capacity to facilitate their child's development, or to access community based activities on behalf of their child. Their findings identified that the most frequently mentioned supports needed by families included information about other services (58%), information about recreational activities (41%), and finding childcare (30%). However, survey results indicated that only about one-half of the families that desired these services actually received these needed supports (Hebbler et al., 2007).

*Family provided health and safety.* Finally, optimal child development is dependent on whether the family is able to provide adequate healthcare, nutrition, and

protection (Guralnick, 2006). The ability of the family to provide for their child's health, nutrition, and safety needs is widely accepted as a key predictor of child development outcomes, for all children with and without disabilities (Garbarino & Ganzel, 2000). However, studies show that children with special needs are at greater risk for health and nutrition challenges related to their disability, such as feeding challenges and chronic medical needs, according to Garbarino and Ganzel, and are disproportionately more likely to live in households at or below the federal poverty level than are children without disabilities (Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008).

The NEILS study by Hebbler et al. (2007) also found a relationship between demographic factors such as low-income, minority status, and limited access to medical care and adequate nutrition – factors strongly related to poor birth outcomes and poorer health and development (Shonkoff & Marshall, 2000). Without support, many families are at-risk for a self-perpetuating transactional cycle in which poverty, via environmental factors, leads to disability, which in turn creates additional financial hardships for the family, resulting in poverty (Emerson, 2007). While the evidence strongly supports the importance of adequate healthcare, nutrition, and a sense of safety for positive child outcomes, families of children with special needs are at a substantially higher-risk of not being able to provide these basic needs without the assistance of outside support and resources (Parish et al., 2008).

Guralnick's conceptualization of these three family interaction patterns and the ability of families to provide quality parent-child interactions; opportunities for appropriate, stimulating experiences; and adequate health, nutrition, and protection for their child, demonstrates the importance of ensuring that families are able to access and



utilize the type of supports needed by their child and family. If not, then they are more likely to experience chronic and long-term stress related to parenting a child with special needs, further comprising their capacity to provide nurturing and responsive care giving, and ultimately negatively affecting the child's developmental trajectory (Guralnick, 2006).

However, if family interaction patterns are optimal, then the child has a greater opportunity for positive developmental outcomes. The family systems model specifically addresses the transactional relationship between the child and his or family, and sets the foundation for understanding the importance of ensuring that families are supported (Bromwich, 1997; Guralnick, 2006; Minuchin, 1985; Parish et al., 2008).

#### *Family Systems Perspectives*

Pearl (1993) describes family systems theory as the understanding that the “family is a system and that actions affecting any one member affect all of the members” (p. 84). Similar to other systems, a family system is dynamic and constantly changing, seeks to maintain homeostasis, and expresses behaviors that have positive functions for the family, according to Pearl. Minuchin (1985), one of the earliest proponents of a family systems theory approach to development, conceptualizes each individual as being interdependent and as such both influences and is influenced by other members of the family system. As such, family systems theory would predict that changes by one member of the family will have an impact on the entire system, a premise that supports one goal of early intervention, namely to positively influence parent behaviors so as to provide the type of interactions that support positive child outcomes.

The family system, consisting of the child, parents, and other family members is the most proximal context for children (Bronfenbrenner, 1992; Minuchin, 1985). Within the family system, parents interact with their child in a transactional manner in which developmental outcomes are influenced by the dynamic and continuous interaction between the child and his or her family (Sameroff & Fiese, 2000). The transactional model holds that the quality and nature of the parent-child relationship and the effect of this relationship on child development is a major influence on child and family outcomes (Shonkoff & Phillips, 2000). Additionally, the transactional perspective sees the role of the parent in terms of his or her capacity to be available to their child, the amount and quality of nurturance and support provided to the child, and the quality of early learning experiences provided to the child (Bruder, 2000; Harbin & Salisbury, 2000). Because the caregiver-child relationship and interactions form the basis of early and later development, it is essential that these interactions are mutually pleasurable and rewarding for both the parent and the child (Bromwich, 1997; Minuchin, 1985).

According to Guralnick and other supporters of family systems theories of development and parenting behaviors, there are many factors that act as either mediators or moderators on family functioning (Bruder, 2000; Guralnick, 1997). These factors include the quality of family social supports (Minuchin, 1985), availability or lack of financial and material resources, the degree of family coherence, level of marital stress (Bromwich, 1997), and personal and cultural beliefs about parenting practices and expectations (Guralnick, 1997).

Mink, Nihira and Meyers (1983) have studied the relationship between family cohesiveness and child outcomes extensively. Their study of 115 families with children

in TMR classes, investigating the relationship between family emotional climate, value orientation, family management style and child outcomes , showed a strong relationship between high levels of family cohesion and harmonious interactions and more positive social-emotional outcomes for children (Mink et al., 1983). Likewise, Hauser-Cram et al.'s (2001) 10 year longitudinal, Early Intervention Collaborative Study (EICS) of the development of 183 children and family well-being, demonstrated that family cohesiveness and mother-child interactions predicted later growth in children's communication, social, and daily living skills during the first 5 years of life growth.

However, the parent-child relationship is transactional and in addition to factors that affect the parent' capacity, there are factors that also reside within the child in the form of his or her individual traits such as temperament, biological risk, or disability (Guralnick, 1997). Hassall's (2005) review of the literature related to parent adaptation to caring for a child with intellectual disability, found that the most frequently cited child characteristic that resulted in parental stress was the extent to which the child exhibited substantial behavior problems, a finding supported by other studies (Weiss, 2002). In contrast to these findings, Dunst et al., (2007) used structural equation modeling to examine the effects of severity of child disability on 250 parents of children birth three; and found no direct or indirect effects of child disability on parental well-being.

### *Social Systems Perspectives*

In comparison to the family systems model, social systems perspectives focus on the effects of social structures outside the immediate family on family functioning and child development (Seligman & Darling, 2007). For example, a parent's cultural values may influence how they perceive their child's disability, or the type of parenting practices

they use. Similar to other transactional models explaining the bi-directional effects of social interactions, social systems theorists posit that individuals are shaped by society, and individuals, in turn, reshape society, according to Seligman and Darling.

In relation to families of children with special needs, Dunst, Trivette, and Deal (1994), describe a social systems perspective in which the family is viewed as “a social unit that is embedded within other formal and informal social support systems and networks” (p. 4). These informal social contexts, such as those within extended family or friends, and formal contexts, such as professionally conducted support groups or early intervention/education services, are interdependent and changes within and between these contexts influence changes in other contexts (Dunst et al., 1988).

The need for social support for families of children with special needs is consistently identified in the literature as one of the most important supports desired by families, as well as related to parent coping and overall well-being (Armstrong, Birnie-Lefcovitch, & Ungar, 2005; Weiss, 2002). Boyd’s (2002) review of literature on the relationship between lack of social support and stress in mothers of children with autism, revealed consistent results within the studies examined, showing that as the level of mother’s social support decreased, there was a corresponding rise in level stress and depression in mothers.

Understanding the interrelatedness of the family systems model and the social systems model has important implications for how family supports are provided. For example, when viewed from a family systems perspective, family support might focus on helping the family, or individual family member to use existing resources to adapt to parenting a child with special needs. On the other hand, within a social systems

perspective, a family might have adequate internal resources, but may need help with accessing and using resources outside the family, such as educational/therapeutic supports for their child or social support for themselves (Seligman & Darling, 2007). The point being, that there are multiple levels upon which support could be provided to families, and therefore, it is important to make sure that the supports offered or provided to families match their expressed needs.

### *Ecological Systems Perspectives*

While family systems perspectives emphasize the parent-child relationships and the resulting interactions, the ecological view of human development expands this concept further by describing how child development is influenced by interactions within and between various environments that exist inside and outside of the immediate family (Bronfenbrenner, 1992; Bruder, 2000). Because the family is the context within which the child develops, and is the most proximal and powerful influence, it is essential that early intervention services support the family's capacity to promote positive development and overall family well-being.

Based on the work of Uri Bronfenbrenner, the ecological system model of development states that growth and development of children is influenced by the interactions between the child, his or her environment, and the relationships that child has with people around him or her (Bronfenbrenner, 1979). This influence is a two-way process in which the child influences his or her environment and that the quality and nature of these mutually influential interactions either enhance and support or hinders the child's development (Bruder, 2000). Similar to the family systems perspectives, the quality of the child's relationships with his or her caregivers is a critical factor that either

positively or negatively influences development. However, the ecological systems approach expands the sphere of influence beyond the family to include the family's social support network and access to community resources (Halpern, 2000).

Bronfenbrenner's ecological systems perspective describes development as occurring within multiple systems and subsystems (Bronfenbrenner, 1979; Garbarino & Ganzel, 2000). The *micro* system includes the family and child, and functions as the immediate context for supporting and enhancing a child's development, according to Garbarino and Ganzel. The *meso* system represents the relationships between the multiple systems within which the family and child function such as extended family, friends, and community (Marshak et al., 1999). The *exosystems*, such as educational systems or the parent's workplace, are systems in which children are not directly situated, but indirectly influence children's development via established policies or work related demands faced by parents, according to Garbarino and Ganzel as well as Marshak et al. The *macrosystem* consists of the ideological and belief systems, which includes cultural, religious, socioeconomic and political elements, according to Marshak et al. Whereas the family and social system perspectives focus primarily on interactions between family members and other significant individuals outside the family unit, ecological systems perspectives addresses the influence of environments and the effects of larger societal factors.

Accordingly, events that occur in one subsystem, such as parent's employment, interact with other systems, such as parent-child interactions, in a transactional manner (Sameroff & Fiese, 2000). Therefore, it is essential that early intervention/special education services take into account factors that influence the child's development

within the child's immediate or proximal system level (i.e., family) as well as more distal system levels, such as school or daycare, neighborhood, family social networks, socio-cultural (Bronfenbrenner, 1992).

Dunst, Hamby and Brookfield (2007) used structural equation modeling to examine the effects of person and environmental variables on parent and family well-being using ecological systems theory to ground their study in the literature. The model evaluated the effects of family characteristics, child disability, family-centeredness, and early intervention program variables on parent perception of control and family well-being. The results of survey data collected from 250 families of children participating in early intervention programs supported the ecological systems perspective that individual well-being and behaviors are affected by multiple person, intervention, and non-intervention variables (Dunst et al., 2007).

In summary, the developmental, family, social, and ecological systems perspectives provide a comprehensive conceptual framework for understanding normative child development as well as the influential role of family, social relationships, culture, and environments in shaping child development. Furthermore, conceptualizing the family, social, and ecological systems perspectives as subsystems of the overarching developmental systems model helps explain how various factors interact in a transactional manner to influence the child's developmental trajectory. In particular, Guralnick's Developmental Systems Model provides a comprehensive explanation of the pathways in which having a child with special needs influences the family's capacity to provide optimal family experiences and quality parent-child interactions.

The following sections discuss how parenting a child with special needs affects the family experience, the type of supports found to help families through the process of adapting to this event, and recommended practices for providing these family supports.

### *Effects of Child's Special Needs on the Family*

When a family is contemplating the birth of their child, they are not planning to have a child with a special need or disability. However, when parents are told that their child has a severe developmental, social, emotional, or behavioral challenge, the “dream” that parents created about their child and his or her future is shattered and a new dream must be developed (Barnett et al., 2003). It is well-documented that having a child with a disability or special need frequently causes substantial stressors that have the potential of negatively impacting the family’s ability to adapt and cope with this unexpected event and their ability to provide the types of experiences children need (Guralnick, 2005a). However; recent trends in research on families of children with special needs is focusing more on identification of family strengths, and greater understanding of the coping strategies and resources that families use to achieve successful adaptation (Summers et al., 1988).

The ABCX model of stress, coping, and adaptation, originally proposed by Hill (1949) to explain family coping and adaptation when faced with crisis, and later expanded to the Double ABCX model conceptualized by McCubbin and Patterson (1983) is increasingly used as a framework for understanding the effects of stress on families of special needs children.

In the ABCX model, the stressor event, such as having a child with a disability (A), interacts with the family’s need for and/or availability of information, social support,



and resources (B), which in turn interacts with how the family makes meaning of their experiences and the family's perception of their ability to cope with the event (C). The resources available to the family, and the family's perception of their capacity to cope with having a child with special needs, ultimately influence whether the family experiences a crisis (X), or if they are able to prevent the situation from becoming a crisis (Hanson & Lynch, 2004; Hassall, 2005; Kelly et al., 2005; McCubbin & Patterson, 1983; Summers et al., 1988).

According to the ABCX model of stress, the presence of a stressor does not itself determine how a family will react to an unexpected or adverse event. Rather, it is the families' capacity to manage the stressor, while simultaneously sustaining interpersonal and familial equilibrium, which is a key predictor of family adaptation (Seligman & Darling, 2007). Additionally, family reactions to stressors is viewed as a dynamic process in which the family confronts new stressors as their child grows and develops or during times of major life cycle transitions (Marshak et al., 1999; Summers et al., 1988).

The ABCX model is consistent with the developmental, family, social, and ecological systems approaches described previously in this chapter. Furthermore, the model supports Guralnick's Developmental Systems Model by providing a framework for understanding various factors that may influence family coping and adaptation. In particular, the model supports identification of interpersonal, family or child characteristics that influence the families need for resources and supports, and the families perceptions of meaning and if they have the resources and supports to manage the stressor event (Kelly et al., 2005). The utility of this model is the ability to use this information to support decision-making about the type of supports an individual family

needs. The two primary constructs associated with the ABCX model - stress and coping/adaptation are described in the next section.

### *Stress*

Considerable research on the effects of a child with a disability on the family identifies anger, anxiety, guilt, stress, despair, and depression as common reactions and threats to the quality of the parent-child relationship (Bailey et al., 2006), which may result in negative outcomes for the child (Goodman & Gottlieb, 2002).

Marshak, Seligman and Prezant (1999) define stress as “a life event or transition impacting the family that can produce change in the family system” (p. 12). Seligman and Darling (2007) describe five types of stresses that families of children with special needs often experience: intellectual stress, instrumental stress, emotional stress, interpersonal stress, and existential stress. Each of these are briefly described in the next section.

*Intellectual stress.* Intellectual stress involves information needs. In particular, families seek to understand the nature of their child’s special needs, and the type of supports and services needed to help their child (Bailey & Powell, 2005). Guralnick (2001) identifies several potential areas that contribute to intellectual stress, including parent concerns about child’s health and future disability related outcomes, behavioral challenges, inadequate or insufficient services, and lack of knowledge on effective parenting strategies.

Bailey and Powell’s (2005) review of 11 studies using the Family Needs Survey Tool, showed that parents identified the need for information as being substantially higher than other domains assessed (e.g., family and social support, financial, explaining to others, childcare, professional support, community services). These studies represented

parents of diverse ethnicities, countries, and age groups, yet the information domain was reported by 52% of respondents as being a definite need, while 28% reported the other domains as being a definite need. They further report that these needs are persistent throughout the child's development, and do not subside, as the child grows older.

*Instrumental stress.* Instrumental stress is related to the family's ability to accommodate their child's special needs into the family's established daily routines. The focus of this task is for families to manage successfully their day-to-day activities that support the family, as well as the child with special needs (Bernheimer & Weisner, 2007; McWilliam, 2005). Families with children who have special needs experience extraordinary challenges with maintaining daily family routines, meeting financial demands, and having time for other members of the family (Guralnick, 2006). To exacerbate this situation, many therapeutic services are offered during traditional working hours (e.g., 9 to 5), which makes it difficult for families to either take their child to services, or to fully participate in their therapeutic programs.

Additionally, families may experience a financial burden because publically funded sources do not always pay for all of the services a family desires for their child (Guralnick, 2006). Parish et al. (2008) found that families of children with special needs experience severe hardships in terms of employment, childcare, and basic needs. In particular, they noted that, in spite of the economic need for two-incomes, many mothers are unable to work due to demands related to caring for their child, or the inability to find quality childcare.

*Emotional stress.* Emotional stress includes family reaction to their child's special needs, and their perceptions of whether they have the interpersonal and family resources

to cope and adapt. Formal and informal social supports are important in helping reduce the effects of stress on the family system (Dunst et al., 1997). The challenges associated with parenting a child with special needs can create substantial levels of emotional stress and threats to parent confidence (Guralnick, 2001). Mothers of children with autism are particularly vulnerable to emotional stress related to their child's intensive developmental needs or behavioral challenges (Boyd, 2002; Moes, 1996).

Boyd's (2002) review of literature examining the relationship between stress and lack of social support in mothers, identified behavior management and child cognitive limitations as the most frequent reason for seeking social support. In spite of this need, they found a paucity of supports available. Gray (2006) supports this relationship and notes a negative correlation between parent depression, anxiety, anger and social support.

*Interpersonal stress.* Interpersonal stress relates to the effects of the child's disability on individual family members, in particular how parents individually cope with parenting a child with special needs and how they work through normal stages of grieving and acceptance (Orsmond, 2005). Studies show that parents of children with special needs experience higher levels of stress, anxiety, and depression that can negatively affect parent-child interactions (Crnic & Stormshak, 1997). Although families whose children do not have disabilities also experience interpersonal stress, families of children with special needs are at higher risk. Some studies relate this type of parental stress with increased rates of divorce (e.g., 20% higher than general population); however, these studies are inconclusive and many families are able to cope and adapt (Seligman & Darling, 2007).

*Existential stress.* Existential stress is associated with how families make meaning of their child's special needs. Successful adaptation is strongly associated with parental cognitive beliefs about the cause of their child's disability, and their conceptualization that there is a positive meaning or purpose (McCubbin & McCubbin, 1987). The phrase "why me" appropriately describes a parents response they discover that their child has a special needs (Seligman & Darling, 2007). One of the primary tasks for parents is to "build new dreams" for their child and themselves, indeed, Barnett et al. (2003) contend that "healthy adaptation is central to parents developing a satisfying attachment with their child" (p. 197).

Each of these areas of stress has the potential to result in a positive or negative effect, depending on the family's coping capacities and their ability to access and utilize the type of social support that is needed at any given time (Crnic & Stormshak, 1997; Marshak et al., 1999). The literature related to coping and adaptation provides the conceptual framework for understanding how families not only adjust, but can also be stronger because of their experiences (Summers et al., 1988).

### *Coping and Adaptation*

It is important to note that not all families react negatively, and that many behaviors typically observed in families of children with special needs are normal, healthy coping strategies that ultimately lead to successful adaptation and accommodation (Walsh, 2002). While there is a substantial body of empirical research documenting the negative effects of stress on families of children with special needs, there is less research focused on how families successfully cope with their child's disability, and ultimately achieve positive adaptation (Summers et al., 1988).

However, the research on coping and adaptation among parents of children with special needs, demonstrates that many families perceive their situation, not as a tragedy, but as an making a positive contribution to their family (Summers et al., 1988). For example, Wikler's (1983) study of chronic sorrow among 27 parents of children with developmental disabilities found that over 75% of parents felt that their experiences made them stronger, with 46% of these responding that they had been made much stronger, according to both Summers et al. (1988) as well as Wikler et al.

In contrast to conventional models of grief and loss accepted within the field of psychology (Kubler-Ross, 1969) in which acceptance and resolution are seen as having a definitive end point or final stage, Barnett et al. (2003) suggest that the term adaptation more accurately reflects the dynamic nature of the parent's journey. Accordingly, they describe the family's process as continuing throughout the child's lifetime in which each new stage or change of events requires the family to re-evaluate and make new adaptations.

In order to help parents through the adaptation process, Barnett et al. (Barnett et al. 2003) developed a parent group intervention that systematically guides parents through the process of identifying and validating feelings, strengths, and supports; helping parents engage in mutual support and sharing; increasing parent's perceptions of available support, improving their skills at seeking information; and promoting parenting sensitivity and effective parenting. Thus far the model has not been empirically tested, and while the parent support group model may work for some (e.g., parents ready to change or comfortable in a group setting), other parents might not achieve a successful

outcome from participation (e.g., the need for ongoing support, beyond the initial 6 week session).

The ability to achieve a sense of mastery and control over unexpected events is considered to be an important task related to coping and adaptation. First described by Taylor (1983) in relation to his work with cancer survivors, he described the need for individuals to develop management control (e.g., feeling of control over event and being able to manage it). Behr et al. (1992) described mastery/control as an individual's belief that one can personally take active steps to control events in one's life (internal control), and/or that events are controlled by others (external control). In relation to parents of children with special needs, Summers et al. (1988) further describe control as having multiple dimensions. They identified the following areas as predictive of parental adaptation, which includes: information control (e.g., learning about the situation); behavioral control (e.g., taking direct action to change or improve the situation); participation control (e.g., taking part in treatments and training); and decisional control (e.g., perceiving that one has control over the decisions that are made) according to Summers et al. as well as Thompson (1981). Related to the construct of mastery and control is the sense of self-efficacy. Desjardin (2005), describes self-efficacy as the "parent's perceived estimations of competence in their parental role and confidence in their own abilities to perform each task" (p. 194). Grounded in Bandura's (1989) social learning theory, an efficacious parent has both the knowledge of how to parent their child effectively as well as the confidence and competency to implement prescribed strategies.

In summary, for most families, the unexpected news that their child has a disability or special need causes some degree of interpersonal and family distress that

threatens their sense of parenting confidence, competence and locus of control. Often, when families experience one or more stressors, their capacity to meet their parenting demands may be threatened, resulting in potentially negative outcomes for the child as well as the family. Because the quality and context of interactions between parent (usually the mother) and child are predictive of later child outcomes, it is important that families are provided the supports needed to maximize their child's growth potential.

### *Family Support Needs*

A study by Affleck et al. (1989) showed that mothers who expressed a need for program services were observed to demonstrate more positive outcomes such as improved sense of competency, perception of control, and improved responsiveness to their child. However, just the opposite was true for mothers who did not report a need for services, but accepted them anyway. In these mothers, the study's authors observed a reduced sense of competence, decreased control, and less responsiveness to their children at the conclusion of their early intervention experience, according to Affleck et al. This study demonstrates that program effectiveness is more than what services are provided, or the quality with which services are implemented, but that an equally strong predictor of successful outcomes is the extent to which services match the unique needs of the family and child.

Several studies indicate that parental adaptation is enhanced when families have adequate formal and informal social supports and feel empowered and competent in their parenting capacities (Crnic & Stormshak, 1997; Dunst & Deal, 1994). Other researchers found that what families wanted most from early intervention was information and support (Summers et al., 1990). There is a substantial body literature and numerous



studies that document the type of supports that families express as being most helpful in coping with parenting a child with a disability or special need. While each study uses slightly different terminology, the most frequently described needs requested by families fall somewhere within the three categories of (a) information, (b) social support, and (c) resources (Guralnick, 2005a).

### *Information*

The need for information is repeatedly cited as one of the most important concerns expressed by parents of children with special needs. Wesley et al. (1997), conducted a qualitative descriptive study using a focus group of 13 parents with children birth to 5 years in order to gain a better understanding of their experiences as participants in early intervention/early childhood special education services. Consistent with findings from other studies, participants expressed a strong need for information about services and family supports. In particular, families requested that information be centralized and provided in a format that was easy for them to understand and use (Summers et al., 1990; Wesley et al., 1997). The researchers concluded that although the results of this study cannot be generalized beyond this study, the information obtained and the processes use to obtain the information (e.g., focus group discussion with parents) is valuable in its utility for program design and development, according to Wesley et al.

### *Social Support*

Armstrong et al. (2005), proposed a conceptual model of the pathway between social support and parent well-being. In their model, social support serves two functions in relation to individual well-being: it supports an individual's sense of well-being even

when not under stress, and it protects an individual from harmful effects of stressful events (p. 272).

Weiss (2002) examined the effects of social support relationship and hardiness on stress in mothers ( $n = 120$ ) of children with autism ( $n = 40$ ), mental retardation ( $n = 40$ ), and children without disabilities ( $n = 40$ ). There were significant differences among participants on hardiness and social support with mothers of typically developing children showing the highest levels of hardiness and mothers of children with autism the least hardy attitudes, with mother of children with mental retardation in between. Measures related to interpersonal support, likewise had significant effects, with mothers of typically developing children reporting more availability of social supports and mothers of children with autism to considerable less available, with mothers of children with mental retardation in between.

In Gray's (2006) longitudinal ethnographic study of 28 families of children with autism examined how families cope with their child's special needs over time. Parents were asked to describe the most important factor in helping them to cope with parenting a child with autism. At the beginning of the study, when their children were young, parents reported that services and supports were readily available and expressed hopefulness that their child would improve and ultimately appear normal.

However, at the 10-year follow up, most of the children were exhibiting moderate to severe autism, and parents were receiving fewer services and supports for their child. Contrary to expectations that parental coping would improve over time, the participant's in Gray's study showed a decline in the use of coping strategies, especially in the form of social support. Additionally, parent use of emotion-focused rather than

problem-focused strategies increased. Gray noted that as coping strategies declined, so did the availability of supports and services, suggesting a negative relationship between level of support and usage of coping strategies. His findings showed that as the need for social support increased as the child got older, that the availability of supports decreased, along with parent coping strategies. Gray's (2006) study shows that that the need for social support remains high throughout the child's development.

### *Resources*

Parish et al. (2008) examined the effects of material and financial hardship on families of children with special needs. The 2002 National Survey of America's Families (NSAF), a national survey of 42,000 households, served as their data source for their national, cross-sectional examination of a subsample of a 28,141 households with children, of which 2,970 had a child with disabilities, and 25,171 a non-special needs child, according to Parish et al. Their results showed that families with special needs children were significantly more likely to experience material and financial hardship, with 78% reporting concerns about not having sufficient food to meet their families' needs.

### *Family-Centered Practice*

A core belief embedded within early intervention/special education services is the recognition of the central role of families the development of young children and the recommendation that services should be family-centered (Dunst, 2002). The rationale for family-centered practices is based on the recognition that the capacity of families to meet the developmental needs of their child is mediated by the formal and informal resources and supports available to the family and the manner in which these resources and

supports are provided (Harbin et al., 2000; Sameroff & Fiese, 2000; Trivette & Dunst, 2000).

The current model of family-centered practice, in which parents are equal partners in their child's therapeutic and education program, has evolved from earlier program models that initially focused on supporting families so they could raise their children at home in order to avoid institutionalization (Bailey & Powell, 2005). Professionals saw their work with families as training and educating parents how to be better teachers at home (Bailey & Powell, 2005; Dunst, 1999; Mahoney et al., 1999), and was based on a deficit model, in which it was presumed that parents were somehow deficient in their parenting capacities, according to Mahoney et al. However, early intervention programs today are based on a family strengths model, which assumes that all families are capable and competent, and that the purpose of early intervention is to promote the ability of families to access the supports they need for effective parenting (Dunst & Deal, 1994).

Describing the critical role of parents in their child's development, Bromwich (1997), in her seminal book, *Working with Families and Their Infants at Risk*, states "a primary function of early intervention is to facilitate and enhance reciprocal, mutually satisfying interactions between infants and their primary caregiver-parents" (p. 8). The ultimate aim of early intervention/special education, according to Bromwich, is to provide each child with the best opportunity to reach his or her long-term optimal potential in physical, cognitive, communication, social, and emotional development, according to Bromwich. The mechanisms suggested to achieve these goals include supporting and encouraging pleasurable interactions between children and parents, helping parents gain a sense of competency, strategizing with parents to reduce stress in

their family, and providing information and access to community supports and services (Bromwich, 1997).

Underscoring the utility of a family-centered approach, The Council for Exceptional Children/Division of Early Childhood states that:

Family-based practices provide or mediate the provision of resources and supports necessary for families to have the time, energy, knowledge, and skills to provide their children learning opportunities and experiences that promote child development. Resources and supports provided as part of early intervention/early childhood special education (EI/ECSE) are done in a family-centered manner so family-based practices will have child, parent, and family strengthening and competency-enhancing consequences. (Trivette & Dunst, 2000, p. 39)

The Association for the Care of Children's Health (1989) defines family-centered care as a philosophy of care that acknowledges and values the central role that the family plays in children with special needs. According to Pearl (1993), family-centered practice consists of the integration of family systems theory, which recognizes that actions affecting one family member affect all other members of the family, and family empowerment, which encompasses the concepts of parent sense of competency and confidence. Bailey et al. (1998) believes that family-centered practice encompasses three broad themes that recognizes the individual nature of families' needs, concerns, and priorities; views families as partners in planning and providing services; respects families as the ultimate decision-maker and the constant in the child's life.

The definition of family-centered early intervention widely accepted by professionals, and the definition used in this study, is defined by Dunst (2002) as:

Beliefs and practices that treat families with dignity and respect; individualized, flexible, and responsive practices; information sharing so that families can make informed decisions; family choice regarding any number of aspects of program practices and intervention options; parent-professional collaboration and partnerships . . . and the provision and mobilization of resources and supports

necessary for families to care for and rear their children in ways that produce optimal child, parent, and family outcomes. (p. 139)

Dunst and Trivette (1988) were among the first within the field of early childhood intervention to describe the core focus of family-centered practice; namely, *to enable and empower* families so they gain a sense of confidence, competency, and control in order to meet their child's developmental needs. Accordingly, to enable means to create opportunities for competence to be displayed or learned and to be empowered implies that the individual attributes changes in behavior or a situation to his or her own actions. A key goal of empowerment is to help families gain a sense of mastery and control over their present and future lives (Zimmerman & Rappaport, 1988).

As such, the primary purpose of family centered practice is to develop and strengthen the families' parenting competencies and confidence in their ability to meet their child's needs (Trivette & Dunst, 2000), to promote parent empowerment (Dunst et al., 1988), parent decision-making (Bailey & McWilliam, 1993), and to ultimately enhance the family's well-being and overall quality of life (Turnbull et al., 2007). Accordingly, family-centered practice recognizes and respects the pivotal role of the child's family and as such are considered integral for successful early intervention (Bailey et al., 1998; Bromwich, 1997; Guralnick, 1998; Pearl, 1993).

#### *Desired Family Support Outcomes*

The core principle of family-centered support is based on the understanding that as primary context for the child, the family exerts the most influential force on a child's development. Mahoney's (2003) empirically based research on the effects of parent training on child outcomes, demonstrates that parent responsiveness to their child is a key

predictor of more positive outcomes for children with special needs (Mahoney et al., 1996). Additionally, the family should be viewed as a partner in their child's early intervention/special education services with their own individual family concerns, priorities, and resources that have a direct impact on the effectiveness of services for their child. (Bailey & Wolery, 1992; Crnic & Stormshak, 1997; Sandall et al., 2000). Finally, a core goal of family support should be to empower parents so they are able to make informed decisions regarding the needs of their child and family, thus enabling them to develop a sense of control, competency, and confidence in their ability to successfully impact their child and family's outcomes (Dunst, 1985).

Similarly, Bailey et al. (2006) proposed that early intervention services should include enhancing the family's perception of support, confidence, and competency in meeting their child's needs. The concept of empowerment, parental competency and sense of confidence in supporting and nurturing their child's growth and development is strongly supported in the literature as a core outcome for early intervention/special education for young children (Bailey & McWilliam, 1993; Bromwich, 1997; Bruder, 2000; Dunst et al., 1988; Hausslein, 1994; Mahoney & Perales, 2003; Sameroff, 1987; Trivette & Dunst, 2000; Turnbull et al., 2007).

According to Bromwich (1997), the ultimate goal of early intervention is to promote optimal outcomes for infants and young children within the context of supportive, nurturing relationships and environments. In order to achieve this, a crucial task of early intervention is to support and encourage parents and other primary caregivers to gain a sense of confidence and competence so they are able to support their child's development. These enabling and empowering experiences are crucial in helping

parents to gain a sense of control and confidence in their capacity to manage their child and family's needs (Dunst et al., 1988).

### *Implications of Study*

The body of qualitative research that explores family perspectives of their experiences with accessing and using information, social support, and resources is limited. Furthermore, most studies conducted to date use closed-ended surveys to measure parent satisfaction with services, rather than perspectives of their experiences (Freedman & Boyer, 2000).

Over 10 years ago, Guralnick called for a second generation of research in the field of early intervention/early childhood special education, that goes beyond asking the question of parent satisfaction, or the extent to which a given practice is effective. The question of whether services for children are effective has been answered in the affirmative. However, there is a real need to gain a deeper understanding of how families experience their participation in services for their children. Because of the subjective nature of parent perspectives, gathering stories from families using open-ended semi-structured interviewing processes generally yields a richer description of family experiences that can be analyzed for common themes and categories (Allen, 2007; Freedman & Boyer, 2000; Shannon, 2004).

All levels of publicly funded education programs, including those serving children with special needs, are accountable for showing evidence that they are meeting the needs of children and families. Because the program being investigated is going through the process of developing new services and supports to meet the needs of families with children over 3 years of age who have special needs, it is appropriate to first



identify the type of supports families need and desire, and their perceptions of experiences that either enhance or inhibit these experiences. The investigated program is committed to family-centered practice that seeks to enable and empower families to achieve a sense of competency, confidence and control over accessing and using supports to meet the needs of their child and family.

### Summary

In summary, the previous sections of this chapter have discussed a brief history and overview of past and present services for families of children with special needs; a systems framework for understanding the effects of parenting a child with special needs on the family; as well as recommendations found in the literature for enhancing family coping and adaptation.

It is well-documented that families of children with special needs experience some degree of stress in relation to parenting a child with special needs. And while some families do experience substantial challenges in coping with and adapting to challenges associated to caring for a child with disabilities, current research indicates that successful, positive adaptation is possible when families are provided information, social support, and resources that are congruent with the individual needs of their family.

In spite of a strong theoretical basis for the importance of family support and the development of comprehensive conceptual models to guide how family supports should be implemented, families of children with special needs continue to have difficulties accessing and utilizing information, social supports, and resources. Even though families of children with substantial developmental challenges are entitled to parent support, education, and training; in practice families often are not able to access adequate family

support, especially after a child transitions from IDEA Part C to Part B services (Meisels & Shonkoff, 2000), or from preschool to kindergarten and later to grade school and beyond (Seligman & Darling, 2007).

Families of children between 3 and 5 years of age in particular, are sandwiched in between two highly stressful events that can affect the ability of a family's system to cope with these stressors with flexibility, stability, and balance: the transition to preschool and the transition to kindergarten (Dunst, 1985). To add further challenges to the family system, there is a dramatic shift in not only what services are provided, but also in how services are provided. The transition procedures that IDEA specify may seem practical in terms of managing and administering these programs; however, both families and early childhood experts feel that the abrupt loss of the positive relationships that families established with early intervention personnel, are at the very least frustrating, and even more so, leave families without a system of support (Harbin et al., 2000). In spite of the increased need for information, social support, and resources families often experience a dramatic reduction or elimination of support services.

## CHAPTER 3: METHODS

This study will explore those factors that parents of children with special needs perceive as enhancing and inhibiting their experiences, as well as, their appraisal of control. The information obtained from this study can guide the investigated program's decision-making about practices that work and should be leveraged or exploited, and those practices that do not work, and should be confronted or mitigated. More importantly, making decisions about what action to take derived from the subjective experiences of parents who will be the ultimate users of the program's services will ensure that they have a voice in shaping future program practices.

While many families readily accept and adapt to having a child with developmental challenges, others experience some degree of stress that triggers a need for information, social support, and additional resources to achieve successful family adaptation (Dunst et al., 1997). In order to gain a better understanding both of the lived experiences of families whose children with special needs participate in early intervention or special education services as well as the meanings they make of these experiences, a mixed methods descriptive and phenomenological study was conducted using a participatory research design. The research questions investigated in this study are as follows (see Appendix A):

RQ 1: What are the lived experiences of families whose children with special needs participate in early intervention or special education services and what meanings to they make of these experiences?

RQ 2: What are families' lived experiences accessing and utilizing information, social support, and resources?

RQ 3: What are families' appraisals of control over their experiences accessing and utilizing information, social support, and resources?

RQ 4: What are families' perceptions of the type of experiences that enhance or inhibit their access and utilization of information, social support, and resources?

RQ 5: To what degree, if at all, is there agreement among families' ratings of the value of enhancing or inhibiting experiences, and their appraisals of control over these experiences?

According to Bruder (2005), a participatory research design is based on the belief that knowledge is socially constructed, contextually grounded, and experience based. Because this approach supports developmental, social, family and ecological systems perspectives utilized in this study, and because it emphasizes interaction and interdependence between and among systems, a participatory research approach was used in this study to explore family experiences of their experiences. In addition to utilizing a participatory approach, the researcher employed mixed methods consisting of both qualitative and quantitative data collection and analysis measures.

Qualitative methods were used to obtain families' lived experiences and the meanings they make of their experiences with accessing and utilizing information, social support, and resources related to their child with special needs between the ages of three and 8 years of age. Open-ended research questions were posed during a single focus group interview consisting of 6 mothers of children diagnosed with mild to moderate autism spectrum disorders in order to capture their stories and the related themes that emerged from their shared experiences (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004).

Quantitative methods were used to further examine participant’s responses to ensure that the study results and findings accurately reflected the perspectives of all participants as a whole, as well as capturing each parent’s individual voice (Sandall, Smith, McLean, & Ramsey, 2002, p. 135). The researcher used descriptive open-ended research questions that were non-directional and consistent with the qualitative and quantitative measures used in this study for both data collection and analysis (Creswell, 2003; Isaac & Michael, 1995). (See Table 1 for research questions and data collection methods.)

Table 1

*Mixed Methods Data Collection*

Research Question	Data Collection Method
RQ 1 What are the lived experiences of families whose children with special needs participate in early intervention or special education services and what meanings do they make of their experiences?	Qualitative
RQ2 What are families’ perceived experiences with obtaining (a) information, (b) social, and (c) resource support?	Qualitative
RQ3 What are families’ perceptions of the type of experiences that enhance or inhibit their attainment of (a) information, (b) social, and (c) resource support?	Qualitative Quantitative
RQ4 What are families’ appraisals of control over these experiences?	Qualitative Quantitative
RQ5 To what extent, if any, is there agreement within or among families’ ratings of the value of enhancing or inhibiting experiences, and their appraisal of control over these experiences?	Quantitative

The researcher developed four pre-determined categories to guide the focus group interview to ensure that information provided by participants related to research question

1 (family lived experiences and the meanings they make of these experiences) and research question 2 (family perceptions of experiences obtaining information, social support, and resources).

The researcher developed the Family Support Survey, a Likert-type tool designed for this study, to collect and analyze quantitative data in order to answer research question 3, (family perceptions of experiences that enhance/inhibit their experiences), and research question 4 (family appraisals of control of their experiences). The use of participant's own responses as the content for the survey was employed as an additional measure to add depth of understanding, as well as to increase confidence in the trustworthiness of their responses (Blue-Banning et al., 2004).

Following the IE<sup>2</sup> Matrix protocol developed by Leigh (2000, 2004, 2005a, 2009), the Family Support Survey tool was organized around categories of influence, referred to as SWOTs (strengths, weaknesses, opportunities, and threats). Factors perceived as enhancing participants' experiences with obtaining desired supports and under participants control are strengths, while factors that are hindering or inhibiting are weaknesses. Factors that are outside of participant's control and enhancing are opportunities, and those that are hindering or inhibiting are threats.

Data for research question 5 (degree of agreement between and among families' responses) was collected from participant's responses on the Family Support Survey and analyzed for group means ratings of responses using measures of central tendency and variability. An hierarchical cluster analysis (Ward's option) was used to identify differences and similarities among participant responses.

As a further measure to enhance interpretation of results and to facilitate decision-making based on participant's responses, the researcher used the IE<sup>2</sup> SWOT Matrix and Grid to plot bivariate data obtained from participants' group means ratings from their survey responses (Leigh, 2000, 2004, 2005a, 2009).

The research design and methods used to collect, analyze, and interpret data collected from interviews with a selected group of parents during the focus group interview are described in this chapter.

### Research Design

The purpose of this phenomenological descriptive and mixed methods study was to explore and describe the lived experiences of families with special needs children over 3 years of age participating in early intervention and special education services. In particular, the study aimed to gain a better understanding of families' lived experiences with accessing and using information, social support, and resources and the meanings they make from these experiences. Additionally, the study examined factors that enhance or inhibit parent experiences, and their appraisal of control over their ability to access desired and needed supports. Furthermore, the study sought recommendations from families regarding what and how the investigated program can provide the type and method of support that they perceive as being beneficial and desired. The results of the study were used to inform the investigated program about practices that families perceive as working or not working in relation to the provision of information, social support, and resources.

### *Philosophical Perspectives*

Creswell (2003) suggests that one of the first steps in designing research is to identify the philosophical perspective that best describes the researchers underlying assumptions about how knowledge is acquired and what is expected to be learned. The three philosophical lenses that are used to frame the nature and tone of the how data was collected, analyzed, and interpreted in this study include the (a) constructivist, (b) advocacy/participatory, and (c) pragmatic perspectives. Each of these perspectives are described in the following paragraphs.

#### *Constructivist*

The underlying assumptions that frame the methods used in this study includes a *constructivist* perspective. A constructivist lens, which posits that “individuals seek understanding of the world . . . and develop subjective meanings of their experiences,” reflects the key goal of this phenomenological research (Creswell, 2003, p. 8). This study sought to understand the meanings that families “construct” from their lived experiences related to parenting a child with special needs (Blue-Banning et al., 2004).

In order to ensure that this research was based on the perspectives of participants being studied to the maximum extent possible, information was obtained using broad and general open-ended questions during a focus group. Although, open-ended questions were developed in advance, the researcher maintained flexibility in providing participants space to share their stories with other families who have had similar experiences. The shared experience with other families helped participants clarify the meanings they attributed to these experiences, resulting in information that reflected individual as well as collective meanings that parents attributed to their experiences of caring for a child



with special needs (Creswell, 2003). Once participant's' views were fully expressed, then they were further categorized and analyzed to gain a better understanding of the meanings of their experiences and the implications of these meanings in guiding practices related to supporting families who have children with special needs.

#### *Advocacy/Participatory*

In addition to a constructivist perspective, an *advocacy/participatory* lens was employed to ensure that interpretation of results reflects the expressed desires and needs of the participating families. Advocacy/participatory perspectives expand on the constructivist approach by more fully engaging participants who are often marginalized by society based on characteristics such as gender, race, or disability (Creswell, 2003). A primary goal of advocacy/participatory approaches is to create opportunities that enable and empower individuals so they can influence improvements or changes in practices that reflect their expressed desires and needs, according to Creswell. The principle goal of this study was to obtain parent perspectives about their experiences and to understand the type of services and supports they desire for their child and family. The researcher presumed that listening to parent's' experiences through a focus group discussion, and then using this information to shape future program practices, would enhance parent's' sense of being empowered and of having control in determining future program practices related to family supports (Creswell, 2003; Mertens, 1998).

#### *Pragmatic*

Finally, a pragmatic approach can be most practical when a goal of research is to identify solutions to a given problem (Creswell, 2003). In this case, the identification of service delivery practices that families perceived as enhancing or inhibiting their

experiences and those practices that promoted internal locus of control. One of the strengths of using a pragmatic lens in research is the placement of a problem in “social science research and then using pluralistic approaches to derive knowledge about the problem” (Creswell, 2003, p. 12; Patton, 1990; Tashakkori & Teddlie, 1998).

Additionally, a pragmatic lens is most compatible with the mixed methods research design used in this study because of its emphasizes on the importance of using multiple approaches for data collection and analysis in order to gain a deeper understanding of a research problem (Creswell, 2003).

The use of the constructivist perspective for developing a better understanding of the meanings that families make of their experiences; an advocacy/participatory perspective for ensuring that families’ voices are heard; and a pragmatic lens to ensured that changes in program practices were guided by parent preferences, were expected to increase the value and utility of information acquired from parents. In terms of practical application, participants were able to have a direct role in determining those program practices that helped them access supports and should be leveraged or exploited, and those that act as barriers and should be confronted or mitigated.

#### *Phenomenological Approach*

Phenomenological studies are frequently used when the primary purpose of research is to examine the meanings of the lived experiences for individuals (Creswell, 1998). A central goal of phenomenological studies is to identify and describe the essential underlying meaning of an event for individuals in order to obtain a better understanding of what Polkinghorne (1989, p. 46) describes as feeling “I understand better what it is like for someone to experience that” (as quoted by Creswell, 1998, p. 55). Isaac (1995)

further suggests that the focus of naturalistic research, such as that found in phenomenological studies, is to gain an understanding of the deeper meanings an individual attributes to his or her experiences. Seligman & Darling (2007) further supports the value of phenomenological studies when stating that it is, “not event itself that is disturbing to the individual, but the meaning they attribute to the event that constitutes the source of problematic behavior and thinking” (p. 12). Because the meaning that families make of their experiences is a key factor influencing how they cope with and adapt to their child’s special needs, it is of paramount importance to fully understand these meanings (Seligman & Darling, 2007).

This study used a naturalistic, phenomenological approach to explore the meanings that parents of young children older than 3 years of age with special needs make of their experiences with obtaining information, social support, and resources, as well as the themes and categories that emerge from these meanings. The results obtained through naturalistic research methods usually are not expected to be generalized or used to establish causality; however, the benefit of using a naturalistic approach to examine the study’s research questions, is that information gathered is free from artificial constraints and manipulation, allowing for multiple perspectives to emerge (Isaac & Michael, 1995).

Unlike experimental research designs, which seek to test hypotheses or explain relationships under controlled conditions, descriptive research aims to examine and describe a situation or event as it is perceived by participants (Isaac & Michael, 1995). Because the primary purpose of this study aimed to explore and accurately describe parent perceptions of the meanings of their experiences, and not to generalize findings

beyond the investigated program, or to test previously developed hypotheses, the use of a descriptive research design for reporting collected data is most applicable to the present study.

### Population

McCall (2002) defines population as “the entire group or set of analysis units under consideration in a study or project” (p. 137). Trochim (2006) describes the population as the group to which researcher wishes to generalize. As a naturalistic inquiry method focusing on a phenomenon as experienced by a particular population, phenomenological research typically does not seek external validity or generalizability to groups outside of the study participants (Isaac & Michael, 1995). The population investigated in this study was limited to families who have had experiences with the phenomenon being study; in this case experiences with parenting children over 3 years of age who are participants in the investigated program’s services.

### *Sampling Methods*

The study used purposive sampling methods to select participants. Tashakkori and Teddlie (1998) suggest that when the total population is not large enough to ensure a small sampling error, or when conducting small-scale, in-depth research projects, it is preferable to select analysis units based on a specified criterion rather than attempt to use random selection approaches. In these instances, purposive sampling techniques are most appropriate for a naturalistic, phenomenological study of participants located at a single location (Creswell, 1998). Creswell states that in a phenomenological study “it is essential that all participants experience the phenomenon being studied” (p. 118). As a purposive sampling technique, criterion sampling specifies further that all individuals

included in the sample be selected because they meet a specified criterion, in the case of this study, parents of special needs children over the age of three and currently participating in the investigated program, or has participated within the past 6 months (Creswell, 1998). Isaac and Michael (1995) adds that one purpose of naturalistic, phenomenological studies is to understand how individuals make meaning of their lived experiences, not to generalize results to a population outside of the investigated population. Therefore, in order to ensure that the participant sample selected for this research have had the experiences being explored, a purposive sampling approach is appropriate and was used for this study.

#### *Sample and Analysis Unit*

The study sample consisted of six parents selected from a total population of 25 families who met the study criterion. Participants were mothers of special needs children over 3 years of age who were participating in the investigated program's services for children over 3 years of age at the time of the study, or who had participated within the past six months. The analysis unit according to McCall (2002) is defined as "that entity, thing, subject, or object, that is the basic unit of interest in addressing an issue, problem, or dilemma" (p. 3). As such, the analysis unit of interest in this study was a parent of a child with special needs over 3 years of age.

#### *Human Subjects*

In accordance with the Pepperdine University policy on research involving human participants/subjects, this study complied with all accepted ethical, federal, and professional standards for research. For the purposes of this study, the term *human*

*subjects* is based on the definition provided in the Pepperdine University's *Protection of Human Participants in Research: Policies and Procedures Manual*:

living individual(s) about whom an investigator (whether professional or student) conducting research obtains (a) data through intervention or interaction with the individual, or (b) identifiable private information. Human subjects may also be referred to as human participants by Pepperdine IRBs in order to recognize the active relationship of persons in our research endeavors. (Hall & Feltner, 2005, p. 10)

All research involving human subjects is bound by the basic ethical principles contained in the federal law passed in July 1974 referred to as the National Research Act (Public Law 93-348) and codified in the federal code of regulations, 45 CFR 46. The researcher took all necessary steps to adhere to the three ethical principles found in the Belmont Report of 1979, which ensures protection of human subjects: (a) respect, (b) beneficence, and (c) justice as illustrated below. The definitions provided by the Pepperdine University's *Protection of Human Participants in Research: Policies and Procedures Manual* (Hall & Feltner, 2005, pp. 11-12) are described in the following paragraphs.

### *Respect*

Two ethical beliefs that underscore the principle of respect include treating individuals as "autonomous agents" and the recognition "that persons with diminished autonomy are entitled to protection." Therefore, all participants were informed that participation is voluntary and apprised of the potential risks and benefits of participation. Furthermore, the privacy of individuals was guarded and confidentiality was maintained as described later in this section.

### *Beneficence*

All researchers have a responsibility to minimize risks to participants and to maximize potential benefits. Participants may experience benefits directly, or benefits may be experienced indirectly to individuals not involved in the research. Because this study did not involve experimentation, treatment, intervention, or manipulation of participants, any benefits gained from this study are expected to be the result of programmatic changes that may occur due to research findings.

### *Justice*

Participants should be selected in a manner that is fair and in which risk and benefit is equitably distributed. The participants selected for this research was based on specific criteria related to the research questions and purpose of the study which aimed to gain a deeper understanding of the lived experiences of families whose children ages 3 to 8 years have special needs and are participating in a single program.

### *Informed Consent*

The researcher ensured that all prospective participants were provided information about the study and were fully aware that participation was voluntary. Informed consent was viewed as an ongoing process that involved both ongoing dialogue between the researcher and participants and written documentation. Of utmost importance was making sure that participants fully understood the “nature of the research and the subject’s participation” (Hall & Feltner, 2005, p. 43). The informed consent form used in this study was adapted from the form located on the Pepperdine Graduate School of Education and Psychology website and is included in Appendix B.

Written consent was obtained from all participants prior to collecting data. Additionally, families were apprised that participation is voluntary and that they could withdraw from participation at any time.

#### *Risk Minimization and Benefit Maximization*

All research with human subjects must ensure that risks to participants are minimal. The Department of Health and Human Services (DHHS) policy for protecting human subjects defines “minimal risk” as follows:

[Minimal risk] means that the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests. (Hall & Feltner, 2005, §45 CFR 46.102i)

Because data were collected through an open-ended interview in which participants control the content of their responses, this study carried minimal psychological or emotional risk to participants. Potential benefits to participants included knowing that they are contributing to improving program practices. No compensation or preferential was provided to individuals participating in the study.

#### *Anonymity*

Hall and Feltner (2005) explain the difference between anonymity and confidentiality in that anonymity is defined as “when a person is not named or identifiable in any manner” (p. 20). Given that the nature of the study involved person-to-person interviewing during a focus group with six participants, anonymity was not possible. However, every effort was taken to protect participants’ privacy and identity in the storage and reporting of all collected data.



### *Confidentiality*

In contrast to anonymity, confidentiality is defined as “when personally identifiable and private information is entrusted to an investigator to not disclose it” (Hall & Feltner, 2005, p. 20). Confidentiality was maintained by utilizing codes to substitute for identifying information and securing all data in a locked cabinet that is accessible only to the principle researcher. Additionally, research records will be maintained by the researcher for at least 3 years after completion of the research and will be made available upon request for inspection and copying by an authorized representative of the IRB, department, or agency supporting the research, as recommended by Hall and Feltner.

### *Institutional Approvals*

The researcher first obtained site approval from the Executive Director of the investigated program. A copy of the memo with approval can be located in Appendix C. Prior to beginning data collection, the researcher submitted a complete application to the Pepperdine Graduate School of Education and Psychology Institution Review Board for consideration of the study for exempt review. It is the policy of Pepperdine University that in order for any research proposal to be approved, the IRB must determine that *all* of the following requirements are satisfied:

1. Risks to the subjects are minimized and are reasonable in relation to anticipated benefits of the research;
2. Selection of subjects is equitable given the purposes and the setting of the research;

3. Appropriate informed consent will be sought from each subject or the subject's legally authorized representative, and such consent will be appropriately documented;
4. The research plan makes appropriate provision for monitoring the data collected to insure the safety of subjects;
5. Appropriate provisions are made to protect the privacy of subjects and to maintain the confidentiality of data;
6. Where some or all of the subjects are likely to be vulnerable to coercion or undue influence, appropriate additional safeguards have been included to protect the rights and welfare of these subjects.

Because data was collected during a focus group, which Hall and Feltner (2005) define as “a small, targeted group of consumers, led by a moderator, whose opinions and perceptions on a certain topic are elicited” (p. 16), there were minimal risks to participants.

A completed application for an exempt review was submitted to the IRB upon approval from the dissertation committee. Because the primary use of the data was to inform program practices and future research with a wider sample of the population, and given the nature of the study and the minimal risks to participants, this study met the following criteria for an exempt review in accordance with Pepperdine’s policies on exempt studies (see Appendix D for IRB approval letter):

The exemption at 45 CFR 46.101(b)(2), for research involving survey or interview procedures or observations of public behavior, does not apply to research with children, Subpart D, except for research involving observations of

public behavior when the investigator(s) do not participate in the activities being observed.

### Data Collection Procedures

The researcher conducted a focus group interview during a single two-hour session with a group of six participants. Data collection was conducted in two phases. Phase 1 consisted of qualitative data collection using open-ended and semi-structured questions to obtain participants lived experiences related to research questions 1 and 2. An IE<sup>2</sup> SWOT analysis protocol was used to collect both qualitative and quantitative data in relation to research questions 3 and 4 pertaining to families' experiences with accessing and using supports, and their appraisals of control over factors that either enhance or inhibit their ability to obtain information, social support, and resources. Phase 2 utilized the IE<sup>2</sup> SWOT Matrix approach and collected quantitative data using the Family Support Survey, a Likert-type tool developed for the purpose of this study. This section describes the procedures used for screening and selecting participants and for conducting the qualitative focus group interview.

### *Participant Recruitment*

The researcher first obtained a list from the investigated program's database of all families to initially screen for those families meeting the eligibility criteria for participation in the study. The list was scanned for the names of parents with children over 3 and under 8 years of age, and were currently participating in services provided by the investigated program, or had participated within the past six months (see Appendix E for recruitment procedures).

The researcher contacted families by phone and explained her role in the study and how they were selected for consideration as participants (see Appendix F for phone script). The researcher then stated the purpose of the study and provided additional details about the nature of focus groups and a general description of how the focus group would be conducted. The researcher assured family members contacted that their names and any information provided would be kept confidential, known only to the researcher. They were informed that participation in the study was voluntary and that they could withdraw at any time. They were apprised that if they should decline to participate, that this would in no way affect their future participation in the investigated program. The family member was informed that 6 to 10 participants would be selected from a total population of 25 and that their affirmative response to participate was not assurance of their selection as final participants for the focus group interview. The researcher coded and categorized all names according to whether they agreed or disagreed to participate in the study or are undecided.

#### *Initial Screening*

The researcher sent a brief introductory letter via email to families who agreed to participate. The purpose of this letter was to screen for their overall perceptions of their experiences with accessing and using supports related to their child's disability. The question was designed to elicit a simple response of "yes/no/sometimes" to the question of "Based on your prior experiences in getting supports...have you been able to get the services and supports you desire for your child and family?" The purpose of this step was to sort respondents based on their response to ensure that the focus group represented a variety of perceptions and was not skewed toward either perception.

Each respondents name was placed in one of three categories based on whether their experiences, (a) helped, (b) hindered, or (c) were sometimes helpful or hindering. Each response were coded with a number. This procedure ensured that the focus group had an equal distribution of participants with positive, negative, neutral experiences. Additionally, this extra step helped guard against possible researcher bias in selecting participants. The researcher contacted family members from each list to confirm that they were still interested in participating in the study. The researcher selected 2 to 4 participants from each list (helped, hindered, neutral), starting from number 1 and working down the list until 2 to 4 names from each category had been selected, for a total 10 names. Final participants were notified by the researcher of their selection and offered a choice of three dates from which the focus group interview would be scheduled.

Every attempt was made to ensure that the date accommodated all selected participants. Of the 10 candidates who met criterion for participation, six accepted and four had scheduling conflicts and were subsequently dismissed. Of the six participants, one parent was from the list of hindering experiences, three were from the list of helpful experiences, and two were from the list of neutral experiences. The research assistant mailed each family a copy of the informed consent form to be signed and returned in a self-addressed and stamped envelope prior to the focus group date.

## Instrument

### *Phase 1: Focus Group Interview Protocol*

The a protocol for conducting the focus group interview was developed and used in Phase 1 of this phenomenological study to collect qualitative data (see Appendix G for the Focus Group Interview Protocol). In speaking of the benefit and value of families’

subjective experiences, Turnbull et al. (2007) recommend that research should focus on the collection of family perspectives that use qualitative methods to analyze family stories of what helps and what hinders their experiences related to accessing and utilizing family supports. The small number of participants ( $N = 6$ ) in this study maximized contributions from all participants enhanced generation of a rich and vast quantity of data (Creswell, 2003).

Initially questions were broad and open-ended to promote responses free from constraint, as well as to allow flexibility to pursue information that may come up, but not expected by the researcher (Isaac & Michael, 1995). To gain a deeper understanding of the meanings that participants made of their experiences, the researcher used probing questions that connected the interview questions to the purpose of the research and to the research questions. The focus group questions were constructed so they were free from jargon or ambiguous terms that may not be familiar to families. As a mixed methods study, one purpose of the qualitative data collected during the focus group interview was to guide the development of statements for a Likert-type survey protocol developed for use in Phase 2. Table 2 shows the relationship between the study research questions and the questions used during the focus group interview.

Table 2

*Relationship between Research Questions and Focus Group Interview Questions*

Research Question	Interview Question
RQ 1 What are the lived experiences of families whose children with special needs participate in early intervention or special education services and what meanings do they make of their experiences?	1
RQ2 What are families' perceived experiences with obtaining (a) information, (b) social, and (c) resource support?	2
RQ3 What are families' appraisals of control over these experiences?	3
RQ4 What are families' perceptions of the type of experiences that enhance or inhibit their attainment of (a) information, (b) social, and (c) resource support?	4
RQ5 To what extent, if any, is there agreement within or among families' ratings of the value of enhancing or inhibiting experiences, and their appraisal of control over these experiences?	5 (see Phase 2)

*Empirical Support for Interview Protocol*

This section summarizes the literature used to ground the interview protocol in the literature. Literature related to each interview question is discussed.

Interview Question 1 asks: “How would you describe your experiences as a parent of a child with special needs? (Probe for experiences with intervention/education programs, transitioning experiences, effects on family).” This question was based on the literature related to the effects of a child’s disability on families and how they cope and adapt to their experiences. The researcher used Guralnick’s Developmental Systems Model as a comprehensive conceptual framework for the effects of child disability on

family (Guralnick, 2005b). The key constructs of this model include current scientific and theoretical understandings of normative development and the essential role of family (Shonkoff & Phillips, 2000).

The developmental systems model describes three important family interaction patterns that are essential for optimal child development: (a) quality of parent-child interactions, (b) optimal family orchestrated learning experiences for their child, and (c) provision for the health, safety, and well-being of the child and family (Guralnick, 2006).

Furthermore, child development is seen as occurring within the context of multiple systems that interact in a transactional manner, such that the actions of one system influence one or more other systems. The systems perspectives used in this study include family systems perspective (Minuchin, 1985), which is viewed as the most proximal and direct influence on child development. The social systems perspective (Dunst et al., 1994), which includes the influence of immediate social relationships within and outside the family unit, as well as larger societal influences such as shared culture, values, beliefs was also utilized. Lastly, the ecological systems perspective (Bronfenbrenner, 1979), which includes the effects of environments and socio-cultural factors at home, community, and society was considered.

In order to understand the effects of disability on family, the research and interview questions were further grounded in the literature related to stress, coping, and adaptation (McCubbin & McCubbin, 1987). A key construct in this model is the influence of family perception of meaning (Taylor, 1983) and appraisal of control on successful adaptation (Zimmerman & Rappaport, 1988).



Interview Question 2 asks: “What has it been like for you to get information, social support, and resources? (Probe for type of information sought and strategies used).” This question is based on the literature that describes three primary areas of support that are essential for family coping and adaptation: information support, social support, and resource support (Guralnick, 2005b).

The need for *information support* is considered one of the most important (Bailey & Powell, 2005). The type of information needed by families includes, information about the child’s condition, current and future services available, effective strategies for parenting their child, and tools for managing behaviors (Mahoney et al., 1999).

*Social support* is seen as critical for coping with stress related to parenting a child with special needs. It is also an important mediating influence of successful adaptation (Dunst et al., 1997).

*Resource support* is conceptualized as both existing resources (already available to family and minimize effects of crisis, and extended resources (new resources needed to meet demands associated with crisis (McWilliam, 2005). Resource support also includes material needs such as financial assistance and help with basic needs such as food, housing, transportation, childcare, and employment.

Interview Question 3 asks: “What or whom do you believe has control over your ability to access and utilize information, social support, and resources? (Probe for factors related to internal control (self), or external control (outside others).” This question is based on the literature related to locus of control and the extent to which parents perceive control as being internal from within the self or external control of the outside other (Smith et al., 2000). Also included is the effects of parent appraisal of control on

perception of their child's disability and belief that intervention services and supports will make a difference in their child's developmental outcomes and family well-being (Trivette, Dunst, & Hamby, 1996).

Interview Question 4 asks: "What has helped you to get information, social support, and resources? (Probe for availability, access, utility, family-centered practice, parent education, parent-to-parent support, motivation, persistence, knowledge of system)." This question is based on the literature related to family-centered practice as the recommended approach for providing services to families of children with special needs (Dunst & Deal, 1994). The literature identifies factors such as helping family to cope with challenges, empower families to work collaboratively, support families to make decisions about services, and provide information to help families more effectively parent their child (Shannon, 2004). Additional areas that are identified as having an enhancing effect on family adaptation includes concepts related to empowerment and parent efficacy, and the type of support practices associated with these (Dunst et al., 2002).

Interview Question 5 asks: "What has hindered your ability to get information, social support, and resources? (Probe for barriers, such as scheduling, work/ family demands, availability, access)." This question is based on the literature related to barriers that have been identified in the literature as hindering a families access to supports, such as the effects of poverty (Garbarino & Ganzel, 2000), parent employment demands, lack of accessibility to quality programs, lack of family friendly practices, or challenges working with publically funded institutions (Bernheimer & Weisner, 2007; Bronfenbrenner, 1992). Additional factors are related to parent perceptions that

professionals withhold information about services, doesn't respect parent opinion, doesn't provide enough information, does not teach parent skills, confusing service coordination system (Dinnebeil & Rule, 1994). Table 3 summarizes the relationship between the focus group interview questions and the related empirical support. It also shows the sources for the concepts used.

Table 3

*Focus Group Questions, Conceptualization, and Literature Source*

Concept	Focus Group Question	Source
Stress, coping, adaptation	1. How would you describe your experiences as a parent of a child with special needs?	(Guralnick, 2005b) (McCubbin & McCubbin, 1987) (Summers et al., 1988)
Information needs Social support needs Resource needs	2. What has it been like for you to get information, social support, resources?	(Bailey & Powell, 2005) (McWilliam, 2005) (Dunst et al., 1997)
Appraisal of control	3. What or whom do you believe has control over your ability to access and utilize supports?	(Smith et al., 2000) (Taylor, 1983)
Family-centered practice Enable and empower Parent-professional relationship	4. What has helped you to get information, social supports, and resources?	(Dunst & Deal, 1994) (McBride et al., 1994)
Parent-professional relationship	5. What has hindered your ability to get information, social supports, and resources?	(Dinnebeil & Rule, 1994)

*Phase 2: Family Support Survey Protocol*

The protocol for developing the family support Likert-type survey instrument used in Phase 2 of this study was adapted from the IE<sup>2</sup> Questionnaire developed by Leigh (2009). The IE<sup>2</sup> SWOT protocol has evolved from the more conventional SWOT analysis model used to measure organizational strengths, weaknesses, opportunities, and threats

(Leigh, 2000, 2005a, 2005b, 2009). The Family Support Survey protocol is located in Appendix H.

Using the IE<sup>2</sup> Questionnaire as a template, the formation of the Family Support Survey protocol was organized around four categories of influence referred to as SWOTs (strengths, weaknesses, opportunities, and threats). Strengths and weaknesses are factors perceived to be within a person's control (internal control) and either helpful (enhancer) or hindering (inhibitor). Opportunities and threats are factors perceived to be in the control of others (external control) and either helpful (enhancer) or hindering (inhibitor).

The four SWOTs were used to structure and organize data collection and generation of participants' statements during the focus group interview. These statements were then entered into the Family Support Survey tool after the focus group, and therefore the final form of the survey was developed after completion of the qualitative data collection phase of the study.

The purpose of the instrument used during phase 2 was to obtain participant ratings as to the degree to which they agreed with the statements generated from the focus group interview following a modified IE<sup>2</sup> SWOT Matrix analysis procedure. The items that participants rated were generated from their statements obtained from the Phase 1 focus group interview, and were typed into a template developed for the study.

The use of quantitative methods during the second phase served multiple purposes. Most importantly, it helped to build trustworthiness in the credibility of qualitative data. Lincoln and Guba (1985) identify four aspects that are used to build trustworthiness into a study's results, referred to as credibility (internal validity),

transferability (generalizability), dependability (external validity/reliability), and conformability (objectivity).

One of the primary purposes for using the Family Support Survey tool as part of quantitative data collection was to increase the credibility of data using member checking and triangulation of data. The procedures for using these are described in this section.

First, participants had an opportunity to individually rate their level of agreement with the statements generated during the focus group. The use of quantitative measures in this manner will create a member check (Isaac & Michael, 1995) for internal consistency in that, participants verified and rated the responses provided during the focus group. In doing, participants were able to correct or add to the information, thus increasing confidence that the data gathered during the focus group reliably reflected each individual participant's perspectives, separate from the collective group perceptions (Bailey et al., 1998).

Second, the triangulation of data collected from both qualitative and quantitative data provided a deeper understanding of parent experiences than could be obtained by using each of these methods alone. Finally, this process enabled the researcher to identify areas of agreement among participants in order further understand how perspectives of experiences vary across participants.

The relationship between the questions used to generate the Family Support Survey statements and the research question it seeks to answer is presented in Table 4. It presents these relationships for research questions 3, 4, and 5.

Table 4

*Relationship Between Research Question and the Family Support Survey Questions*

Research Question	Family Support Survey Questions
RQ3 What are families' appraisals of control over their experiences accessing and utilizing information, social support, and resources?	1a, 2a, 3a
RQ4 What are families' perceptions of the type of experiences that enhance or inhibit their access and utilization of information, social support, and resources?	1b, 2b, 3b 1c, 2c, 3c
RQ5 To what extent, if any is there agreement within or among families' ratings of the value of enhancing or inhibiting experiences, and their appraisal of control over these experiences?	1a, 1b, 1c 2a, 2b, 2c 3a, 3b, 3c

*Empirical Support for the Family Support Survey Tool*

The following section presents the relationship between the questions used to generate the Family Support Survey statements and the related research questions.

Empirical support to ground the survey questions in the literature was previously described in Phase 1 and will not be repeated here. Given that the Family Support Survey is designed to emerge organically from participants' own statements generated during the focus group interview, the questions described below were utilized for the purpose of organizing and categorizing probing questions and the resulting statements according to the four SWOTs.

The underlying conceptual beliefs related to the focus group questions used to generate families' statements reflecting their attributions of control and perception of factors that help or hinder their ability to access and use of information, social support, and resources (SWOTs), are presented in Table 5 and described as follows:

1. Information

- a. To what extent do you believe that you have control or that control is by some outside other?
- b. To what extent, if any, do you agree with each of the following statements regarding factors that have helped you to access and use information?
- c. To what extent, if any do you agree with each of the following statements regarding factors that have hindered your access and use of information?

2. Social Support

- a. To what extent do you believe that you have control or that control is by some outside other?
- b. To what extent, if any, do you agree with each of the following statements regarding factors that have helped you to access and use social support?
- c. To what extent, if any, do you agree with each of the following statements regarding factors that have hindered your access and use social support?

3. Resources

- a. To what extent do you believe that you have control or that control is by some outside other?

- b. To what extent, if any, do you agree with each of the following statements regarding factors that have helped you to access and use resources?
- c. To what extent, if any, do you agree with each of the following statements regarding factors that have hindered your access and use of resources?

Table 5 summarizes the relationship between the Family Support Survey and its related theoretical and conceptual foundations. It also shows the sources for the concepts used.

Table 5

*Family Support Survey Theoretical and Conceptual Foundations*

Concept	Family Support Survey Questions	Source
Appraisal of Control	1. To what extent do you believe that you have control or that control is by some outside other?	(Smith et al., 2000) (Taylor, 1983)
Access Information, Social Support, Resources	2. To what extent do you agree that each statement helps you access and use of... a. Information b. Social support c. Resources	(Dunst & Deal, 1994) (McBride et al., 1994)
Barriers Information, Social Support, Resources	3. To what extent do you agree that each statement hinders your access and use of ... a. Information b. Social Support c. Resources	(Dinnebeil & Rule, 1994)

*Expert Review and Field Testing of Instruments*

A panel of experts with the content and experiential background reviewed the Focus Group Interview and Family Support Survey protocols. Their review provided the researcher with feedback on the credibility and dependability of the focus group



interview questions. Modifications of questions were made as recommended for questions lacking credibility and dependability. (The Expert Panel Review protocol for the focus group and Family Support Survey are located in Appendix I.)

#### *Focus Group Interview Protocol Review*

The focus group interview protocol and questions were field tested with a sample of 3 parents of special needs children over 3 and less than 8 years of age and who had experiences with the issues raised by the research and interview questions. These families were not included in the final study. The purpose of field-testing was to ensure that the participants had the information to answer the questions, that the researcher and participants had a shared understanding of the meaning of the questions, and that the questions were clear and unambiguous (Isaac & Michael, 1995). This process enabled the researcher to test the focus group procedure to identify and address procedural and structural challenges that might impede data collection.

Once the focus group interview questions and protocol were reviewed by the panel of experts and field tested with a sample of families, the researcher made the recommended changes in the protocol and procedures used during Phase 1 of the focus group interview. As an exploratory, sequential mixed methods research design, quantitative data was collected from the participants during Phase 2 of the focus group using a rating scale adapted for this study. The following section discusses the process of developing the Family Support Survey.

#### *Family Support Survey Protocol Review*

The Family Support Survey questions and form were field tested with a sample families with special needs children over 3 years of age and who have experiences with

the issues raised by the research and interview questions. These families were not included in the final study. The purpose of field-testing was to ensure that the participants had the information to answer the questions, that the researcher and participants had a shared understanding of the meaning of the questions, and that the questions were clear and unambiguous (Isaac & Michael, 1995). This process enabled the researcher to test the focus group procedure to identify and address procedural and structural challenges that might impede data collection.

The focus group interview questions and protocol, and the Family Support Survey questions and form were reviewed by the panel of experts and field tested with a sample of families. Once the reviews were returned, the researcher made any recommended changes in the protocol and procedures to be used during the Phase 1 focus group interview and Phase 2 administration of the Family Support Survey.

#### In-Depth Data Collection Process

Data collection was conducted in two phases. Phase 1 collected qualitative data and phase 2 collected quantitative data. Phase 1 was further broken down into three steps. While steps one and two used open ended and semi structured questions, step three introduced more structured and guided questions based on the IE<sup>2</sup> SWOT Analysis protocol developed by Leigh (2000, 2005a, 2005b, 2009).

Qualitative data alone was collected in relation to research questions 1 and 2; however, research questions 3 and 4 consisted of collecting both qualitative and quantitative data using the IE<sup>2</sup> SWOT Matrix protocol as described by Leigh (2000, 2005a, 2005b, 2009). The researcher utilized Leigh's six steps for implementing an IE<sup>2</sup> SWOT Analysis protocol to organize qualitative and quantitative data collection (Leigh,

2000, 2005a, 2005b, 2009). According to Leigh's protocol, steps one through three follow a conventional SWOT approach, while steps four through six include quantitative collection and analysis processes that are unique to the IE<sup>2</sup> Matrix protocol (Leigh, 2000, 2005a, 2005b, 2009).

### *Phase I: Qualitative Data*

#### *Open-Ended Focus Group Interview*

The researcher conducted the focus group in a conference room located at the investigated program, which comfortably accommodated the six participants, plus the principle interviewer and two research assistants. Because the size of the focus group was small, the entire group was interviewed together. The focus group interview lasted 2 hours. The Focus Group Interview Questions and administration procedures used for the focus group interview are located in Appendix J.

The first step of the focus group interview focused on gaining a better understanding of families' lived experiences and the meanings they make. The principle researcher, with support from two trained research assistants collected qualitative data using open-ended and semi-structured questions designed to obtain data related to research question 1. Following recommendations proposed by Tashkkori and Teddlie (1998), the interviewer, who is the principle researcher, began with broad questions designed to elicit participant perspectives of their lived experiences as participants in early intervention/special education services related to their special needs child between 3 and 8 years of age, and the meanings they make of these experiences. Probing questions were used to elicit deeper meanings from participants' responses.

The second step used open-ended and semi-structured questions related to research question 2 in order to obtain families' experiences with accessing and utilizing information, social support, and resources related to their child with special needs. In addition to the use of open-ended questions, the researcher developed four pre-determined categories of semi-structured questions to guide the focus group interview to ensure that information provided by participants was consistent with answering research questions 1 and 2.

To ensure that participant responses were recorded accurately during the focus group interview, a trained research assistant recorded participant's responses on large poster paper and another assistant simultaneously entered the responses into a pre-developed computer template that mirrored the poster paper format. In addition, the focus group interview was audio recorded. The researcher took extensive descriptive notes to record observations such as gestural or body language or environmental factors that add depth to participant responses (Creswell, 2003); as well as reflective notes to record personal thoughts, feelings, initial impressions, and interpretations (Bogdan & Biklen, 1992).

#### *IE<sup>2</sup> SWOT Analysis: Steps One Through Three*

An IE<sup>2</sup> SWOT (strength, weakness, opportunity, threat) analysis was used to structure the focus group interview and to facilitate organization of participant responses. When used conventionally, a SWOT analysis approach is generally used by organizations to identify factors that inhibit or enhance desired performance indicators within both internal and external environments. In this context, enhancers are (internal) strengths and (external) opportunities.

The IE<sup>2</sup> SWOT analysis is implemented in six steps. Steps one and two pertain to participant recruitment and convening the focus group. Step three of the IE<sup>2</sup> SWOT Matrix protocol consisted of collecting Phase 1 qualitative data for research questions 3 and 4. Steps four through six described in Phase 2 pertain to quantitative data collected for research questions 3 and 4. The relationship between the IE<sup>2</sup> SWOT Matrix steps (Steps 1 through 6), related data collection phase, and data analysis procedures are located in Table 6.

Table 6

*Relationship Between the IE<sup>2</sup> SWOT Procedure and Data Collection and Analysis*

IE <sup>2</sup> SWOT Step	Phase	Data Collection	Data Analysis
Step one: Participant recruitment	-----	-----	-----
Step two: Convening the focus group	-----	-----	-----
Step three: Identify / categorize SWOTs	Phase 1	Qualitative	Quantitative
Step four: Analyze / rate SWOTs	Phase 2	Quantitative	Quantitative
Step five: Synthesize SWOTs	Phase 2	Quantitative	Quantitative
Step six: Interpret findings / deliberate action	Phase 2	Quantitative	Quantitative

*Step one: Recruiting stakeholders.* Determining who should participate was the first step in generating the IE<sup>2</sup> SWOT Matrix analysis. Participants considered for the study were individuals most directly influenced by decisions made because of the IE<sup>2</sup> SWOT Matrix process. Leigh suggests that participation of individuals with “both high power and interest” should be a primary consideration when deciding whom to include in a focus group (Leigh, 2005b, p. 9).

Therefore, as described earlier in this chapter, families had been selected to participate in the focus group IE<sup>2</sup> SWOT Matrix analysis because they have had prior experiences with accessing and utilizing information, social, and resource supports after their child's third birthday and because they are highly interested in improving access and utility of supports for themselves and other families. Because the size of the focus group was small and relatively homogenous, the IE<sup>2</sup> SWOT Matrix analysis was conducted among the entire group, rather than by forming breakout groups, which might be used with a larger or more diverse group of participants (Leigh, 2005b).

*Step two: Convening the focus group.* Considerations in this step include logistical factors such as where and when to hold the focus group, as well as more practical factors related to the implementation of the focus group. As previously described, the focus group was held at the center at a time when families who participated would already be attending a social skills program with their child. The reasoning for this was that families already felt comfortable and familiar at this location. Furthermore, convening the focus group during the social skills program provided childcare and utilized a time that families already committed, thus eliminating the need to add an additional activity to their weekly commitments. Finally, the center had a comfortable conference room within which to conduct the focus group interview.

In addition to logistical matters, this step includes making sure that participants understand the nature of the focus group process, and ensures that individuals understand key terms that will be utilized. As cited by Leigh (2009), a definition of SWOTs provided by Claire Capon is as follows: *strength*: an internal enhancer, competence, valuable resource or attribute; *weakness*: an internal inhibitor, lack of a competence, resource or

attribute; *opportunity*: an external enhancer, possibility that can be pursued to gain a benefit; and *threat*: an external inhibitor, “performance reducing factor” (pp. 115-116).

While the above terms are commonly used within organizations to measure performance, they are less likely to be familiar to families of children with special needs. Therefore, the terms used in this study were modified to represent meanings that parents will more likely understand. For the purposes of this study, the following terms are used and defined as follows:

1. Internal enhancer: a family strength or asset that supports or helps a family’s access and utilize supports;
2. Internal inhibitor: a family challenge or deficit that impedes a family’s access and utilization of supports;
3. External enhancer: a factor outside of the family that supports or helps a family’s access and utilize supports; and
4. External inhibitor: a factor outside of the family that impedes access and utilization of supports.

*Step three: Identifying and categorizing SWOTs.* The third step of the SWOT analysis involves recording SWOTs as participants in response to questions asked by the facilitator provide them. The interviewer, in this case the researcher used the focus group interview protocol to generate participants experiences related to accessing and using information, social support, and resources. Following the SWOT protocol, parents were first asked to differentiate between factors related to obtaining supports that they believed to be either within their control or under the control of others. Next, they were asked to identify factors that either enhanced or inhibited their experiences with accessing and

utilizing information, social support, and resources. At the end of step three, factors related to families experiences with accessing and using supports were identified, categorized, and qualified according to whether these factors were perceived as being either internally controlled and an enhancer (strengths) or inhibitor (weaknesses); or externally controlled and an enhancer (opportunities) or inhibitor (threats).

Phase 1 of qualitative data collection was completed at this point once participants had indicated satisfaction that they fully expressed their perceptions and had reached agreement that their responses were recorded accurately. When used as a final stage of an IE<sup>2</sup> SWOT Matrix analysis, the ability to prioritize SWOT's or to determine the degree to which a factor enhances or inhibits desired results or the extent to which these factors are perceived as being internally or externally controlled is limited (Leigh, 2005b).

A noted weakness associated with most SWOT approaches, is the lack of procedures to quantify results, which diminishes the value of SWOTs as a tool for making informed decisions based on results. At best, a SWOT approach is useful for describing a situation from the perspective of individuals who participated in generating the SWOTs. However, given that some individuals are less inclined to voice opinions within a group setting, there is no way to determine if the results truly represent the collective and individual perspectives, or just the perspectives of those who were more vocal (Leigh, 2000, 2005a, 2005b, 2009). In order to address this weakness of a conventional SWOT analysis, this study utilized the SWOTs generated by participants related to research questions 3 and 4 to develop a Family Support Survey adapted from the IE<sup>2</sup> Questionnaire developed by Leigh (2000, 2005a, 2005b, 2009). Steps four through six of the IE<sup>2</sup> SWOT protocol are described in the next section.



*Phase 2: Quantitative Data Collection*

*IE<sup>2</sup> SWOT Analysis: Step Four*

*Step four: Analyzing SWOTs.* Step four of a typical SWOT analysis involves what Leigh refers to as “deliberation” or a discussion of what actions to take based on respondents comments (Leigh, 2000, 2005a, 2005b, 2009). In a conventional SWOT analysis, this involves asking participants to rank order their responses in terms of priority, in order to make decisions about which factors are most urgent and should be addressed immediately. Frequently, this step is conducted at a separate meeting by a select workgroup, usually individuals with decision-making roles (Leigh, 2005b).

As conventionally used, SWOT models consist of a 2 x 2 matrix consisting of the dialectic comparison of two levels of factors that provides a framework for “constructing and reconstructing problems” that can visually show the manner in which opposing factors interact (p. 4). Figure 1 illustrates a conventional SWOT matrix.

External	Internal
Opportunities O <sub>1</sub> : O <sub>2</sub> : O <sub>3</sub> :	Strengths S <sub>1</sub> : S <sub>2</sub> : S <sub>3</sub> :
Threats T <sub>1</sub> : T <sub>2</sub> : T <sub>3</sub> :	Weaknesses W <sub>1</sub> : W <sub>2</sub> : W <sub>3</sub> :

*Figure 1.* Sample of conventional SWOT matrix. Adapted with permission from Leigh, 2005b.

According to Leigh, one advantage of the IE<sup>2</sup> SWOT protocol is the added step of engaging stakeholders in establishing and prioritizing the value of each SWOT

numerically. In doing so, the information gathered can be quantified and therefore more useful in making decisions regarding how the information is to be used (Leigh, 2000, 2005a, 2005b, 2009). Furthermore, this step increases credibility (internal validity) and dependability (reliability) as statements can be cross-checked with participants by giving each an opportunity to review the final analysis.

The process of developing the Family Support Survey, the instrument used to collect participants' ratings of their degree of agreement for the SWOTs generated during the focus group has already been described. The following sections provide more detail on administering, scoring, analyzing, and interpreting results using the IE<sup>2</sup> SWOT Matrix and Grid developed by Leigh (2000, 2005a, 2005b, 2009). See Appendix K for Family Support Survey Administration Protocol.

*Rating degree of internal/external control.* Using the Family Support Survey tool, this step of the IE<sup>2</sup> analysis was accomplished by having participants rate the degree to which they attributed internal or external control over their experiences with accessing and utilizing informational, social support, or resources. An 11-point scale ranged from -5 being complete external control or highest inhibitory effect, to +5 being complete internal control or highest enhancing effect, with zero representing a perception that factors are either neutral or have minimal effect. This scale was used to generate participant responses (Leigh, 2000, 2005a, 2005b, 2009).

*Rating cost/benefit of enhancers/inhibitors.* After participants rated their perception of control over their experiences, then they were asked to rate the degree to which they perceive their experiences as either enhancing or inhibiting their access and utilization of information, social supports, or resources. Again, the rating scale used an

11-point scale ranging from (-5 = highly costly inhibitors) to (+5 = highly valuable enhancers) with zero reflecting a neutral perception is used to rate responses.

The Family Support Survey analysis results in 2 bipolar scales: one for perception of a factor as being either an enhancer or an inhibitor, the other for locus of control, in the case of this study, the degree to which families perceive their experiences as enhancing or inhibiting their access to information, social supports, or resources. The responses obtained during the focus group were analyzed qualitatively for categories and themes related to family experiences and meanings. Additionally, responses were analyzed quantitatively to identify the extent to which parents agreed with the responses given during the focus group (Tashakkori & Teddlie, 1998); and the extent to which a parent individually attributed control over these experiences as being internal (self) or external (professional or outside factor).

The researcher used the SWOT/IE<sup>2</sup> Matrix analysis model in this study to facilitate the prioritization of participant perceptions of experiences that they identified as being either enhancing or inhibiting, and their attribution of control over these experiences. Additionally, the information generated by the IE<sup>2</sup> analysis provided a useful format for later organization and analysis of data collected during the focus group interview (Leigh, 2000, 2005a, 2005b, 2009).

### *Trustworthiness*

The use of the quantitative IE<sup>2</sup> Matrix corroborated qualitative data from the focus group interview ensured increased *trustworthiness* in the credibility (internal validity), transferability (external validity), dependability (reliability), and confirmability (objectivity) according to Lincoln and Guba (1985). *Credibility* was achieved by using

member checks with participants throughout the focus group to ensure that their stories are recorded accurately.

Additionally, the data collected and analyzed using a SWOT and IE2 Matrix analysis approach provided a better understanding of the type experiences that families perceive as being value added and the various factors that enhance or inhibit these experiences. Additionally, results helped to identify the extent to which families appraisals of control are internal or external. *Confirmability* was enhanced by ensuring that ratings were based on criteria that families viewed as meaningful, which can be used to make programmatic decisions about practices that, should be maintained, improved, reduced or extinguished. Finally, if this process is completed on a regular basis as part of ongoing program evaluation, programs can establish a feedback loop for improving program practices, thus establishing greater *transferability* (external validity). Furthermore, it is more likely that program practices will meet the needs of families based on those factors that they perceive as enhancing their experiences and that maximize a sense of internal control over accessing and utilizing information, social support, and resources (Isaac & Michael, 1995).

Engaging participants in the additional step of rating each factor enabled the researcher to gain an understanding of the strength of agreement between and among family responses and *dependability* (reliability) that results accurately reflect participant perspectives. The value of gathering data from parents using the IE<sup>2</sup> approach enabled families to have a direct impact on the future of how program practices are maintained, improved, reduced, or extinguished. Thus, participants can gain a sense of power and control knowing that their participation will lead to desired changes. In this sense, the

participants are viewed as equal partners and become a “voice” for themselves and others (Creswell, 2003, p. 10).

### Analytical Techniques

The researcher analyzed and integrated the themes derived from the qualitative data into a narrative description that seeks to provide the reader with a better understanding of family experiences in accessing and utilizing information, social, and resource support as well as the meanings that families make of these experiences.

Table 7

#### *Research Questions and Analytical Techniques*

Research Questions	Analytical Techniques
RQ1 What are the lived experiences of families whose children with special needs participate in early intervention or special education services and what meanings do they make of their experiences?	Stevick-Colaizzi-Keen method (Moustakas, 1994)
RQ2 What are families’ perceived experiences with obtaining (a) information, (b) social, and (c) resource support?	Stevick-Colaizzi-Keen method (Moustakas, 1994)
RQ3 What are families’ perceptions of the type of experiences that enhance or inhibit their attainment of (a) information, (b) social, and (c) resource support?	Descriptive measures (Tashakkori & Teddlie, 1998); Measures of central tendency and measures of variability
RQ4 What are families’ appraisals of control over these experiences?	Descriptive measures (Tashakkori & Teddlie, 1998); Measures of central tendency and measures of variability
RQ5 To what extent, if any, is there agreement within or among families’ ratings of the value of enhancing or inhibiting experiences, and their appraisal of control over these experiences?	Ward’s method of hierarchical cluster analysis; IE <sup>2</sup> Matrix and Grid Analysis

Data obtained from the rating scale was analyzed using descriptive measures of central tendency to determine the mean, range, and standard deviation of response items. Ward's method hierarchical cluster analysis was conducted to identify the degree of similarity and difference for each item on the rating scale. A description of the specific data analysis techniques that were used for each research question is presented in the text of this section and is presented in Table 7.

## Data Analysis

### *Phase I: Qualitative Data*

#### *Data Reduction*

One of the most challenging tasks of qualitative methods is the management of the vast amount of data collected. The process of data reduction involves making decisions about how data is selected, simplified and transformed so that it can be analyzed in light of the research questions under investigation (Berkowitz, 1997).

The researcher first reviewed transcribed data by reading it in its entirety several times, writing notes in the margins to further clarify meanings and to add texture to statements (Creswell, 1998). The primary purpose of this first step is to ensure an understanding of the essence of parent's experiences and the meanings they make of these experiences. Key statements were identified and developed into categories or themes based on the meanings that emerge from the data.

#### *Analysis*

Although qualitative analysis strategies do not follow the same standardized rules associated with quantitative inferential approaches, the process of analysis is not haphazard or lacking in its use of systematic methods. A primary goal in the analysis of

qualitative data revolves around the identification of patterns, themes, and categories of meanings that emerge from the data (Berkowitz, 1997). The central objective is to gain a deeper understanding of multiple perspectives of a particular phenomenon.

The researcher used a modified Stevick-Colaizzi-Keen method (Moustakas, 1994) using the following steps described by Creswell (1998):

1. The researcher began with a full description of her own experience.
2. The researcher found statements from the interview about participant's experiences and list significant statements (horizontalization of data) and developed a list of "nonrepetitive, nonoverlapping statements" (p. 147).
3. The researcher grouped these statements into "meaning units," and wrote a description of the "textures" (textural description) of participant experiences, using verbatim examples.
4. The researcher then reflected on her own description using imaginative variation to seek all possible meanings and divergent perspectives and differing frames of reference in order to construct a description of how participants experienced the phenomena.
5. The researcher constructed an overall description of the meaning and essence of participant's experience.
6. The researcher followed this process first for her own account of the experience and repeated for each participant.

#### *Phase 2: Quantitative Data*

Data obtained from the rating scale was analyzed first using descriptive measures of central tendency to determine the mean, range, and standard deviation of response

items. Next, a Ward's method cluster analysis was conducted to identify the degree of similarity and difference for group means ratings for each item on the rating scale. The final step of the quantitative data analysis consisted of plotting bivariate data from the group means ratings on the IE<sup>2</sup> SWOT Matrix and Grid.

#### *IE<sup>2</sup> SWOT Analysis: Step Five*

*Synthesizing SWOTs.* The researcher first analyzed the quantitative data from the Family Support Survey to determine frequency of responses on individual items related to factors perceived as enhancing or inhibiting, and appraisal of control as being either internal (self) or external (outside). The researcher then computed measures of the mean, range, and standard deviation for each item.

A Ward's hierarchical cluster analysis of group means for each item was conducted. A cluster analysis method was selected because of its utility as an exploratory statistical tool that reduces data and forms groups or clusters from individual cases that can be analyzed to identify those factors that are most similar and those that are less alike. A hierarchical cluster analysis approach using the Ward's method available within the SPSS software program was selected because of its ANOVA-type approach that minimizes *within-group* distances and maximizes *between* groups differences (Burns & Burns, 2008). The results of the cluster analysis as generated by SPSS are presented using three different output formats, as follows:

1. Cluster Membership Table: Discussion of cluster membership for each SWOT factor.
2. Agglomeration Schedule Table: Discussion of similarities and distances for clusters derived from the hierarchical cluster analysis.



3. Dendrogram: Discussion of a visual interpretation of the data using a hierarchical tree diagram, for each SWOT factor.

The results from the hierarchical cluster analysis are discussed in Chapter 4: Findings.

#### *IE<sup>2</sup> SWOT Analysis Step Six*

*Interpreting findings and deliberating action.* The final step for the IE<sup>2</sup> SWOT analysis consisted of plotting each SWOT factor data point into one of the four respective SWOT quadrants on the IE<sup>2</sup> Matrix Grid, a Cartesian coordinate system used to represent the relationship between and differences among each Strength, Weakness, Opportunity and Threat (Leigh, 2000, 2005a, 2005b, 2009). The magnitude and placement of each single data point is analyzed in relation to each other, as well as analyzing cluster membership and placement on the grid. Plotting the bivariate data within the two-dimensional IE<sup>2</sup> Matrix grid in this manner provides for a visual representation of the SWOT data that illustrates both individual responses as well as how these responses “hang” together in clusters (Leigh, 2000, 2005a, 2005b, 2009). The utility of using a visual depiction of data is that numerical and narrative data analysis is easier for individuals to grasp the relationship between factors.

Figure 2 illustrates a sample of what a completed IE<sup>2</sup> SWOT Matrix might look like based on a sample of group means ratings plotted on the matrix.

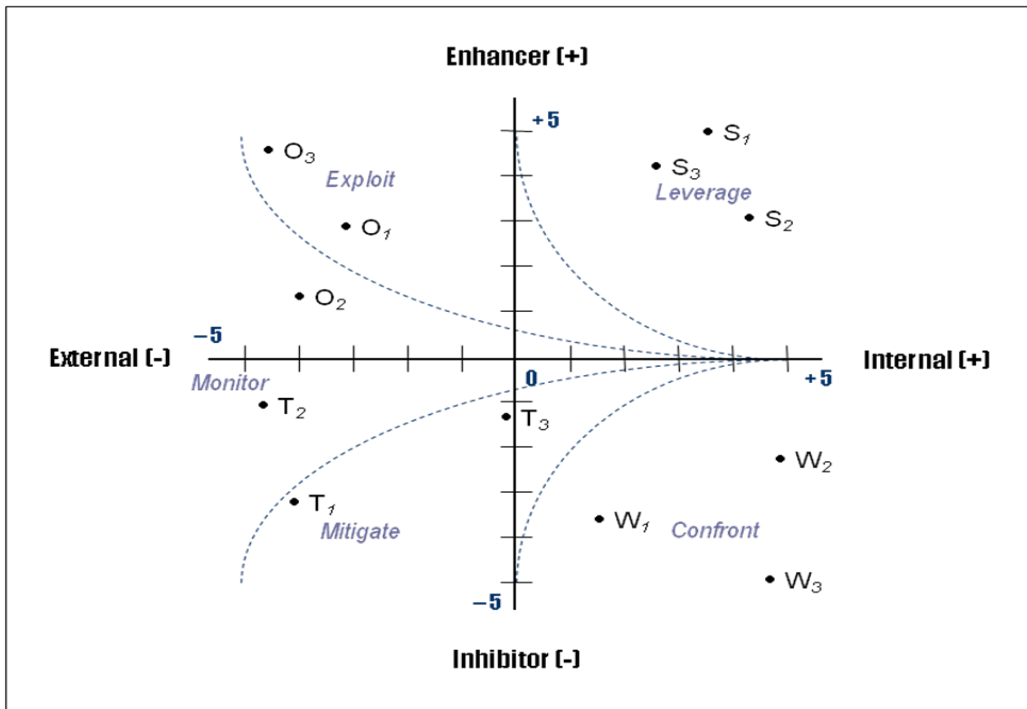


Figure 2. Sample of IE<sup>2</sup> SWOT matrix. From “SWOT Analysis,” by D. Leigh, 2010, Handbook of Improving Performance in the Workplace, p. 116. Copyright 2010 by International Society for Performance Improvement. Reprinted with permission.

Additionally, according to Leigh (2000, 2005a, 2005b, 2009), it can facilitate analysis and interpretation of data in making informed decisions about elements that should be:

- Leveraged (for strengths under substantial internal control that also act as strong enhancers of performance)
- Monitored (for opportunities and threats under substantial external control but minimally enhancing or inhibiting performance)
- Confronted (for weaknesses under substantial internal control that also act as strong inhibitors of performance)

- Mitigated (for threats that are under minimal external control that substantially inhibit performance)
- Exploited (for opportunities that are under minimal external control that substantially enhance performance)

When applied to the purpose of this study, namely to identify parent's appraisals of control and perceptions of factors that enhance or inhibit their access and utilization of information, social supports, and resources, these terms might be modified as follows:

- *Build* upon family strengths to enhance access and use of supports (for strengths that are under substantial internal control and that act as strong enhancers for accessing desired supports)
- *Monitor* (for opportunities and threats having strong appraisals of control as being in the hands of others but having minimal influence over access and use of supports)
- *Identify* family needs for supports and reduction in barriers to access and use of supports (for weaknesses under substantial internal control that act as strong inhibitors for accessing desired supports)
- *Eliminate* gaps between family needs and/or desires for supports and their ability to access and use these supports (for threats under minimal external control that substantially inhibit access and use of supports)
- *Enhance* access and use of desired supports (for opportunities that are under minimal external control that families perceive as being substantially helpful)

Figure 3 illustrates a sample of a completed IE<sup>2</sup> SWOT Matrix for family support using fictional data based on a sample of group means ratings plotted on the matrix.

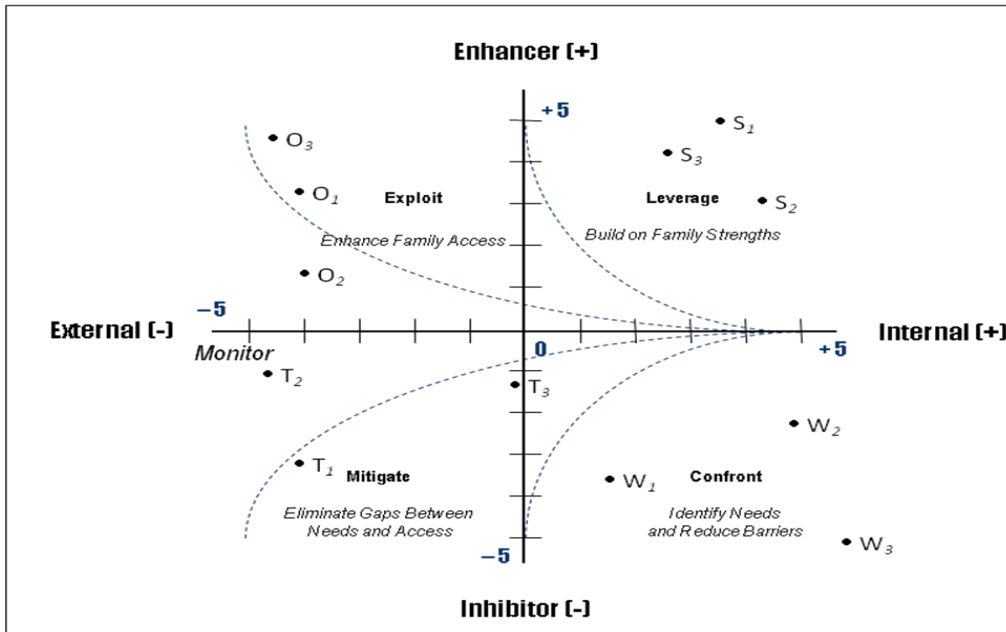


Figure 3. Sample of IE<sup>2</sup> SWOT matrix for family support. The data in this table are adapted from “SWOT Analysis,” by D. Leigh, 2010, *Handbook of Improving Performance in the Workplace*, p.135. Copyright 2010 by International Society for Performance Improvement. Adapted with permission.

### Summary

The researcher presented the methods and rationale for the qualitative and quantitative data collection and analysis methods selected for use in this study. A detailed description of the focus group interview protocol was provided and the use of the IE<sup>2</sup> SWOT Matrix protocol as a method for organizing the collection, analysis, and interpretation of qualitative and quantitative data. The data collection tools and procedures for data collection and analysis were discussed. Chapter 4 will present the findings of data collection and analysis related to each of the five research questions.

## CHAPTER 4: FINDINGS

### Introduction

This chapter presents the findings of the mixed methods descriptive and phenomenological study aimed at gaining a deeper understanding of the lived experiences of families' participation in early intervention/special education services for their special needs children and the meanings they make of these experiences. Additionally, this study explored parent perspectives of the type of experiences that either enhance or inhibit their ability to access and utilize information, social support, and resources related to their child's special needs, as well as the extent to which parents attribute these factors as being within or outside of their control.

### *Research Questions*

This study addressed the following research questions:

RQ 1: What are the lived experiences of families whose children with special needs participate in early intervention/special education services, and what meanings do they make of these experiences.?

RQ 2: What are families' lived experiences accessing and utilizing information, social support, and resources?

RQ 3: What are families' appraisals of control over their experiences accessing and utilizing information, social support, and resources?

RQ 4: What are families' perceptions of the type of experiences that enhance or inhibit their access and utilization of information, social support, and resources?

RQ 5: To what degree, if at all, is there agreement among families' ratings of the value of enhancing or inhibiting experiences, and their appraisals of control over these experiences?

### *Procedures*

#### *Qualitative Procedures*

Using the procedures described in Chapter 3, the researcher conducted a two-hour focus group with six parents of children over the age of 3 years who have special needs. Qualitative data was collected during the focus group using open-ended and semi-structured questions related to parent's lived experiences and the meanings they make of these experiences in order to answer research question 1. Open-ended and semi-structured questions related to experiences with accessing and utilizing information, social support, and resources were used to collect data for research question 2. An IE<sup>2</sup> SWOT protocol was used to collect qualitative data related to research questions 3 and 4 pertaining to parents' perceptions of factors that enhance or inhibit their access and use of information, social supports, and resources and the degree to which they attribute control over these factors as being within (internal) or outside (external). Qualitative data obtained from the focus group interview were analyzed for clusters and themes using a data reduction and content analysis using a modified Stevick-Colaizzi-Keen method and is described in detail in the data analysis section of this chapter (Moustakas, 1994).

#### *Quantitative Procedures*

Quantitative data was collected three weeks later using the Family Support Survey (FSS), a Likert-type tool developed for this study using statements derived from

participants responses obtained from focus group interview data collected for research questions 3 and 4. Following the IE<sup>2</sup> SWOT Analysis protocol developed by Leigh (2000, 2005a, 2005b, 2009), data collected, and the subsequent formation of the questionnaire, were organized around four categories of influence, referred to as SWOTs (strengths, weaknesses, opportunities, and threats). Strengths and weaknesses are factors perceived to be within a person's control (internal control), with strengths representing factors that are seen as being helpful (enhancer) and weaknesses are seen as being a hindrance (inhibitor) towards obtaining something desired. Opportunities and threats are factors that are viewed as being in the hands of others (external control), with opportunities perceived as being helpful (enhancer) and threats as a hindrance (inhibitor) to achieving something desired.

Quantitative data obtained from the Family Support Survey tool was analyzed using measures of central tendency and Ward's Method hierarchical cluster analysis option in the computer software program, SPSS 17.0.0. The final analysis, interpretation and determination of action to take based on data was conducted using the IE<sup>2</sup> SWOT Analysis Matrix and Grid developed by Leigh (2000, 2005a, 2005b, 2009).

#### Participant Characteristics

The researcher recruited participants from a list of 25 families who met the eligibility criteria for the study. Criteria for participation was being a parent of a child with special needs between the ages over 3 years of age currently participating in services provided by the investigated program, or who had participated within the prior six months.

Using a prepared script, the researcher contacted prospective participants to explain the purpose of the study and to ask if they wanted to participate. Every attempt was made to accommodate the schedules for the maximum number of parents. Six mothers were ultimately selected for the study. A research assistant mailed each parent a packet that contained information that explained the study, the informed consent form, and the date of the focus group.

Because childcare was an issue for some participants, the focus group was conducted on a day when the investigated program conducted a social skills group. Five of the six participants' children participated in the group and the remaining parent did not bring her child. Refreshments were served as the focus group was conducted in the early evening. The focus group was held in a small and comfortable conference room adjacent to the room where the social skills group was located.

All six participants were mothers, two Latina and four Caucasian. One mother worked full-time outside of the home, while the remaining five were either full-time homemakers or worked part-time from the home. The study participants were all parents with substantial experiences with accessing and using supports and participating in a continuum of services (e.g., regional center, early intervention, preschool, kindergarten, and elementary school).

Five of the six parents returned the *Child Characteristics Questionnaire* (see Appendix L). One mother was the parent of a female age 7 years, and five of the mothers were parents of males ages 5 ½, 6 ½, 7, 8, and 9 years. The child who was 9 years of age was included since he had turned nine just prior to the beginning of data collection. All children had a diagnosis of mild to moderate autism spectrum disorder and were



participants of the investigated program’s adaptive and social skills services that enhance functional communication, social interaction, self-regulation, and self-help skills so they can more fully participate in typical family routines and age appropriate community based activities. The length of time of participation in the investigated program ranged from 3 to 7 years of age (see Table 8).

Table 8

*Child Characteristics*

Parent	Child’s Gender	Child’s Present Age	Child’s Age at Start	Child’s Time in Program
1	Male	5 ½ years	2 ½ years	3 years
2	Female	7 years	3 years	4 years
3	Male	6 ½ years	2 years	4 years
4	Male	8 years	2 years	6 years
5	Male	9 years	2 years	7 years
6	Male	N/A	N/A	N/A

Data Collection

The researcher developed a Focus Group Interview Protocol to guide the open-ended and semi-structured interview to collect qualitative data. The Family Support Survey tool was developed for this study to obtain quantitative data of participant ratings of the degree to which they agreed with responses generated during the focus group interview. The Focus Group Interview Protocol and the Family Support Survey were reviewed by a panel of three experts and submitted for approval by the Pepperdine University’s Institutional Review Board (IRB). Once IRB, the expert panel and site administrator approval was obtained, participants were recruited and data was collected. Data collection occurred in two phases. Phase 1 collected qualitative data and phase two

collected quantitative data as described in detail in chapter 3. Data collection procedures are briefly reviewed.

### *Phase 1: Qualitative Data*

#### *Focus Group Interview*

Phase 1 of qualitative data collection consisted of three steps that occurred during a single two-hour focus group session with six participants. The researcher recorded participants' responses using an audio recorder and took copious notes. Additionally, one research assistant entered participants' statements into a computer-generated spreadsheet designed for this study. The focus group began with broad and open-ended questions that incrementally became more structured in order to ensure that data collected addressed the study's research purpose.

The first step of qualitative data collection consisted of initially using broad and open-ended questions free from constraint to gain families' lived experiences with accessing supports for their special needs child after age three and the meanings they made of these experiences in order to answer research question 1.

The second step of qualitative data collection pertained to participants' perceptions of experiences related to research question 2 involving accessing and utilizing information, social supports, and resources. In addition to the open-ended questions, the researcher developed four pre-determined categories of semi-structured questions to guide the focus group interview to ensure that information provided by participants was consistent with answering research question 1 related to families lived experiences and research question 2 related to families experiences with accessing and utilizing information, social support, and resources.

Using a SWOT analysis based on Leigh's (2000, 2005a, 2005b, 2009) IE<sup>2</sup> Matrix protocol, the third step collected qualitative data related to research questions 3 and 4 pertaining to parents' perceptions of factors that enhance or inhibit their access and use of supports, as well as their appraisals of control as being internal or external.

As discussed in Chapter 3, conventional definitions for SWOTs are not familiar to parents. Furthermore, as traditionally defined, the information sought during a SWOT analysis are based on factors more relevant to organizational and business planning and evaluation. Therefore, in order to increase the practicality and utility of the IE<sup>2</sup> SWOT protocol for the population and research questions under study, the researcher modified the definition of terms for each of the SWOT quadrants as follows:

1. Internal enhancer (strength): a family strength or asset that supports or helps a family access and utilize supports;
2. Internal inhibitor (weakness): a family challenge or deficit that impedes family access and utilization of supports;
3. External enhancer (opportunity): a factor outside of the family that supports or helps family access and utilize supports; and
4. External inhibitor (threat): a factor outside of the family that impedes access and utilization of supports.

The researcher explained these terms to the participants prior to asking questions designed to generate participants' responses related to research questions 3 and 4. Once the researcher was confident that participants understood the terms, the interview proceeded by asking participants to describe their experiences with accessing and utilizing supports with respect to their perceptions of control as being within or outside of

themselves, and factors that they believed either enhanced or inhibited their access to information, social support, and resources.

A research assistant recorded participants' responses verbatim on large 18" X 24" poster paper and entered into a computer spreadsheet simultaneously by another research assistant. The researcher later transcribed participants' statements to create the Family Support Survey used for collecting quantitative data described in the next section. All direct quotes were obtained from the six participants in this study.

### *Phase 2: Quantitative Data Collection*

#### *IE<sup>2</sup> SWOT Matrix Analysis*

Phase 2 collected quantitative data. Expanding upon qualitative data collected during the focus group interview, the researcher proceeded with the IE<sup>2</sup> SWOT Matrix protocol to collect quantitative data related to research questions 3 and 4. Participants' statements were listed and organized into one of four SWOT categories, known as strengths, opportunities, weaknesses, and threats. According to Leigh (2000, 2005a, 2005b, 2009), in an IE<sup>2</sup> SWOT Matrix approach, experiences that are perceived as being within the participant's control and enhance their experiences are referred to as *strengths* (internal enhancers); while those that are perceived as being within their control but inhibit their experiences are considered *weaknesses* (internal inhibitors). Experiences that participants perceive as being outside of their control and enhance their experiences are *opportunities* (external enhancers); and experiences that are perceived as being outside of their control and inhibit their experiences are referred to as *threats* (external inhibitors).

The researcher then reviewed participant responses for statements that reflected their perceptions of experiences that they believed to be either an internal enhancer

(strength), internal inhibitor (weakness), external enhancer (opportunity) or external inhibitor (threat). Within each of these four quadrants, items were separated into additional categories of information, social supports, and resources.

The transcribed verbatim and paraphrased statements from the SWOTs were coded and numbered and then entered into the Family Support Survey tool based on their relevancy to one of the corresponding four quadrants of the SWOT matrix (e.g., strengths, weaknesses, opportunities, and threats). To maximize the reliability and validity of the tool, items used on the survey tool matched participants' original statements as closely as possible. As a result, many items do not follow strict rules of grammar. The final completed version of the Family Support Survey tool is located in Appendix M.

The Family Support Survey tool used an 11-point Likert-type rating scale that ranged from -5 (high external or inhibitor) to +5 (high internal or enhancer), with a value of (0) in between. A demographic information questionnaire was developed to capture information about the child's gender, age, length of time receiving services and current services the child was receiving.

The Family Support Survey tool, along with the *Child Characteristics Questionnaire*, designed to capture basic demographic information, was mailed to each of the six participants with a returned, self-addressed envelope. Parents were instructed to rate the extent to which they individually agreed that the statements represented experiences they perceived as being within or outside their control, and act as an enhancer or inhibitor to their access and utilization of information, social support, and resources.

A staff member of the investigated program who was not associated with the research study received returned surveys. The staff member opened and separated the Family Support Survey (FSS) from the demographic information in order to de-identify participant's responses. All six participants returned the survey and five participants returned the demographic questionnaire. The researcher entered participant responses into a computer generated spreadsheet and analyzed for group mean ratings, range of scores, standard deviations, and similarities and differences among responses using the SPSS Statistics Tool 17.0.0.

### Data Analysis

As stated in Chapter 3, the purpose of this descriptive and phenomenological mixed-methods study was to gain a deeper understanding of the lived experiences of families' participation in early intervention/special education services for their special needs children and the meanings they make of these experiences (Creswell, 1998). In particular, this study sought to explore family perspectives about the type of experiences that either enhance or inhibit their ability to access and utilize information, social support, and resources and the extent to which they perceive these experiences as being within or outside of their control.

One of the challenges when analyzing qualitative data is reducing the vast amount of data collected so that it can be analyzed in light of the research questions under investigation (Berkowitz, 1997). The researcher used a modified Stevick-Colaizzi-Keen method (Moustakas, 1994), described in Chapter 3, for analysis of qualitative data collected in this study. This approach included a coding process used to organize data

into meaningful patterns, clusters and themes that support study's research questions (Creswell, 2003).

The quantitative data obtained from participants' ratings of SWOT factors on the Family Support Survey were first analyzed for the extent to which there was agreement among participants' responses as measured by group means, standard deviations, and range of ratings related to strengths, weaknesses, opportunities, and threats. Second, the researcher entered participants' ratings into the SPSS software program using Ward's hierarchical cluster analysis option for patterns of cluster membership among group means ratings for each SWOT factor, and the degree of differences and similarities among clusters. These differences and similarities were analyzed through three SPSS outputs: the cluster membership, the agglomeration schedule, and the dendrogram. Each of these will be described in further detail under the quantitative analysis section of this chapter.

The third and final stage of quantitative data analyses consisted of plotting the bivariate group means data on the IE<sup>2</sup> Martix Grid developed by Leigh (2000, 2005a, 2005b, 2009) to facilitate interpretation of participants' responses and to guide prioritization and action to take in response to the results. Each of these are discussed in more detail later in this chapter.

The following section will discuss the transcription and analysis of qualitative data obtained during the focus group interview related to research questions 1 and 2. Analysis and discussion of results from quantitative data will follow.

### *Transcription and Analysis of Qualitative Data*

The researcher transcribed the qualitative data using QSR NVivo 8, a computer software program designed for analysis of qualitative data. The researcher and two research assistants, who also assisted with conducting the focus group, independently read and reviewed written transcripts for significant statements, making notes and coding for themes and patterns related to research question 1 and research question 2. The researcher met with the two assistants to discuss patterns and themes and achieved consensus on the resulting categories and themes that were ultimately used for this study (horizontalization of data). The study results of qualitative data obtained during the focus group interview yielded seven clusters and related themes related to research question 1, and six clusters and related themes related to research question 2. All direct quotes were obtained from the six participants of this study and are noted as P1, P2, P3, P4, P5, P6 (e.g., P1 meaning parent 1) and placed in parenthesis at the end of each quote. The resulting categories and related themes are discussed below.

#### *Clusters and Themes for Research Question 1*

Significant statements were categorized using the criterion selected in advance to facilitate analysis of data related to research question 1 aimed at gaining a deeper understanding of meanings of participants' lived experiences with parenting a child with special needs. Results for research question 1 are described.

#### *Meanings of Parent's Lived Experiences*

In order to answer research question 1, to gain a deeper understanding of the phenomenon of parents' lived experiences with parenting children with special needs and the meanings they make of their experiences, the researcher asked open-ended questions



and probes during a single focus group interview. Analysis of transcripts of participants' responses in relation to research question 1, resulted in seven clusters pertaining to parents' lived experiences and the meanings they make of their experiences as the parent of a child with special needs. The order in which the clusters were sequenced for discussion in this study is based on existing research related to family coping and adaptation patterns when confronted with having a child with a disability (Creswell, 1998; Marshak et al., 1999; McCubbin & McCubbin, 1987; Taylor, 1983). Themes were assigned to one of these seven clusters based on relevancy to that cluster. The seven clusters and their associated themes that emerged from the data include:

1. Diagnosis Period
2. Effects on Marriage
3. Community Experience
4. Empowerment
5. Interpersonal Well-being
6. Adaptation, Benefit, Hopefulness
7. Future Needs

The following clusters and themes that emerged are described in the following sections using verbatim statements to illustrate parent perspectives about their experiences and the meanings they make.

*Diagnosis period.* A predominate theme that emerged from the focus group discussion was that the period around the child's diagnosis was particularly challenging for the parents. Parents reported feeling overwhelmed, confused and alone during this time. Additionally, participants expressed feeling hopeful in the beginning that their child

would no longer require services once they turned 3 years of age. However, once their child turned three and received a definitive diagnosis of autism, they reported feeling sadness at the prospect that their child's special needs would be life-long and the resulting implications of that realization. One parent stated that it was still difficult to see other mothers with their typical infants, as it reminded her of her own hopes and dreams when she was expecting her child. Verbatim statements reflecting participants' experiences surrounding the diagnosis period (with participant number in parenthesis) include:

For the first 3 years I can remember a lot of dark times and thinking that we were never going to get out it. . . . not understanding what was going on. (P1)

In the beginning, I remember very clearly, when we started and he perked up right away. . . . I thought in a few months we would be done. (P5)

I had this specific expectation about what it would be like to have a child . . . . I remember when they told me she was diagnosed. (P1)

*Effects on marriage.* Each parent reported disruption in their marital relationship at some point during the time from diagnosis until the present, often as a result of one parent, usually the mother, feeling as if the primary responsibility of caring for their child rest upon them. Communication between spouses was reported as an area that was especially valuable as a source of support and as being essential for being able to manage and cope with their child's special needs. Verbatim statements reflect participants' perceptions about the effects of having a child with special needs on the marital relationship (with participant's number in parentheses) include:

You don't have an outlet, and also your marriage, you don't know what it is going to do . . . you have no idea, you are home all day . . . your husband comes home from work . . . you are supposed to have dinner . . . and you are crying . . . and they are like "what happened . . . you had a therapist here . . . what is going on?"

. . . Your run of emotions and you can't even talk to each other . . . you have no way . . . that puts a huge strain . . . you have to put that together and services . . . and try to be supermom and you're not. . . . I think without having solid communication between the two of you, personally for myself, I am not going to be able to get through those days. . . . I can't deal with it alone. (P1)

*Community experiences.* One of the most challenging areas for families revolved around taking their child into the community. Activities that are routine for most families, such as shopping, dining in a restaurant, going to church or participating in community-based recreational events were especially difficult due to their child's lack of self-regulation and disruptive behaviors. Parents reported experiences where they felt judged by others for not being able to manage their child; and in particular felt that having a child with autism exacerbated this because their special need is not physically obvious to others. Participants expressed feeling as if, on the one hand, they should explain the nature of their child's disability to strangers, while on the other hand, feeling resentment and annoyance at having to do so in order to maintain a sense of competency as a parent. One parent, whose child exhibited substantial and visibly recognizable challenges, reported that this was not an issue for her, because it was more obvious to strangers that her child had a special need, and therefore responded with increased tolerance and understanding. The feelings expressed by parents (with participants' number in parentheses) include:

They are not looking at her, but they are staring at me thinking what are you going to do about it. (P1)

If you do not have much of an issue caring what other people think, I think it is easier for you, but if you are someone who does, it makes it hard . . . you do not want him to bother anyone. (P4)

There is this constant thing that gosh my child is really disrupting this room right now, but it is his right to be here, but they paid for dinner . . . how do you balance

that. . . . Of course, I want him to have the right to be everywhere that every child has the right to be, but I also do not want to be a menace to society. . . . Where do you draw the line? (P5)

*Empowerment.* Whereas during the early years of receiving a diagnosis of their child's special needs participants expressed feeling judged and fearful of taking their child out in the public, as the child got older, and they developed increased feelings of confidence and a sense of competency in their parenting. As a result, participants appeared to feel more empowered and more likely to verbally express their feelings to others. One theme that emerged was the feeling that strangers who interjected opinions about how the parent should handle their child were rude, and therefore deserved a less than polite response as evidenced in the following comments. Parents' expressions (with participant's number in parentheses) include:

If you are an autism expert do you have some suggestions for me about how to handle this? [Statement in reaction to a comment made by a stranger to one parent while waiting in line at a store.] (P3)

The best comebacks are the ones that make people eat their words. (P4)

I think the longer you are in this world (related to special needs) the better you get at dealing with on lookers. (P6)

*Interpersonal well-being.* While the four parents of children with more mild symptoms of autism reported that their situation improved over time, the two parents of children with more severe challenges described themselves as feeling "burned out and exhausted" as their child got older. One reason cited for this was the relentless care giving needed for a child with significant special needs in terms of supervision and management of different therapies that the child needs. One parent's comment that sums up this feeling (with participant's number in parentheses) include:

I had more strength in the beginning . . . but several years later I feel more burned out now because I don't get a lot of the feedback about progress that other parents might get . . . it starts to feel very isolating because you feel like professionals don't even have the answers for you. . . . It gets harder for me. (P5)

*Adaptation, benefit, and hopefulness.* All participants shared the feeling that as their child got older they could see that having a child with special needs also had a positive benefit for them. However, reaching this belief was by no means a linear process, but was marked by periods of ups when they felt hopeful, and other times when they felt discouraged when their child did not reach a level of progress that the parent desired. Participants with children who were less challenged were more likely to report feeling hopeful for their child's future. A universal theme in this area was the belief that their child enabled them to make friends with individuals they otherwise would never have known. In addition, they expressed that the experience enhanced their growth as a person by making them stretch beyond their comfort zone. Parents' verbatim statements (with participant's number in parentheses) include:

Once kindergarten kicked in, I thought ok, this is doable, we could maintain. . . . Now first grade and then second grade there is a *BIG* (italics added for emphasis) light at the end of the tunnel. (P1)

I learned to take it a day at a time. (P4)

I can now say that it is a blessing because I have met the most incredible people in my life. . . . These kids are the future and they are going to run the world. . . . For me it is about patience . . . that every little thing means something and it should mean something to me, whether how minute, how small (sic), and then there is beauty in it . . . she sees it and I need to see it too. (P1)

I have had to stretch and have not even come close to stretching as far as I should outside my comfort zone . . . having to push for things . . . and doing things that are uncomfortable for you that maybe you could get away without doing if your child were developing typically. (P2)

*Future needs.* Participants also identified obstacles within the service delivery system as contributing to negative experiences for them. Speaking about future needs for her child, one parent shared that her regional center service coordinator felt that the parent should need less services, as the child gets older. A concern shared by all participants (with participant's number in parentheses) include:

How is it going to be coordinating their world... are they still going to be tantruming at the age of 15? (P6)

She (regional center service coordinator) made a comment to the effect of . . . that we (the parent) would need less support as time goes on because we know how to find resources—excuse me—and I thought it is just so ridiculous . . . your child changes . . . sometimes the further you get into it the more you don't know. (P5)

That seems to be the ongoing theme—services are intended to be more time limited, and there is an idea that once your child goes through a certain amount of time your child will be cured or parents will know what to do, navigate on your own, manage it on your own. (P4)

Even with everything (services) I have now, I am at the edge a lot of the time, so if I lost (them) it would be really, really hard . . . not just getting through the next year. . . . It is really about that long term and what happens when he is not going to school 6 hours per day and he is 22 years old and if he still needs a tremendous amount of support. (P5)

#### *Summary of Clusters and Themes for Research Question 1*

The summary table of the seven clusters and related themes of parents' lived experiences and the meanings they make of these experiences are located in Table 9.

Participants' responses obtained from the open-ended question asking them to describe their experiences with parenting a child with special needs and the meanings that they make from these experiences revealed several categories and themes. The periods surrounding their child's diagnosis and key transitions, such as from early intervention to preschool and from preschool to kindergarten were particularly difficult for participants. One area that was especially problematic for these parents was managing reactions from

individuals they encountered when they took their child into the community. All parents experienced conflicted feelings of inadequacy (e.g., should be able to manage child) and anger (e.g., my child has a right to be here too). Parents expressed feelings of empowerment when they were able to stand up for themselves and their child when confronted with perceived insensitive and ill-informed comments from bystanders.

Table 9

*RQ 1: Parent's Lived Experiences and Related Meanings*

Cluster	Theme
1. Diagnosis period	<ul style="list-style-type: none"> <li>• Challenging</li> <li>• Overwhelmed and confused</li> <li>• Sadness</li> </ul>
2. Effects on marriage	<ul style="list-style-type: none"> <li>• Disruption</li> <li>• Sense of responsibility</li> <li>• Communication</li> <li>• Importance of spousal support</li> </ul>
3. Community experiences	<ul style="list-style-type: none"> <li>• Difficulty going into community</li> <li>• Feeling judged by others</li> <li>• Managing child's behaviors</li> </ul>
4. Empowerment	<ul style="list-style-type: none"> <li>• Increased feelings of competence and confidence</li> <li>• Able to deal with stranger reactions</li> <li>• Increased strength to manage child in public</li> </ul>
5. Interpersonal well-being	<ul style="list-style-type: none"> <li>• Burn-out and exhaustion</li> <li>• Feelings of isolation</li> </ul>
6. Future needs	<ul style="list-style-type: none"> <li>• Service delivery system obstacles</li> <li>• Concerns about having services and supports</li> <li>• Government funding/budget issues</li> </ul>
7. Adaptation, benefit, hopefulness	<ul style="list-style-type: none"> <li>• Friendships formed with other parents</li> <li>• Feeling able to manage child's needs in long-term</li> <li>• Experience makes parent better person</li> <li>• Stretch beyond comfort zone</li> </ul>

Most participants expressed concern for the future around the availability of services for their child, as they get older. In general, these concerns were related to

factors within the service delivery system at a macro level. For example, participants cited the expectation by the service coordinator that parents should need fewer services as the child gets older, whereas the families felt that they were likely to require at least the same level of services, and perhaps even an increase as their child progresses in their development. However, parents in the study also seemed to have attained a sense of positive meaning and well-being related to their child's special needs as indicated in statements about friendships formed and their own personal growth.

In order to more closely examine participants' experiences specifically related to accessing and utilizing supports pertaining to their child's special needs, the researcher used open-ended and semi-structured questions around the categories of information, social support, and resources.

#### *Clusters and Themes for Research Question 2*

Research question 2 sought to gain a deeper understanding of families' lived experiences with accessing or utilizing (a) information, (b) social support, and (c) resources. In order to elicit participant responses, the researcher asked the question "what has it been like for you to get supports related to your child's special needs or the needs of your family?" The interviewer asked probing questions in order to understand better the type of information desired, as well as where and how they accessed information. Probes for experiences with social support focused on eliciting perceptions related to what or whom participants rely on for support and how they go about getting support. In order to gain a deeper understanding of family experiences with accessing resources, the researcher used probing questions that inquired about the type of resources they needed or desired, and where they access resources



The researcher transcribed participants' statements during the focus group interview. Similar to coding and data reduction procedures used for research question 1, statements were reviewed and coded for relevancy to one of three areas related to research question 2, (a) information, (b) social support, or (c) resources. This criterion was selected in advance to facilitate analysis of data. The resulting clusters and themes are discussed below.

Content analysis of experiences related to accessing and utilizing information resulted in two clusters and related themes and includes:

1. Access to Information
2. Type of Information

Content analysis of experiences related to accessing and utilizing social support resulted in two clusters and related themes and includes:

1. Informal Support
2. Formal Support

Content analysis of experiences related to accessing and utilizing resources resulted in two clusters and related themes and includes:

1. Access to Resources
2. Type of resources

#### *Experiences with Accessing and Utilizing Information*

Participants' responses regarding their experiences with accessing and utilizing information revealed two primary themes: (a) where and how they access information, and (b) the type of information they desired.

*Access to information.* A primary theme that emerged concerned parent experiences with learning about the various sources of information available and how to obtain this information. Parents expressed that the early days during which their child was beginning early intervention/education services were particularly challenging, but that the longer their child participated in services, the more knowledgeable they became. In fact, one parent shared that she now uses her years of experience and knowledge to reach out to other parents of children just entering the system.

I was talking to a mom in the waiting room and she has a child who is newly diagnosed . . . I handed her my phone number because she doesn't know about respite and how to get it. (P3)

Participants shared that when they first began participating in services, they relied heavily upon service coordinators and/or early intervention professionals for information. However, a universal theme shared among participants was frustration with not being informed about the “buzz words” needed to advocate effectively for services on behalf of their child. Furthermore, they felt that the system was constantly changing and that it was difficult to keep up to date about the “new lingo” they needed to use in order to obtain desired services. The following comments that illustrate parent’s perceptions of these experiences (with participant’s number in parentheses) include:

I think that there was information, but at the time, I do not think it was nearly enough. . . . I do not think the therapists knew enough, not as far as the child goes, but as far as the regional center went (in reference to therapist lack of knowledge about the regional center). (P5)

There was no connection about what you could/should get or what language to use to get what you needed. (P3)

I did not know anything . . . what to look for . . . what to ask for . . . and how to go about finding things. (P6)

Without exception, the parents unanimously agreed that other parents of children with special needs were their best source of information. In particular, they described the importance of opportunities to talk with other parents in the Center's waiting room. Other sources of information that participant's found useful included resource guides, books, the internet, conferences, and experts.

We got all of our information from us (referring to other participants of the focus group). . . . I could not wait to get into the waiting room, so that I could eavesdrop . . . and absorb everything they were saying. . . . Nobody told me anything except the other moms. . . . That was the only place I ever got my information. (P2)

But, I think still information, mostly I have gotten from other parents . . . the majority of how to put it to work . . . how they take what you might read about or hear about at a conference and actually implement. (P4)

My very first book was *The Child with Special Needs* (Stanley Greenspan) . . . that was my Bible . . . I carried it with me all the time. (P1)

*Type of information.* Participants expressed that the type of information they most desired related to services that were available, their child's disability, and treatment approaches to help their child. Additionally, parents expressed that they wanted this information to be vetted, easy to read, and non-biased.

In response to the question of the kind of information they found to be important, one parent summed it up with her statement "services, services all the way around," a sentiment corroborated by other participants. Initially parents expressed that they were most concerned about where and how to get services. Parent's verbatim statements (with participant's number in parentheses) include:

We don't know what to ask for, but nobody specifically here will tell you. . . . I felt there was a lot of confusion, that they did not work together very well . . . the Center therapist did not know what was out there . . . and could not suggest things to you to ask the regional center. (P4)

In addition to wanting to know about services available, participants also wanted accurate information about their child's disability. Additionally, they expressed a desire for information about treatment approaches that was available in a format that was easy for parents to understand. A common theme expressed was large amount of information available and lack of time to read it all. Furthermore, participants wanted information that was accurate, unbiased and abbreviated.

I wanted them (therapists) to teach him (child) and me. (P5)

There are studies by researchers, but it is out there in the academic world . . . nothing is filtered down. (P2)

There is so much information . . . almost too much information . . . not usable information. (P4)

We need the reader's digest version . . . I don't have time to read anything more than a . . . magazine. (P3)

I was too afraid to go to the internet and search autism and be afraid of what was going to come . . . but maybe if it is in print at the center . . . and has been vetted . . . we know this may be believable, good information. (P2)

### *Experiences with Accessing and Utilizing Social Support*

In response to the question of what or who families rely on for support and how they access support, participants' experiences clustered around two themes of either informal support (i.e. spouse, family and friends, and other parents with special needs children) or formal support (i.e. intervention program, organized and structured parent support groups, and individual/family therapy). Results of participant's responses are summarized in the following section.

Participants described the investigated program's center, and in particular the waiting room area, as a place where they met other parents, as a "lifeline" and a "lovely

place to be.” In addition to sharing resources and information, they expressed a sense of a shared experience and of feeling as if they were not in this alone. While the overwhelming majority of comments reflected positive experiences related to the Center, there were a few exceptions. One parent, who had been involved with the program when it was located in a smaller facility, described the waiting room as being very tiny and that there were no opportunities to connect with other parents. However, this parent also stated that once the center relocated to larger facilities where she was able to connect with other parents while sitting in the waiting area, her experiences were much more positive.

*Informal support.* Informal support refers to the types of supports that parents develop on their own and primarily involves spouses, family, friends, community and other parents of children with special needs. All of the participants were married and expressed that their spouses were an important source of support. In particular, they felt that good communication was essential for helping them to manage and cope with the demands that accompany parenting a child with special needs. In contrast, when effective communication was lacking, participants felt that it put a strain on the marital relationship.

I think without having that solid communication between the two of you . . . personally for myself I am not going to be able to get through those days . . . I can't deal with it alone . . . he needs to know when to step in and take over. (P1)

Family and friends, as well as faith-based organizations also emerged as a source of support that participants relied upon a lot. Support from these sources appeared to be helpful in enabling families to maintain their connections with their community and

important friendships they had prior to having a child with special needs. Parent's verbatim statements (with participant's number in parentheses) include:

I felt fortunate. . . . I feel like I have maintained a good amount of friends outside of the special needs community. . . . I do rely a lot on friends and family. (P6)

And church . . . they have done a lot for my son. . . . They have provided a buddy for him. . . . There are more children with autism and they have created a buddy program. (P6)

I found some families in my neighborhood. . . . They have been very supportive of us as a family. (P1)

By far, the social support that participants experienced as being most meaningful to them was their relationships with other parents of children with special needs. This source of support seemed to be especially important to participants' emotional well-being.

*Formal support.* In contrast to informal support, formal support is typically accessed by parents through their child's intervention/education programs, caseworkers, structured and organized parent support groups and organizations, as well as individual and/or family therapy.

All of the parents expressed that the investigated program's Center was a primary place where they both received and gave one another emotional support. As discussed earlier under participant experiences with accessing and utilizing information, the Center was a place where families felt they could get reliable information from one another.

Parent's verbatim statements (with participant's number in parentheses) include:

We were very sheltered in our little bubble [at the Center] . . . those were the only people I could relate to . . . sitting in the waiting room listening to other parents . . . thinking I want to be here 24 hours a day because they understand my pain . . . that is how I felt. (P2)

That's why I say sometimes finding parents who have a child who is similar . . . they will be able to related to the idea of autism . . . but also to what you are going through . . . so we seek each other out on purpose. (P5)

One theme that emerged from the focus group discussions was the value of the Center's waiting room area as a place where families felt a sense of belonging through their shared experiences.

Being in a room . . . even if you don't know people's names but happen to be there when you are . . . just picking up that vibe . . . listening to their conversations . . . seeing them deal with their child . . . ok I have been there . . . that's not a bizarre situation. . . . I have been in that situation myself . . . so you feel like that is your connection. . . . This is the only place where you truly belong . . . because every other place you stand out like a sore thumb . . . in the lobby waiting for therapy to start you belong. . . . We are all the same here. . . . There is no judgment. . . . It makes you feel secure. . . . It is a lovely place to be. (P2)

Eyes kind of light up when you see the same people in the waiting room. . . . You talk with others who are probably going through the same things. (P1)

I needed to talk with other parents. . . . Now I feel like we have a 24/7 hour waiting room all the time where we can put all of our ideas to the table and people can bring up all sorts of things. (P2)

I did not spend a lot of time in the waiting room. . . . The only interaction with parents was the social skills groups when there was a parent support group at the same time. (P3)

I trusted her (interventionist) . . . that she would lovingly take care of him. (P2)

Other groups were KEN Project [Parent Advocacy Training] and Sunday mornings [church] . . . everyone gave me different things . . . at the Center I talk about IEPs and the emotional aspect of going through the journey . . . most support groups tend to focus on logistics [such as intervention programs] and diets . . . which we all need desperately . . . but [I] also go to support groups to deal with emotional aspect of it. (P6)

While parent support groups and organizations were perceived as being supportive, experiences with their child's intervention/education programs and caseworkers were mixed.

I try to talk to my caseworker once a year because talking to her always creates a problem. (P5)

She (caseworker) mails me about things going on and asks if I would like to be included in this . . . I think this is good . . . I hear the horror stories and I have been very lucky. (P1)

### *Experiences with Accessing and Utilizing Resources*

Questions directed at exploring families' experiences with accessing and utilizing resources sought to gain a better understanding of how and where families access resources and the type of resources they access and utilize. Resources are areas of support such as services, therapies, medical care financial needs, housing, respite care or childcare. Participants' experiences with accessing and utilizing resources centered on the challenges they encountered with getting desired services for their child or fears that their child would lose services.

*Access to resources.* While participants felt that services and supports were relatively easy to obtain when their children prior to his or her third birthday, as their child grew older participants expressed fears about losing services. This feeling was the result of fewer services offered as well as the threat of elimination of services due to the state budget problems and/or changing policies by agencies that funded services. Parent's verbatim statements (with participant's number in parentheses) include:

But the truth is, even with everything I have now, I am at the edge a lot of the time, so if I lost that (services), it would be really, really hard. (P5)

At our last IPP [Individual Program Plan] meeting our regional center coordinator said that we have to develop an exit plan . . . "we can't just keep coming up with new things to work on" . . . like the most ridiculous thing I have worked on in my life. . . . I just was floored. . . . I mean I am going to fight it. (P5)

That seems to be an ongoing theme . . . services are intended to be more time limited and there is this idea that once your child goes through a certain amount of



time your child will be cured or parents will know what to do, navigate on your own, manage on your own. (P4)

In an ideal world regional center and the school district, the program, everybody would be going—here is all that we have . . . this is what is available for you—but this does not happen . . . so it depends on the parent. (P4)

*Type of resources.* Participants most frequently mentioned respite care as an essential resource and as a “lifesaver.” Many of the types of resources that participants desired have already been discussed under the previous sections of information and social support. Other resources that parents found helpful included the online search engine Google, and conferences geared to parents of family members with autism. Parent’s verbatim statements (with participant’s number in parentheses) include:

Respite is a lifesaver. (P2)

I love Google. (P6)

My regional center coordinator offered . . . you need respite care . . . I have been very lucky to have a good caseworker who always tells me about new and upcoming things . . . I have not had one problem with my coordinator. (P1)

In contrast, parents also expressed frustration that professionals were not always forthcoming about the possible resources available and in some instances gave misleading and inaccurate information about the type of services their child could receive.

It is really about that long-term and what happens when he is not going to school 6 hours a day and he is 22 years old and if he still needs a tremendous amount of support. (P5)

Regional center won’t pay for the diapers that your child is most comfortably with because it is not part of what they send out . . . but with a kid with sensory issues, it is the stupidest policy I have ever heard of. (P3)

*Summary of Clusters and Themes for Research Question 2*

The summary table for each of the six categories and related themes related to research question 2 are located in Table 10.

Table 10

*RQ 2: Experiences Accessing and Utilizing Information, Social Support, and Resources*

Cluster	Theme
1. Access to information	<ul style="list-style-type: none"> <li>• Locating information</li> <li>• Using information</li> </ul>
2. Type of information	<ul style="list-style-type: none"> <li>• Services available</li> <li>• Child's disability</li> <li>• Treatment approaches</li> <li>• Parent friendly</li> <li>• Accurate and non-biased</li> </ul>
1. Informal support	<ul style="list-style-type: none"> <li>• Spouse</li> <li>• Family and friends</li> <li>• Parent-to-parent</li> </ul>
2. Formal support	<ul style="list-style-type: none"> <li>• Intervention program</li> <li>• Parent support groups and organizations</li> <li>• Individual/family therapy</li> </ul>
1. Access to resources	<ul style="list-style-type: none"> <li>• Where to locate resources</li> <li>• How to access resources</li> </ul>
2. Type of resources	<ul style="list-style-type: none"> <li>• Information</li> <li>• Social support</li> <li>• Services for their child</li> </ul>

Comments indicated that lack of information about their child's special needs, access to services and resources, and support from other parents were crucial factors that contributed to their ability to cope and eventually adapt to their child's situation. In contrast, when families encountered obstacles, such as professionals' lack of knowledge

about resources and services available, or not knowing how to help families access these services, participants expressed dissatisfaction and frustration.

On a positive note, parents unanimously identified the value and importance of the support they received from other parents while attending services at the investigated program's center. Without exception, parents cited the center as their primary source of support during the early period of their child's diagnosis. Because of the benefit they received from this informal network of support, several parents went on to establish a parent support group for all parents at the center that operated independently from their participation in formal services offered by the Investigated Program's Center.

#### Analysis of Quantitative Data

Research questions 3 and 4 sought to gain a deeper understanding of families' appraisals of control and their perceptions of factors that either enhance or inhibit their ability to access and utilize information, social supports, and resources. Quantitative data obtained from the Family Support Survey expanded upon the qualitative data collected for research questions 3 and 4 during the focus group. According to Leigh (2009), "description alone is not analysis" (p. 128), that is, it is not enough to name and sort SWOTs by internal or external control, and the influence they have on enhancing or inhibiting a phenomenon. What distinguishes the IE<sup>2</sup> SWOT analysis from a conventional SWOT approach is the added step in which each stakeholder (parents in this study) quantitatively rates the degree to which each SWOT factor is controlled internally or externally, and the degree to which these factors are enhancers or inhibitors of something desired, in this study access and utilization of supports.

The Family Support Survey tool was adapted from Leigh's IE<sup>2</sup> questionnaire in which participants' statements are categorized into one of the four SWOTs (Leigh, 2009). Factors that are under the control of parents and act as enhancers are strengths and those that act as inhibitors are weaknesses. Factors under the control of others act as enhancers are referred to as opportunities, while those that act as inhibitors are threats. The purpose of this step is to ensure that all participants' have an equal opportunity to voice their own individual perspectives.

By quantifying the SWOTs, participants' responses can be further analyzed using descriptive measures of central tendency to determine the degree of agreement and variability among group means ratings, and through statistical methods, such as cluster analysis to explore similarities and differences between and among SWOT factors. Finally, the use of quantitative measures allows for the use of the IE<sup>2</sup> SWOT Matrix and Grid protocol to enhance interpretation and prioritization of action based on the expressed desires and needs of participants (Leigh, 2000, 2005a, 2005b, 2009).

### *Research Question 3*

Research question three addressed families' perceptions of their influence of control over their experiences with obtaining and utilizing (a) information, (b) social support, and (c) resource support. In order to obtain participants' responses, the interviewer asked the question, "Who do you think has control over whether you get the supports you desire and/or need for your child and family?" Further probing questions were asked to better understand whether participants perceived control as being internal (i.e., within parent control) or external (i.e., outside parent control, or in the hands of others). Perception of control as being internal (within parent control) or external (control

by others), has been described in the literature as an important factor that influences families' perceptions about their child's disability and their beliefs that intervention services and supports will make a difference in their child's developmental outcomes and family well-being (Mahoney et al., 1996; Taylor, 1983; Trivette et al., 1996).

#### *Research Question 4*

Research question 4 asked, "What are families' perceptions of the type of experiences that enhance or inhibit their attainment of (a) information, (b) social support, and (c) resource support?" The purpose of the corresponding segment of the focus group interview was to gain a deeper understanding of parent's perceptions about experiences that helped them or made it hard for them to access information, social support, or resources related to their child's disability and family needs. A consistent finding in the literature is the importance of services and supports being offered in a family-centered manner in which the child and family's individual needs are not based on a "one-size-fits-all" approach (Dunst et al., 2002).

The following sections discuss the SWOTs identified by participants and entered into the Family Support Survey (FSS). Group means ratings related to their experiences with accessing and utilizing information, social support, and resources are described. Use of the IE<sup>2</sup> SWOT Matrix protocol structure, the section is organized into four SWOT categories of (a) strengths, (b) weaknesses, (c) opportunities, and (d) threats. Within each of these four SWOTs is a discussion of factors related to information, social support, and resources.

### *Strengths*

Strengths generated from the IE<sup>2</sup> SWOT Analysis refer to factors within the family's control and function as family strengths or assets that help the family in accessing and using supports. Responses obtained from participants during the IE<sup>2</sup> SWOT Matrix Analysis interview resulted in nine factors that participants described as being within their control and as helping them access and utilize information, social support, and resources related to their child's disability. Three of the nine Strengths factors related to experiences with obtaining information, three to utilizing social support, and three to accessing resources and services.

#### *Information Strengths*

The three Strengths factors and group mean ratings that related to information were:

S1. Knowledge of the proper "lingo" needed to get services for my child ( $M = 3.50$ ,  $SD = 1.22$  for internal control and ( $M = 4.83$ ,  $SD = 0.41$  for helpfulness).

S2. Knowledge of my child's disability and how to help my child ( $M = 3.83$ ,  $SD = 0.75$  for internal control and  $M = 4.83$ ,  $SD = 0.41$  for helpfulness).

S3. Knowledge of services available for my child ( $M = 3.00$ ,  $SD = 1.41$  for internal control and  $M = 4.67$ ,  $SD = 0.52$  for helpfulness).

Participants' group means ratings for appraisals of control over factors that influence their access and use of information were the lowest for "knowledge of services available for my child" (S3), ( $M = 3.00$ ,  $SD = 1.41$ ), and highest for "knowledge of my child's disability and how to help my child" (S2), ( $M = 3.83$ ,  $SD = 0.75$ ).

Participants' responses related to factors they perceived as enhancing their access and utilization of information were lowest for "knowledge of services available for my child" (S3), ( $M = 4.67, SD = 0.52$ ). Two factors received the highest (and same) group means rating for helpfulness "knowledge of the proper lingo needed to get services for my child" (S1), and "knowledge of my child's disability and how to help my child" (S2), ( $M = 4.83, SD = 0.41$ , respectively).

While factors S1 and S3 received the highest group means ratings for variability for appraisals of control ( $SD = 1.22, SD = 1.41$ , respectively), factors S2 and S1 had the lowest (and same) degree of variability for perception of value as enhancing access and use of information ( $SD = 0.41$  for both S2 and S1).

#### *Social Support Strengths*

The three Strengths factors and group mean ratings related to social support were:

S4. Connect with other parents who share my experience ( $M = 4.50, SD = 0.84$  for internal control and  $M = 4.17, SD = 1.17$  for helpfulness).

S5. Maintain friendships outside of the special needs community ( $M = 4.67, SD = 0.52$  for internal control and  $M = 4.67, SD = 0.52$  for helpfulness).

S6. Maintain good communication with my spouse and a supportive marital relationship ( $M = 4.50, SD = 0.84$  for internal control and  $M = 4.50, SD = 0.84$  for helpfulness).

Participants' appraisals of control for factors that help them obtain social support were lowest for "connecting with other parents who share my experience" (S4), ( $M = 4.50, SD = 0.84$ ), and highest for "maintaining friendships outside of the special needs community" (S5), ( $M = 4.67, SD = 0.52$ ).

Group mean ratings of participant's responses related to experiences they perceived as enhancing access and utilization of social support were lowest for "connecting with other parents who share my experience" (S4), ( $M = 4.17$ ,  $SD = 1.17$ ) and highest for "maintaining friendships outside of the special needs community" (S5), ( $M = 4.67$ ,  $SD = 0.52$ ).

The variability for both appraisals of internal control and perceptions of helpfulness for the three social support factors was relatively low, with the exception of factor S4 (opportunities to connect with other parents with a shared experience), which had a much higher degree of variability for helpfulness ( $M = 4.17$ ,  $SD = 1.17$ ).

#### *Resources Strengths*

The three Strengths factors and group mean ratings related to resources were:

S7. Build positive relationships with professionals ( $M = 4.17$ ,  $SD = 1.17$  for internal control and  $M = 4.33$ ,  $SD = 0.82$  for helpfulness).

S8. Advocate for services for my child ( $M = 4.17$ ,  $SD = 0.98$  for internal control and  $M = 4.67$ ,  $SD = 0.52$  for helpfulness).

S9. Be involved in getting services for my child ( $M = 4.33$ ,  $SD = 0.82$  for internal control and  $M = 4.67$ ,  $SD = 0.52$  for helpfulness).

Group means ratings for appraisals of control over factors that help parents access and use resources were lowest for "building positive relationships with professionals" (S7), ( $M = 4.17$ ,  $SD = 1.17$ ) and highest for "being involved in getting services for my child" (S9), ( $M = 4.33$ ,  $SD = 0.82$ ).

Participants group means ratings of factors they perceived as helping them obtain resources were lowest for "building positive relationships with professionals" (S7), ( $M =$



4.33,  $SD = 0.82$ ), and highest for “being involved in getting services for my child” (S9) ( $M = 4.67$ ,  $SD = 0.52$ ).

The factor with the lowest degree of variability for control and helpfulness was “being involved in getting services for my child” (S9), ( $SD = 0.82$  and  $SD = 0.52$ , respectively). The highest degree of variability for both control and helpfulness was “building positive relationships with professionals” (S7), ( $SD = 1.17$  and  $SD = 0.82$  respectively). Results for the Family Support Survey’s Strengths Factors are presented in Table 11. These are organized by the following categories: information, social support, and resources.

### *Summary of Strengths*

The three factors related to social supports (S4, S5, and S6) received the strongest appraisals of control out of all the Strengths factors, with “maintaining friendships outside of the special needs community” (S5), having the strongest degree of internal control as well as the lowest degree of variability. The three factors related to appraisals of control over accessing and using information received the lowest group means rating for internal control out of any of the strengths factors, with the lowest being “knowledge of my child’s disability (S3).

In contrast to participants’ high appraisals of control for two of the social support factors “connecting with others parents who share my experience (S4) and “maintaining good communication with my spouse and a supportive marital relationship” (S6), these factors received the lowest group means ratings for enhancing access and use of social support. However, it is important to note that strengths factors that enhance participants’

access and use of information, social support, and resources were relatively high and all received group means ratings ranging from  $M = 4.17$  to  $M = 4.84$ ).

Furthermore, whereas all information factors received low appraisals of control, two of the information factors “knowledge of the proper lingo” (S1), and “knowledge of my child’s disability and how to help my child” (S2) were perceived as being the most helpful and desired. Not only did these receive the highest group mean rating as enhancers, they also resulted in the lowest degree of variability, suggesting a strong degree of agreement among participants that knowing the right words to use to get services, as well as knowing how to help their child were perceived by parents as being as being helpful. It is noteworthy, that while knowing the proper lingo (S1) received the strongest degree of agreement that this factor enhanced parents’ capacity to access information ( $M = 4.83$ ,  $SD = 0.41$ ), their perception of control over this same item was relatively low and showed a high degree of variability ( $M = 3.50$ ,  $SD = 1.22$ ).

Participants’ group mean ratings for resources indicated a relatively high degree of agreement among parents that advocating for services for their child (S8), and being involved in getting services for their child (S9) were the most valuable enhancing resource factors and were appraised as being moderately to strongly under their control. Building positive relationships with professionals (S7) received the lowest rating for appraisal of control, as well as a having a high degree of variability among participant’s group means ratings.

Table 11

*Family Support Survey Results for SWOT Strengths Factors*

The factor listed below . . .	. . . is under my <u>control (+)</u>		. . . and is <u>helpful (+)</u>	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Information				
1 Knowledge of the proper “lingo needed to get services for my child.	3.50	1.22	4.83	0.41
2 Knowledge of my child’s disability and how to help my child.	3.83	0.75	4.83	0.41
3 Knowledge of services available for my child.	3.00	1.41	4.67	0.52
Social Support				
4 Connect with other parents who share my experience.	4.50	0.84	4.17	1.17
5 Maintain friendships outside of the special needs community.	4.67	0.52	4.67	0.52
6 Maintain good communication with my spouse and a supportive marital relationship.	4.50	0.84	4.50	0.84
Resources				
7 Build positive relationships with professionals.	4.17	1.17	4.33	0.82
8 Advocate for services for my child.	4.17	0.98	4.67	0.52
9 Be involved in getting services for my child.	4.33	0.82	4.67	0.52

*Weaknesses*

Responses obtained from participants from the Family Support Survey resulted in 10 items that participants perceived as being under their control and as inhibiting their capacity to access and utilize information, social support, and resources. For the purposes of this study, weaknesses are defined as a family challenge or deficit that impedes family access and utilization of supports. Three of the 10 Weakness factors related to

experiences with obtaining information, three to utilizing social support, and four to accessing resources and services.

Note that hindering factors are presented in the negative and as such, lower numbers are perceived as being less hindering, whereas higher numbers are perceived as being more hindering, with -5 being strongly inhibiting and 0 as having a neutral inhibiting effect.

### *Information Weaknesses*

The three Weakness factors and group mean ratings that related to information were as follows:

W1. Lack of time to read or keep up with research ( $M = 3.00$ ,  $SD = 0.89$  for internal control and  $M = -3.83$ ,  $SD = 0.75$  for perception of inhibiting effects).

W2. Not accessing or using research resources ( $M = 4.17$ ,  $SD = 0.75$  for internal control and  $M = -3.50$ ,  $SD = 0.84$  for perception of inhibiting effects).

W3. Not knowing how to help my child ( $M = 4.17$ ,  $SD = 0.75$  for internal control and  $M = -3.17$ ,  $SD = 0.75$ ) for perception of inhibiting effects).

Participants' group means ratings for appraisals of control over factors that influence their access and use of information were lowest for "lack of time to read or keep up with research" (W1), ( $M = 3.00$ ,  $SD = 0.89$ ), and highest for "not knowing how to help my child" (W3), ( $M = 4.17$ ,  $SD = 0.75$ ).

Participants' responses related to factors they perceived as being the least inhibiting to their access and use of information was factor W3 ( $M = -3.17$ ,  $SD = 0.75$ ), whereas the most inhibiting factor was W1 ( $M = -3.83$ ,  $SD = 0.75$ ).

All three Weakness factors related to accessing information had similar and moderately high variability ratings for both control ( $SD = 0.89$  for W1, and  $SD = 0.75$  for W2 and W3), and hindering effects ( $SD = 0.75$  for W1 and W3, and  $SD = 0.84$  for W2).

#### *Social Support Weaknesses*

The three Weakness factors and group mean ratings that related to social support were as follows:

W4. Isolated from other parents who have children with special needs ( $M = 4.33$ ,  $SD = 0.82$  for internal control and  $M = -2.60$ ,  $SD = 1.76$  for perception of inhibiting effects).

W5. Not reaching out to other parents who share my experience ( $M = 4.33$ ,  $SD = 0.82$  for internal control and  $M = -2.17$ ,  $SD = 1.17$  for perception of inhibiting effects).

W6. Not getting support from my spouse ( $M = 3.83$ ,  $SD = 0.75$  for internal control and  $M = -1.83$ ,  $SD = -1.33$  for perception of inhibiting effects).

Participants' appraisals of control pertaining to factors that inhibit access to social supports were strongest (and the same) for control over being "isolated from other parents who have children with special needs" (W4), and "not reaching out to other parents who share my experience" (W5), ( $M = 4.33$ ,  $SD = 0.82$ , respectively). The lowest group means rating for control for social supports was "not getting support from my spouse" (W6), ( $M = 3.83$ ,  $SD = 0.75$ ).

Group means ratings of parents responses pertaining to experiences they perceived as being the most inhibiting to accessing social support pertained to feelings of being "isolated from other parents who have children with special needs" (W4), ( $M = -$

2.60,  $SD = 1.76$ ) and the least inhibiting for “not getting support from my spouse” (W6), ( $M = -1.83$ ,  $SD = 1.33$ ).

While appraisals of control had a moderate degree of variability for social support weakness factors, the perceptions of factors that hinder social support had a high degree of variability (range from  $SD = 1.17$  for W5 to  $SD = 1.76$  for W4).

#### *Resources Weaknesses*

The four Weakness factors and group mean ratings that related to resources were:

W7. Not knowing what services and supports are available ( $M = 3.50$ ,  $SD = 1.76$  for internal control and  $M = -3.00$ ,  $SD = 2.00$  for perceptions of inhibiting effects).

W8. Not being involved in making sure that my child gets services he/she needs ( $M = 4.50$ ,  $SD = 0.84$  for internal control and  $M = -3.50$ ,  $SD = 1.38$  for perceptions of inhibiting effects).

W9. Not trusting that the system (e.g., school or regional center) has my child’s best interests in mind ( $M = 3.00$ ,  $SD = 0.89$  for internal control and  $M = -3.83$ ,  $SD = 0.98$  for perceptions of inhibiting effects).

W10. Letting other’s decide what services my child will receive ( $M = 4.00$ ,  $SD = 1.26$  for internal control and  $M = -3.83$ ,  $SD = 1.17$  for perceptions of inhibiting effects).

Participant’s appraisals of control over whether or not they are involved in making sure that their child gets needed services (W8) obtained the highest group means rating and a moderate degree of agreement ( $M = 4.50$ ,  $SD = 0.84$ ). Participant’s rating of

“not knowing what services and supports are available” (W7) received a relatively low group means rating of control ( $M = 3.50$ ,  $SD = 1.76$ ).

Participants’ group means ratings of factors that enhance or inhibit use of resources showed that “not knowing what services are available” (W7), ( $M = -3.00$ ,  $SD = 2.00$ ) had the lowest degree of effect on hindering access and utilization of resources, but also had the highest degree of variability. While “not trusting that the system, such as school or regional center, has my child’s best interests in mind” (W9) had the strongest effect, and a relatively low degree of variability ( $M = -3.83$ ,  $SD = 0.98$ ). Results of SWOT factors identified as weaknesses are presented in Table 12.

#### *Summary of Weaknesses*

Parent’s responses pertaining to factors perceived as being under their control ranged from a group means of  $M = 3.00$  ( $SD = 0.89$ ) for “lack of time to read or keep up with research” (W1), to a high of  $M = 4.50$  ( $SD = 0.84$ ) for parental involvement in getting services for their child (W8). The group means ratings on the 10 items related to factors perceived as inhibiting their experiences resulted in a wide range of scores, from a low of  $M = -1.83$  ( $SD = 1.33$ ) for “not getting support from my spouse” (W6), to a high of  $M = -3.83$  ( $SD = 0.75$ ) for “lack of time to keep up with research” (W1).

Ratings of two factors related to information, “not accessing or using research resources,” and “not knowing how to help my child,” indicated that participants perceived a relatively high level of control and degree of agreement over these factors ( $M = 4.17$ ,  $SD = 0.75$  for W2 and W3, respectively). In contrast, group mean ratings of control over “lack of time to read or keep up with research” (W1), was moderately low

( $M = 3.00$ ,  $SD = 0.89$ ) and received the highest group means ratings for inhibiting access to information and the lowest degree of variability ( $M = -3.83$ ,  $SD = 0.75$ ).

Table 12

*Family Support Survey Results for SWOT Weakness Factors*

The factor listed below . . .		. . . is under my control (+)		. . . and is a hindrance (-)	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Information					
1	Lack of time to read or keep up with research.	3.00	0.89	-3.83	0.75
2	Not accessing or using research resources.	4.17	0.75	-3.50	0.84
3	Not knowing how to help my child.	4.17	0.75	-3.17	0.75
Social Support					
4	Isolated from other parents who have children with special needs.	4.33	0.82	-2.60	1.76
5	Not reaching out to other parents who share my experience.	4.33	0.82	-2.17	1.17
6	Not getting support from my spouse.	3.83	0.75	-1.83	1.33
Resources					
7	Not knowing what services and supports are available.	3.50	1.76	-3.00	2.00
8	Not being involved in making sure that my child gets services he/she needs.	4.50	0.84	-3.50	1.38
9	Not trusting that the system ( school or regional center) has my child's best interests in mind.	3.00	0.89	-3.83	0.98
10	Letting other's decide what services my child will receive.	4.00	1.26	-3.83	1.17

Weakness factors related to accessing and utilizing social supports had a wide range of variability for appraisals of control. Participants perceived a relatively high degree of agreement on the extent to which they had control over accessing and using social support, with scores ranging from  $M = 3.83$ ,  $SD = 0.75$  to  $M = 4.33$ ,  $SD = 0.82$ .

However, group means ratings of the extent to which these factors inhibited access and



use of social support was the lowest among all 10 weakness items, as well as the highest degree of variability ( $M = -1.83, SD = 1.33$  to  $M = -2.50, SD = 1.76$ ). Each of the social support survey questions received at least one participant rating of 0; for example, the ratings for “isolation from other parents” (W4) ranged from 0 to -5; “not reaching out to other parents” (W5) ranged from 0 to -3; and “not getting support from my spouse” (W6) ranged from 0 to -3.

Participant’s perceptions of control over resources and whether or not they are involved in making sure that their child gets needed services (W8) obtained the highest average group mean rating and a moderate degree of agreement ( $M = 4.50, SD = 0.84$ ). Parent’s perceptions of their lack of “trusting that the system has my child’s best interests in mind” (W9) received the lowest group mean rating for control ( $M = 3.00, SD = 0.89$ ).

Factors that parent’s perceived as inhibiting their access and use of resources were in the moderate range with “letting others decide what services my child will receive” (W10) receiving the highest group mean rating ( $M = -3.83, SD = 1.17$ ). Responses related to “not knowing what services and supports are available” (W7) indicated that parent’s perceived this as having the lowest degree of effect on hindering their ability to access and use resources ( $M = -3.00$ ). An outlier rating of 0 by one participant resulted in a wide dispersion of ratings (0, 5, 4, 4, 4, 4), resulting in the lowest level of agreement of any of the ten items ( $SD = 2.00$ ).

Two factors, “lack of time to read or keep up with research” (W1), and “not trusting that the system (e.g., school or regional center) has my child’s best interests in mind” (W9), received the same and lowest group means ratings for appraisals of control ( $M = 3.00, SD = 0.89$ ). Furthermore, these two factors had the same and highest group

means ratings for perceptions of hindering access to social supports ( $M = -3.83$ ,  $SD = 0.75$ ).

### *Opportunities*

Participant responses from the Family Support Survey resulted in 17 items they perceived as being outside of their control and as enhancing their access and utilization of information, social support, and resources. Opportunities are defined as external enhancers that families perceive as being outside of their control and that support their access and utilization of supports. There are six opportunities factors related to access and use of information, five factors related to social supports, and six factors related to obtaining resources.

#### *Information Opportunities*

The six opportunities factors and group mean ratings related to information were:

- O1. Quality of information (e.g., easy to read, understandable, abbreviated, filtered, non-biased;  $M = -3.33$ ,  $SD = 1.86$  for external control and  $M = 4.50$ ,  $SD = 0.84$  for helpfulness).
- O2. Resource guide with information about books, websites, and phone numbers of resources available ( $M = -2.83$ ,  $SD = 1.17$  for external control and  $M = 4.50$ ,  $SD = 0.84$  for helpfulness).
- O3. Conferences for parents of special needs children ( $M = -2.50$ ,  $SD = 1.64$  for external control and  $M = 4.33$ ,  $SD = 0.52$  for helpfulness).
- O4. Experts, advocates, others who share information about laws, rights, and services ( $M = -3.17$ ,  $SD = 2.48$  for external control and  $M = 3.83$ ,  $SD = 0.75$  for helpfulness).

O5. Internet ( $M = -2.83$ ,  $SD = 1.17$  for external control and  $M = 4.17$ ,  $SD = 0.75$  for helpfulness).

O6. Other parents of children with special needs ( $M = -2.00$ ,  $SD = 0.89$  for external control and  $M = 4.00$ ,  $SD = 0.89$  for helpfulness).

Participants group means ratings for appraisals of external control (in the hands of others) related to information were strongest for “quality of information (e.g., easy to read, understandable, abbreviated, filtered, and non-biased” (O1), ( $M = -3.33$ ,  $SD = 1.86$ ). Getting information from “other parents of children with special needs” (O6) received the lowest rating of control as being in the hands of others ( $M = -2.00$ ,  $SD = 0.89$ ).

Group means responses related to perceptions of experiences that enhance parents’ access to information was highest for “quality of information” (O1), ( $M = 4.50$ ,  $SD = 0.84$ ). Parents’ perceived experiences related to getting information from “experts, advocates, and others” (O4) was perceived as being the least enhancing ( $M = 3.83$ ,  $SD = 0.75$ ).

Participants’ rating of appraisal of control over obtaining information from other parents of children with special needs ( $M = -2.00$ ) indicated they perceived this as being more within their control than under the control of others. Furthermore, group means ratings for this factor reflected the highest average degree of agreement for appraisals of control among participants ( $SD = 0.89$ ) out of all 17 items within the opportunities section of the Family Support Survey (FSS).

Participant’s mean ratings indicated that the quality of information available (e.g., easy to read, understandable, filtered, non-biased; O1), and access to resource guides that

helped them identify books, websites (O2) were perceived as having a high enhancing value ( $M = 4.50$ ,  $SD = 0.84$  for both items O1 and O2).

### *Social Support Opportunities*

The five opportunities factors and group mean ratings related to social support were:

O7. Formal support groups (e.g., emotional/logistical support from program or parent organizations, or therapy from a licensed therapist;  $M = -2.33$ ,  $SD = 1.75$  for external control and  $M = 4.67$ ,  $SD = 0.52$  for helpfulness).

O8. Parent-to-parent support (e.g., Mom's Club or Parent Advisory Boards;  $M = -1.83$ ,  $SD = 1.83$  for external control and  $M = 3.83$ ,  $SD = 0.75$  for helpfulness).

O9. Close friends with others who do not have children with special needs ( $M = -3.50$ ,  $SD = 1.52$  for external control and  $M = 4.33$ ,  $SD = 0.82$  for helpfulness).

O10. Understanding and support from others (e.g., spouse, family, friends, and neighbors;  $M = -2.33$ ,  $SD = 2.25$  for external control and  $M = 4.17$ ,  $SD = 0.98$  for helpfulness).

O11. Other parents of children with special needs ( $M = -2.67$ ,  $SD = 1.75$  for external control and  $M = 4.33$ ,  $SD = 0.82$  for helpfulness).

Responses related to factors that enhance or help parents access and use social support (O8) ranged from a low of  $M = 3.83$  ( $SD = 0.75$ ) to a high of  $M = 4.67$  ( $SD = 0.52$ ) for item (O7). Participants rated access and utilization of formal support groups, such as that provided by a licensed therapist or a formal disability related organization

(O7), as being a highly valuable enhancer ( $M = 4.67$ ). Furthermore, participants mean group ratings for this factor indicated a low degree of variability ( $SD = 0.52$ ).

Experiences related to perceptions of receiving understanding and support from others (e.g., spouse, family, friends, and neighbors) was seen as being highly enhancing (O10), ( $M = 4.17, SD = 0.98$ ).

### *Resources Opportunities*

The six opportunity factors and group mean ratings related to resources were:

- O12. Places to meet other parents and share experiences (e.g., program lobby/waiting area;  $M = -2.17, SD = 1.94$  for external control and  $M = 4.50, SD = 0.55$  for helpfulness).
- O13. Parent support organizations (e.g., TACA, KEN Project, Autism Speaks;  $M = -2.17, SD = 1.47$  for external control and  $M = 3.83, SD = 1.17$  for helpfulness).
- O14. Good schools, supportive teachers and vice-principals ( $M = -3.17, SD = 1.47$  for external control and  $M = 4.67, SD = 0.52$  for helpfulness).
- O15. Professionals who know what services are available and how to get them ( $M = -3.33, SD = 1.51$  for external control and  $M = 4.50, SD = 0.52$  for helpfulness).
- O16. Parent Resource Room ( $M = -2.83, SD = 1.94$  for external control and  $M = 4.17, SD = 0.98$  for helpfulness).
- O17. Good Luck ( $M = -4.17, SD = 0.98$  for external control and  $M = 4.17, SD = 0.98$  for helpfulness).

Group mean ratings related to participants appraisals of control over experiences with accessing resources and services ranged from a low of  $M = -2.17$  ( $SD = 1.94$ ) to  $M = -4.17$  ( $SD = 0.98$ ). Participants perception of “good luck” (O17) received the highest rating of out of all opportunity factors of being almost completely outside of their control ( $M = -4.17$ ). Additionally, this item showed the least amount of variability ( $SD = 0.98$ ), indicating a high degree of agreement among participants with this rating.

Participant’s mean group ratings of factors that enhance their access and utilization of resources ranged from a low of  $M = 3.83$  ( $SD = 1.17$ ) to high of  $M = 4.67$  ( $SD = 0.52$ ). Access to good schools, supportive teachers and vice-principals (O14); professionals who know what services are available and how to get them (O 15); as well as places to meet other parents and share experiences (O12) received the highest ratings of all opportunity factors that enhanced participants’ experiences ( $M = 4.67$ ,  $SD = 0.52$ ,  $4.50$ ,  $SD = 0.55$ ,  $4.50$ ,  $SD = 0.55$ , respectively). The summary of participant’s group mean ratings of opportunities factors is presented in Table 13.

### *Summary of Opportunities*

Group mean ratings of participants’ responses were in the low to moderate range for perceptions of control as being in the hands of others. The lowest group means ratings of  $M = -1.83$  ( $SD = 1.83$ ) was for control over access and use of parent-to-parent support (O8). The highest group means rating of  $M = -4.17$  ( $SD = 0.98$ ) pertained to perceptions that “good luck” in getting services is sometimes almost entirely in the control of others (O17). The majority of response items ( $n = 11$ ) clustered around relatively low scores that ranged from  $M = -1.83$  to  $M = -2.83$ , indicating a perception of control as being neither completely outside (external) or within (internal) participants’ control.

Table 13

*Family Support Survey Results for SWOT Opportunities Factors*

The factor listed below . . .		. . . is outside of		. . . and is	
		<u>my control (-)</u>		<u>helpful (+)</u>	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Information					
1	Quality of information	-3.33	1.86	4.50	0.84
2	Resource guide with information about books, websites, phone numbers of resources available.	-2.83	1.17	4.50	0.84
3	Conferences for parents of special needs children.	-2.50	1.64	4.33	0.52
4	Experts, advocates, others who share information about laws, rights, services.	-3.17	2.48	3.83	0.75
5	Internet	-2.83	1.17	4.17	0.75
6	Other parents of children with special needs.	-2.00	0.89	4.00	0.89
Social Support					
7	Formal support groups	-2.33	1.75	4.67	0.52
8	Parent-to-parent support	-1.83	1.83	3.83	0.75
9	Close friends with others who do not have children with special needs.	-3.50	1.52	4.33	0.82
10	Understanding and support from spouse, family, friends, neighbors	-2.33	2.25	4.17	0.98
11	Other parents of children with special needs.	-2.67	1.75	4.33	0.82
Resources					
12	Places to meet other parents and share experiences	-2.17	1.94	4.50	0.55
13	Parent support organizations	-2.17	1.47	3.83	1.17
14	Good schools, supportive teachers and vice-principals.	-3.17	1.47	4.67	0.52
15	Professionals who know what services are available and how to get them.	-3.33	1.51	4.50	0.55
16	Parent Resource Room	-2.83	1.94	4.00	0.89
17	Good Luck	-4.17	0.98	4.17	0.98

It is noteworthy that responses related to appraisals of control over factors that are perceived as enhancing their experiences, resulted in ratings with the highest degree of variability (range = 0.89 to 2.48) as well as the highest number of items that received at least one rating of “0” (items O1, O3, O4, O7, O8, O10, O11).

Getting information from “experts, advocates, and others who share information about laws, rights and services” (O4) showed moderate strength as a factor perceived as being within participants’ control ( $M = -3.17$ ); however, variability of ratings for this factor was the highest out of all opportunity factors ( $SD = 2.48$ ), indicating a low average degree of agreement. For example, four of the six respondents rated this factor as being completely outside of their control (-4, -5, -5, -5), while two responses were rated as being completely within control of the parent (0, 0).

Participants’ rating of appraisal of control over “obtaining information from other parents of children with special needs” (O6) indicated they perceived this as being more within their control than under control of others ( $M = -2.00$ ). Furthermore this factor showed the highest average degree of agreement among participants ( $SD = 0.89$ ) out of all survey items within the opportunities section of the Family Support Survey (FSS).

Going to “conferences for parents of children of special needs” (O3) was also viewed as enhancing their access to information, and obtained the highest average degree of agreement among participants’ ratings of opportunity factors they perceived as being enhancers ( $M = 4.33$ ,  $SD = 0.52$ ).

Group mean ratings for appraisal of control related to social support factors were overall low, indicating a perception that control was not completely outside of parent’s control. The factor that received the highest rating of being outside of parent’s control



related to “having close friends with others with children who do not have special needs” (O9), ( $M = -3.50$ ,  $SD = 1.52$ ). Although there is a wide range of variability between responses, this factor had the lowest standard deviation among all of the social support factors related to perceptions of control.

Accessing resources, such as informal supports, having places to meet other parents (O12), and availability of more formal parent supports (O13), were perceived by participants as being more within their control than in the control of others ( $M = -2.17$ ,  $SD = 1.94$ ,  $M = -2.17$ ,  $SD = 1.47$  respectively). However, group mean ratings of appraisals of control over resources, such as “good schools and supportive teachers” (O14), and “professionals who know what services are available and how to get them” (O15), indicated that parents perceived a low to moderate degree of agreement that control is in the hands of others ( $M = -3.17$ ,  $SD = 1.47$ ;  $M = -3.33$ ,  $SD = 1.51$  for O14 and O15, respectively).

In contrast, to a high degree of variability among participants’ perceptions of the degree to which their experiences were perceived as being under the control of others ( $SD = 0.89$  to  $SD = 2.48$ ), the group mean ratings of the extent to which these factors enhanced their experiences resulted in a relatively high degree of agreement among participants ( $SD = 0.52$  to  $SD = 1.17$ ).

### *Threats*

Participant responses from the Family Support Survey resulted in 14 items participants’ perceived as being outside of their control and as inhibiting their access and utilization of information, social support, and resources. Threats are defined as external

inhibitors that families perceive as being outside of their control and that impede their access and utilization of supports.

Four items related to perceptions of experiences with accessing and using information, five factors pertained to social support, and five items related to factors that participants' perceived as inhibiting access to resources.

### *Information Threats*

The four Threats factors and group mean ratings related to information were:

T1. Inadequate information (e.g., biased, not usable, too much, clinical, dry, depressing, negative, not about my child's unique needs;  $M = -4.83$ ,  $SD = 0.41$  for external control and  $M = -3.83$ ,  $SD = 0.75$  for perception as being an inhibitor).

T2. Misinformation and misconceptions about disabilities ( $M = -4.17$ ,  $SD = 1.17$  for external control and  $M = -3.67$ ,  $SD = 1.51$  for perception as being an inhibitor).

T3. Emphasis on cure and recovery in media ( $M = -4.00$ ,  $SD = 1.10$  for external control and  $M = -3.50$ ,  $SD = 1.64$  for perception as being an inhibitor).

T4. Program does not keep families up to date about new services available ( $M = -3.00$ ,  $SD = 1.41$  for external control and  $M = -4.00$ ,  $SD = 0.63$ ).

Participants' experiences appraisals of external control with accessing and utilizing information was lowest for "programs that do not keep families up to date about new services" (T4), ( $M = -3.00$ ,  $SD = 1.41$ ). The highest degree of control as being in the hands of others related to a "lack of adequate information (e.g., biased, too much, not related to child's needs, etc." (T1), ( $M = -4.83$ ,  $SD = 0.41$ ).

### *Social Support Threats*

The five Threats items and group mean ratings related to social supports were:

T5. Reactions from others (e.g., lack of tolerance, being judgmental;  $M = -4.50$ ,  $SD = 0.55$  for external control and  $M = -3.50$ ,  $SD = 0.84$  for perception as being an inhibitor).

T6. Lack of awareness or understanding from family and friends of what it is like to parent a child with special needs (e.g., “sit in my shoes”;  $M = -3.50$ ,  $SD = 0.84$  for external control and  $M = -2.50$ ,  $SD = 1.38$  for perception as being an inhibitor).

T7. Unsolicited advice about how to raise my child ( $M = -4.67$ ,  $SD = 0.52$  for external control and  $M = -3.50$ ,  $SD = 1.52$  for perception as being an inhibitor).

T8. Lack of opportunities to meet and connect with other parents who share my experience ( $M = -1.33$ ,  $SD = 1.51$  for external control and  $M = -1.83$ ,  $SD = 1.72$  for perception as being an inhibitor).

T9. Responsibilities other than my child who has special needs, such as work and family ( $M = -2.83$ ,  $SD = 1.60$  for external control and  $M = -1.83$ ,  $SD = 1.72$  for perception as being an inhibitor).

Factors participants’ perceived as being Threats ranged from a low group means rating of  $M = -1.33$ ,  $SD = 1.51$  to a high of  $M = -4.67$ ,  $SD = 0.52$  for appraisal of control over being able to obtain social support. Factors perceived as inhibiting their experiences ranged from  $M = -1.83$ ,  $SD = 1.72$  to  $M = -3.50$ ,  $SD = 1.52$ ). Participants’ group mean ratings for “not having opportunities to meet and connect with other parents who share

my experience” (T8), was the factor that parents’ perceived as being the least controlled by others ( $M = -1.33, SD = 1.51$ ); and was also rated as having the lowest effect on inhibiting their ability to get support from other parents ( $M = -1.83, SD = 1.72$ ).

#### *Resources Threats*

The five Threats factors and group mean ratings related to resources were:

- T10. Case Managers/Service Coordinators: do not provide information about services and how to get them ( $M = -3.33, SD = 1.86$  for external control and  $M = -4.33, SD = 0.82$  for perception as being an inhibitor).
- T11. Services Offered by the System: time limited, not sensitive to my child’s individual needs or preferences (e.g., diapers or a “one-size-fits-all” approach to providing services;  $M = -4.17, SD = 0.75$  for external control and  $M = -4.17, SD = 0.98$  for perception as being an inhibitor).
- T12. System Policies/Procedures: inflexible, changing rules and terms about who gets what, services are allocated on policy rather than need ( $M = -3.83, SD = 0.98$  for external control and  $M = -4.67, SD = 0.52$  for perception as being an inhibitor).
- T13. Program Facilities: not comfortable, too small, not appropriate for my child’s age ( $M = -2.50, SD = 1.38$  for external control and  $M = -2.50, SD = 1.38$  for perception as being an inhibitor).
- T14. Legislative Factors: that influence funding or cuts in services for my child ( $M = -3.83, SD = 1.60$  for external control and  $M = -4.17, SD = 1.60$  for perception as being an inhibitor).

The threat factor related to parents' perceptions of "inadequate information that is biased and not usable" (T1) received the highest mean rating and average degree of agreement that control is in the hands of others ( $M = -4.83, SD = 0.41$ ) and a moderate mean rating and degree of agreement that this factor hinders their access to information ( $M = -3.83, SD = 0.75$ ). The factor parents perceived as inhibiting their access to services and supports the most was related to "system policies and procedures that are inflexible and allocated on policy rather than the needs of the child" (T12), ( $M = -4.67, SD = 0.52$ ). The summary of items identified as being threats are presented in Table 14.

Table 14

*Family Survey Results for SWOT Threats*

	The factor listed below . . .	. . . is outside of <u>my control (-)</u>		. . . and is a <u>hindrance (-)</u>	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Information					
1	Inadequate information, biased, not usable, too much	-4.83	0.41	-3.83	0.75
2	Misinformation and misconceptions about disabilities.	-4.17	1.17	-3.67	1.51
3	Emphasis on cure and recovery in media.	-4.00	1.10	-3.50	1.64
4	Program doesn't keep families up to date about new services available.	-3.00	1.41	-4.00	0.63
Social Support					
5	Reactions from others, lack of tolerance, judgmental	-4.50	0.55	-3.50	0.84
6	Lack of awareness or understanding from family and friends of what it is like to parent a child with special needs	-3.50	0.84	-2.50	1.38
7	Unsolicited advice about how to raise my child.	-4.67	0.52	-3.50	1.52
8	Lack of opportunities to meet and connect with other parents who share my experience.	-1.33	1.51	-1.83	1.72
9	Responsibilities other than my child who as special needs	-2.83	1.60	-1.83	1.72

*(table continues)*

	The factor listed below . . .	. . . is outside of		. . . and is a	
		<u>my control (-)</u>		<u>hindrance (-)</u>	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
10	<i>Case Managers/Service Coordinators:</i> do not provide information about services available and how to get them.	-3.33	1.86	-4.33	0.82
11	<i>Services Offered by System:</i> time limited, not sensitive to my child's individual needs or preferences, "one-size-fits-all" approach	-4.17	0.75	-4.17	0.98
12	<i>System Policies/Procedures:</i> inflexible, changing rules and terms, services allocated on policy rather than need.	-3.83	0.98	-4.67	0.52
13	<i>Program Facilities:</i> not comfortable, too small, not appropriate for my child's age.	-2.50	1.38	-2.50	1.38
14	Legislative factors that influence funding or cuts in services for my child.	-3.83	1.60	-4.17	1.60

### *Summary of Threats*

In comparison to opportunity factors in which participants perceived the majority of responses as being neither outside (external) nor within (internal) participants' control, the majority of threat factors (n = 9) were perceived as being more under the control of others (external) than within their control (internal).

Parents' ratings related to information indicated a strong degree of agreement that control over the quality of information, such as being usable or related to their child's special needs, was perceived as being almost entirely in the hands of others. Furthermore, participants' perceived this same factor as having a moderate effect as a factor that inhibited their ability to obtain information.

Participants' group mean ratings of social support, relating to reactions of others such as lack of tolerance or being judgmental (T5), indicated a strong agreement among parents, that this factor was perceived as being more in the hands of others. However,

perceptions of the extent to which this inhibited their experiences with obtaining social support were moderate.

Participants' group mean ratings of factors related to resources, revealed a strong degree of agreement that, service system policies such as, inflexibility, changing rules about who gets services, and how services are allocated (T12) are factors that strongly inhibit parents' access to resources. Appraisals of control revealed a perception that this factor was moderately outside of parent's control ( $M = -3.83$ ,  $SD = 0.98$ ).

Responses related to services as being "time limited, not sensitive to my child's individual needs or preferences or a one-size-fits-all approach to providing services," was perceived as being almost completely in the hands of others, such as the service system ( $M = -4.17$ ,  $SD = 0.75$ ), as well as inhibiting parents' access to resources for their child ( $M = -4.17$ ,  $SD = 0.98$ ).

#### *Summary for Research Question 3 and 4*

Results from the Family Support Survey revealed both strong agreement and wide variability among participants' group means ratings concerning the relative effect of various factors on their ability to access and utilize information, social support, and resources. Results from group means ratings, showed that parents viewed access and use of information as being highly valued; however their ratings also indicated that information was not always strongly within their control. Additionally, although information is readily available, the parents expressed that it is not always accessible (e.g., overwhelming, biased, misinformation, etc.).

Social support from family, friends, and other parents of children with special needs was important to participants and perceived as being strongly within their control.

The area that emerged as having the strongest inhibiting effect was lack of information about services and supports and difficulties in getting this information from individuals who provide or fund services.

In order to understand more fully the group means rating of the degree of agreement for appraisals of control over these factors and the group means rating of the value or impact these factors have over their experiences, the researcher conducted a cluster analysis to explore similarities and differences among group means ratings.

#### *Research Question 5*

Research question 5 asked the question to what degree, if at all, is there agreement among families' ratings of the value of enhancing or inhibiting experiences, and their appraisals of control over these experiences. In order to identify similarity or distance within and among participant's group means ratings related to their perceptions of control (internal or external) and helpfulness (enhance or inhibit) obtained during the IE<sup>2</sup> SWOT Matrix Analysis phase of the focus group interview, the researcher conducted a cluster analysis using a hierarchical cluster analysis (Ward's method) using SPSS software.

#### *Hierarchical Cluster Analysis Results*

A cluster analysis method was selected because of its utility as an exploratory statistical tool that reduces data and forms groups or clusters from individual cases that can be analyzed to identify those factors that are most similar and those that are less alike. The first step in conducting the cluster analysis involved making a determination as to the number of clusters that best represented the data for each of the four SWOT quadrants. The number of clusters that can be selected is largely subjective; however, because the nature of this study was to explore the meaning of families' experiences and



to identify homogeneity among responses, it was desirable to allow the number of clusters derived from the data to emerge naturally, rather than specifying a predetermined number prior to data collection and analysis (Burns & Burns, 2008). Therefore, a hierarchical cluster analysis approach using the Ward's method available within the SPSS software program was selected because of its ANOVA-type approach that minimizes *within-group* distances and maximizes *between* groups differences (Burns & Burns, 2008). The results of the cluster analysis as generated by SPSS are presented using three different output formats, as follows:

1. Discussion of cluster membership for each SWOT factor, illustrated by the respective cluster membership table.
2. Discussion of similarities and distances for clusters derived from the hierarchical cluster analysis illustrated by the agglomeration schedule for each SWOT factor.
3. Discussion of a visual interpretation of the data using a dendrogram, a hierarchical tree diagram, for each SWOT factor.

The results from the hierarchical cluster analysis for the IE<sup>2</sup> SWOT data are presented in the following sections, in the order of strengths, weaknesses, opportunities and threats. Within each SWOT is a discussion of the three outputs described above, cluster membership, agglomeration schedule, and dendrogram.

#### *Cluster Analysis Results: Strengths*

A cluster analysis was conducted of the participant's ratings of appraisals of internal control over the nine Strengths factors from the Family Support Survey, and the

degree to which they perceived these factors as either enhancing or helping their experiences related to accessing and utilizing information, social support, and resources.

*Cluster membership.* The hierarchical cluster analysis using the Ward's method (SPSS software) identified four clusters for the SWOTs Strengths factors:

1. Cluster 1: S1 and S3
2. Cluster 2: S2, S8, S9
3. Cluster 3: S4, S5, S6
4. Cluster 4: S7

*Cluster 1.* The first cluster consisted of two survey factors: (a) knowledge of the proper “lingo” needed to get services for my child (S1), and (b) “knowledge of services available for my child” (S3).

*Cluster 2.* Cluster 2 consisted of three factors: (a) “knowledge of my child’s disability and how to help my child” (S2), (b) “advocate for services for my child” (S8), and “be involved in getting services for my child” (S9).

*Cluster 3.* Cluster 3 consisted of the three items related to participants’ experiences with accessing and using social supports: (a) “connect with other parents who share my experience” (S4), (b) “maintain friendships outside of the special needs community” (S5), and (c) “maintain good communication with my spouse” (S6).

*Cluster 4.* The final resource factor, “build positive relationships with professionals” (S7) is a single outlier.

*Agglomeration schedule.* The agglomeration schedule table shows the degree of similarity and distance in terms of a coefficient calculation performed by the SPSS hierarchical cluster analysis program. Each “case” (strengths factor) begins as its own

cluster, which are ordered into clusters starting with individual clusters that are most similar. The linking of factors continues by either creating new clusters or adding single clusters or cluster groups to existing clusters, and so on until all factors form one final cluster (Garson, 2010).

The agglomeration schedule table (Table 15) shows the sequence or stages within which Strengths factors were clustered. Strengths factors S8 and S9 joined first, with factor S2 linking at a slightly farther distance, indicating that they were the most familiar of all nine factors. Factors S5 and S6 formed next, followed by S1 and S3. The remaining cluster linkages joined in order of their similarity or distance to a member of one of the existing cluster groupings until all clusters come together as one final cluster, in this case factors S1 and S4. Strengths factor, “building positive relationships with professionals” (S7), was the most dissimilar from the other eight items and was the last single factor to link to the cluster formed by factors S4, S5, S6. Note that the first cluster formed (S8 and S9) and the final cluster (S1 and S4) come together at a considerable distance, illustrating dissimilarity between the four clusters for strengths factors. The cluster membership and agglomeration schedule is located in Table 15.

*Dendrogram results.* In order to visually illustrate how each of the clusters “hang” together, the SPSS hierarchical cluster analysis plots clusters according to their relative similarity and distance using the coefficient scores depicted in the agglomeration schedule table (Burns & Burns, 2008).

The point at which the proximity coefficients were combined is displayed on the dendrogram (Figure 4). The markers that are closer together, located on the far left column, indicate a lower distance and higher similarity or likeness. Conversely, items

that are farther apart (gradually moving along towards the right of the graph) indicate a greater distance and increasing levels of dissimilarity.

Table 15

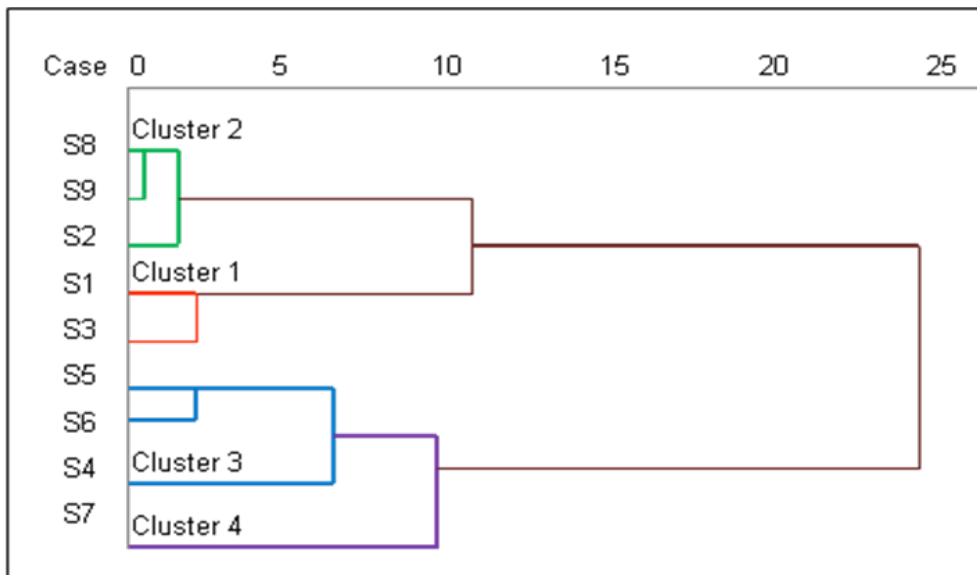
*Cluster Membership and Agglomeration Schedule for SWOT Strengths*

Cluster Membership		Agglomeration Schedule SWOT Strengths Factors						
Case	4 Clusters	Stage	Cluster Combined		Coefficients	Stage Cluster First Appears		Next Stage
			Cluster 1	Cluster 2		Cluster 1	Cluster 2	
S1	1	1	8	9	2.500	0	0	2
S2	2	2	2	8	6.000	0	1	7
S3	1	3	5	6	10.000	0	0	5
S4	3	4	1	3	14.000	0	0	7
S5	3	5	4	5	22.000	0	3	6
S6	3	6	4	7	32.750	5	0	8
S7	4	7	1	2	44.350	4	2	8
S8	2	8	1	4	69.333	7	6	0
S9	2							

Reading from the top down and from left to right, the dendrogram visually illustrates the formation of clusters. Mirroring the agglomeration schedule, factors S8 and S9 form the first cluster with S2 joining next. Factors S5 and S6 are the two factors that form the next cluster before adding S4 at a much farther distance. The remaining clusters form at increasingly greater distances as illustrated by the dendrogram. The final single factor to join a cluster is S7, which indicates a higher degree of dissimilarity and is a “runt” (outlier). The final linkage occurs when factors S1 and S4 come together, as shown on the far right of the dendrogram. The cluster analysis dendrogram for SWOT Strengths is presented in Figure 4.

*Cluster Analysis Results: Weaknesses*

A cluster analysis of the ten Weakness factors from the Family Support Survey was conducted on group means ratings of participants' perceptions of experiences related to accessing and using information, social support, and resources. The analysis examined the extent to which families perceive that they have complete internal control over factors that influence their experiences, as well as the extent to which these factors hinder or inhibit their ability to access and use information, social support, and resources related to their child with special needs. See also the additional dendrograms in Appendix N.



*Figure 4.* Cluster analysis dendrogram: Strengths.

*Cluster membership.* The hierarchical cluster analysis using the Ward's method (SPSS software) identified four clusters for the SWOTs Weaknesses factors:

1. Cluster 1: W1 and W9
2. Cluster 2: W2, W3, W8, W10

3. Cluster 3: W4, W5, W6

4. Cluster 4: W7

*Cluster 1.* The first cluster consisted of two survey factors: (a) “lack of time to read or keep up with research” (W1), and (b) “not trusting that the system (e.g., school or regional center) has my child’s best interests in mind” (W9).

*Cluster 2.* Cluster 2 consists of four weakness factors (W2, W3, W8, and W10), of which two relate to families experiences with accessing information, (a) “not accessing or using research sources” (W2), “and not knowing how to help my child” (W3). Two factors are from the category of resources: (a) “not being involved in making sure that my child gets services he/she needs” (W8), and (c) “letting others decide what services my child will receive” (W10).

*Cluster 3.* The third cluster consisted of three items related solely to the category of social supports: (a) being “isolated from other parents of children who do not have special needs” (W4), (b) “not reaching out to other parents who share my experience” (W5), and (c) “not getting support from my spouse” (W6).

*Cluster 4.* The fourth cluster consisted of a single factor that is a “runt” (outlier), “not knowing what services and supports are available” (W7).

*Agglomeration schedule.* The agglomeration schedule Table shows the degree of similarity and distance reported as a coefficient calculation (determined by SPSS hierarchical cluster analysis). Each “case” (i.e., weakness factor) begins as its own cluster, which is ordered into clusters starting with individual clusters that are most similar. The linking of factors continues by either creating new clusters or adding single

clusters or cluster groups to existing clusters, and so on until all factors form one final cluster.

The agglomeration schedule table shows that weakness factors W8 and W10 were the most similar form the first clustering. Factors W2 and W3 link together next, followed by the grouping of W4 and W5. Weakness factor W9 does not join with factor W1 until a greater distance (W1 and W9), indicating that these two factors are more dissimilar. The remaining cluster groups form at increasingly greater distances when W8 joins cluster W2 and W6 joins cluster W4. The weakness factor (W7) is the last and final factor, and joins cluster W1 at the farthest point of any of the weakness factors. The cluster membership table and agglomeration schedule are located in Table 16.

Table 16

*Cluster Membership and Agglomeration Schedule for SWOT Weaknesses*

Cluster Membership			Agglomeration Schedule for SWOT Weakness Factors					
Case	4 Clusters	Stage	Cluster Combined			Stage Cluster First Appears		Next Stage
			Cluster 1	Cluster 2	Coefficients	Cluster 1	Cluster 2	
W1	1	1	8	10	3.500	0	0	5
W2	2	2	2	3	7.500	0	0	5
W3	2	3	4	5	12.500	0	0	6
W4	3	4	1	9	20.500	0	0	7
W5	3	5	2	8	33.250	2	1	8
W6	3	6	4	6	50.917	3	0	8
W7	4	7	1	7	72.917	4	0	9
W8	2	8	2	4	102.000	5	6	9
W9	1	9	1	2	148.800	7	8	0
W10	2							

*Dendrogram results.* In order to visually illustrate how each of the clusters “hang” together, the SPSS hierarchical cluster analysis plots clusters according to their relative similarity and distance using the coefficient scores depicted in the agglomeration schedule table (Burns & Burns, 2008). The point at which the proximity coefficients were combined is displayed on the dendrogram (Figure 5). The markers that are closer together, located on the far left column, indicate a lower distance and higher similarity of factors or likeness. Conversely, items that are farther apart (gradually moving along towards the right of the graph) indicate a greater distance and increasing levels of dissimilarity.

Reading from the top down and from left to right, the dendrogram visually illustrates the formation of clusters. Mirroring the agglomeration schedule, clusters formed by factors W8 and W10, W2 and W3, and W4 and W5 are the closest to each other and therefore more similar. The considerable distances between each additional stage of cluster formation indicate a considerable degree of dissimilarity exists among the weakness SWOT factors. The longer linkage of W7 with the other factors shows that it is the most dissimilar factor and as such is a “runt” (outlier). The point at which the final two clusters form is at considerable distance as shown by the long linkage lines that form to the right of the dendrogram. The summary of the dendrogram for SWOT Weaknesses is located in Figure 5. See also the additional dendrograms in Appendix N.



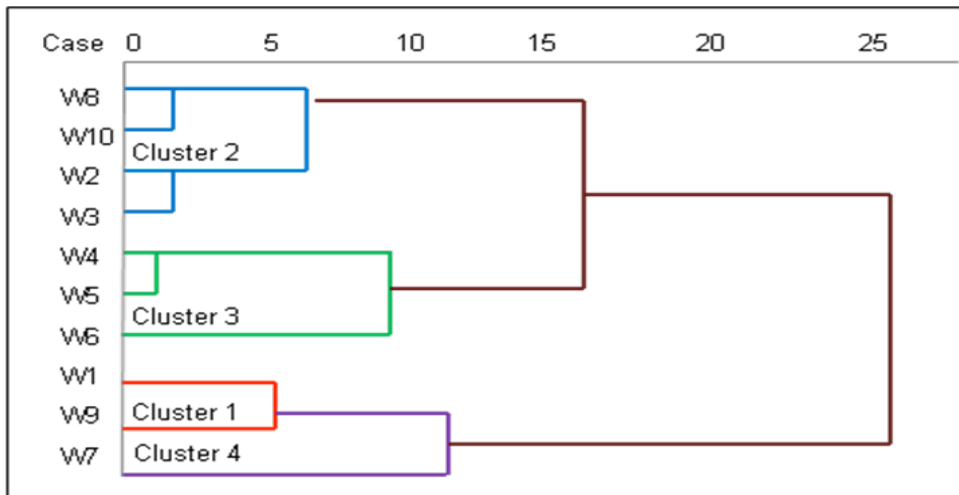


Figure 5. Cluster analysis dendrogram: Weaknesses.

#### *Cluster Analysis Results: Opportunities*

A cluster analysis of the 17 opportunities SWOT factors from the Family Support Survey was conducted to explore how the group means ratings of participants' perceptions of experiences related to accessing and using information, social support, and resources "hang together." That is, do any of the opportunities items cluster together because of similarities and/or differences. The analysis examined factors related to the extent to which families attribute external control as being completely in the hands of others, as well as the extent to which their experiences enhance or help their ability to access and use supports.

*Cluster membership.* The hierarchical cluster analysis using the Ward's method (SPSS software) identified six clusters for SWOT opportunities factors include:

1. Cluster 1: O1, O2, O3, O6
2. Cluster 2: O4, O9
3. Cluster 3: O5, O17

4. Cluster 4: O7, O11, O14, O15
5. Cluster 5: O8, O13, O16
6. Cluster 6: O10, O12

*Cluster 1.* Cluster 1 consisted of four opportunities SWOT factors from the Family Support Survey. All factors in cluster one related to information: (a) “quality of information” (O1), (b) access to “resource guides with information about how to locate resources” (O2), (c) going to “conferences for parents of special needs children” (O3), and, (d) “getting information from “other parents of children with special needs” (O6).

*Cluster 2.* Cluster 2 consisted of two SWOT opportunities factors. One related to access and use of information such as accessing information through “experts, advocates, and others who share information about laws, rights, and services” (O4). The second factor in the cluster was parents’ experiences with having “close friends with others who do not have children with special needs” (O9).

*Cluster 3.* Cluster 3 consisted of two SWOT opportunities factors, of which one factor related to parents’ experiences using the “internet” (O5), and the other to parents’ perceptions that accessing resources is largely a matter of “good luck” (O17).

*Cluster 4.* Cluster 4 contained four opportunities factors. Two factors related to social support such as (a) “formal support groups” (O7), (b) “getting support from “other parents of children with special needs” (O11). The remaining two factors pertained to family experiences with accessing and using resources, (a) “good schools and supportive teachers” (O14), and (b) “professionals who know what services are available and how to get them” (O15).

*Cluster 5.* Cluster 5 consisted of three factors, one from social supports, (a) “parent-to-parent support” (O8), and two pertaining access to resources such as (b) formal “parent support organizations” (O13), and (c) a “parent resource room” (O16).

*Cluster 6.* The sixth and final cluster consists of two factors, one from experiences with obtaining social supports “understanding and support from others” (O10), and having “places to meet other parents and share experiences” (O12).

*Agglomeration schedule.* The agglomeration schedule table shows the degree of similarity and distance reported as a coefficient calculation (determined by SPSS hierarchical cluster analysis). Each “case” (i.e., opportunities factor) begins as its own cluster, which is ordered into clusters starting with individual clusters that are most similar. The linking of factors continues by either creating new clusters or adding single clusters or cluster groups to existing clusters, and so on until all factors form one final cluster.

The agglomeration table for opportunities shows clearly delineated clusters with the first cluster grouping consisting of opportunities factors O10 and O12, which were the most similar. Each of the next three linkages (O2 and O3; O14 and O15; O13 and O16) are also close together indicating a high degree of similarity among these factors. The next cluster groupings continue to form at greater distances as clusters begin linking to other nearby clusters. The final cluster linkages occur at considerably greater distances that increase sharply with the linking of O1 and O2; O7 and O10; and O4 and O8. The final linkages form with cluster O1 connecting to cluster O7. The cluster membership table and agglomeration schedule are located in Table 17.

Table 17

*Cluster Membership and Agglomeration Schedule for SWOT Opportunities*

Cluster Membership		Agglomeration Schedule for SWOT Opportunities Factors						
Case	6 Clusters	Stage	<u>Cluster Combined</u>			<u>Stage Cluster First Appears</u>		Next Stage
			Cluster 1	Cluster 2	Coefficients	Cluster 1	Cluster 2	
O1	1	1	10	12	3.500	0	0	12
O2	1	2	2	3	8.000	0	0	6
O3	1	3	14	15	13.000	0	0	9
O4	2	4	13	16	18.500	0	0	10
O5	3	5	7	11	26.500	0	0	9
O6	1	6	2	6	34.667	2	0	11
O7	4	7	4	9	44.167	0	0	13
O8	5	8	5	17	54.167	0	0	14
O9	2	9	7	14	65.667	5	3	12
O10	6	10	8	13	78.167	0	4	13
O11	4	11	1	2	98.000	0	6	14
O12	6	12	7	10	118.500	9	1	16
O13	5	13	4	8	139.400	7	10	15
O14	4	14	1	5	167.567	11	8	15
O15	4	15	1	4	212.500	14	13	16
O16	5	16	1	7	282.000	15	12	0
O17	3							

*Dendrogram results.* The point at which the proximity coefficients were combined is displayed on the dendrogram (Figure 6) of opportunities factors and visually illustrates how the clusters “hang” together. Thus, the markers that are closer together with lower distance indicate higher similarity of factors or likeness. Conversely, items that are farther apart indicate greater distance and increasing levels of dissimilarity. Reading from the top down and from left to right, the dendrogram shows a pattern of

distinct clusters, with three of the clusters groupings located fairly close to each other (O10 and O12; O2 and O3; O14 and O15; O13 and O16).

The remaining cluster groupings spread a wide distance across the dendrogram as illustrated by the linkage points that are positioned closer to the far right end of the dendrogram tree. The distances between linkage points show there is likely a high degree of dissimilarity that exists among the opportunities factors. The first cluster formed (O10 and O12) does not link with any other clusters until the twelfth stage near the final stages of cluster formation. The final linkages between O7 and O10; O4 and O8; O1 and O2, all occur at a sizeable distance from any of the other clusters. The dendrogram illustrating the similarity and distances among the 17 opportunities factors is located in Figure 6. See also the additional dendrograms in Appendix N.

#### *Cluster Analysis Results: Threats*

A cluster analysis of the 14 threat factors from the Family Support Survey was conducted on group means ratings of participants' perceptions of experiences related to accessing and using information, social support, and resources. The analysis examined the extent to which families attribute control as being completely in the hands of others, as well as the extent to which their experiences hinder or inhibit their experiences with accessing supports.

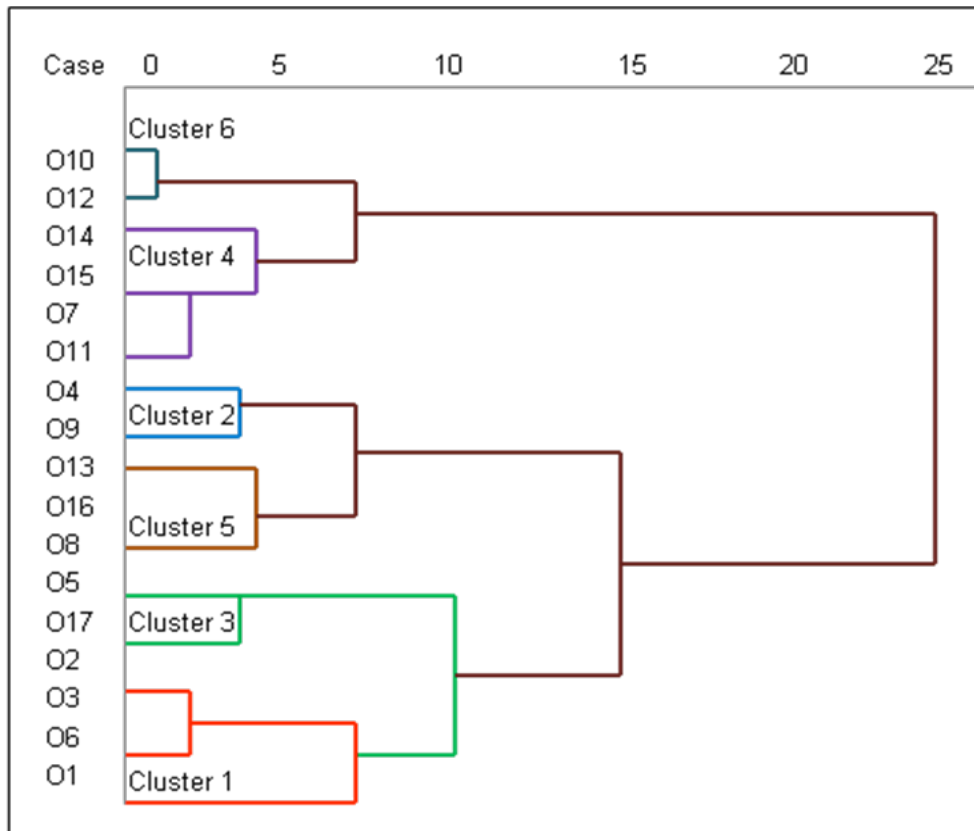


Figure 6. Cluster analysis dendrogram: Opportunities.

*Cluster membership.* The hierarchical cluster analysis using the Ward’s method (SPSS software) identified four clusters for SWOT Threats:

1. Cluster 1: T1, T2, T5, T11, T12
2. Cluster 2: T3, T4, T7, T10, T14
3. Cluster 3: T6, T9, T13
4. Cluster 4: T8

*Cluster 1.* Cluster 1 consisted of five survey factors. The first two Threats factors pertain to experiences related to families’ access and use of information, such as “inadequate information” (e.g., biased, not usable, too much, clinical, and dry), (T1), and

“misinformation and misconceptions about disabilities” (T2). Of the two other factors, one related to related to experiences with accessing social support, “reactions from others” (e.g., lack of tolerance, being judgmental, etc.), (T5), and one concerned experiences with resources, such as system policies and procedures that are “inflexible and have changing rules and terms about who gets services” (T12).

*Cluster 2.* Cluster 2 consisted of five items, of which two related to information that puts too much “emphasis on cure and recovery in media” (T3) and “programs that don’t keep families up to date about new services available” (T4). One factor related to social supports and experiences such as getting “unsolicited advice about how to raise my child” (T7). The last two items pertained to experiences with accessing resources such as case managers who “do not provide information about services” (T10), and “legislative factors that influence funding or cuts in services for my child” (T14).

*Cluster 3.* Cluster 3 includes two factors that pertain to social support, “lack of awareness or understanding from family and friends of what it is like to parent a child with special needs” (e.g., “sit in my shoes”) (T6), and having “responsibilities other than my child who has special needs” (e.g., other children, family, work), (T9). Parents perceptions of experiences with program facilities that “are not comfortable, too small, not appropriate for my child’s age” (T13) was the only factor related to resources.

*Cluster 4.* Cluster 4 contains a single outlier (T8) concerning a “lack of opportunities to meet and connect with other parents who share my experience.”

*Agglomeration schedule.* The agglomeration schedule table shows the degree of similarity and distance reported as a coefficient calculation (determined by SPSS hierarchical cluster analysis). Each “case” (i.e., threats factor) begins as its own cluster,

which is ordered into clusters starting with individual clusters that are most similar. The linking of factors continues by either creating new clusters or adding single clusters or cluster groups to existing clusters, and so on until all factors form one final cluster.

The agglomeration table for Threats SWOT factors shows that the first clusters were formed by the linkages of (T11 and T12), (T4 and T10), and (T1 and T5), thus, were the most similar. The next stage of clusters came together at farther distances (T3 and T14, T3 and T7, T2 and T11, T6 and T13).

The remaining clusters were formed as existing clusters linked with other nearby clusters at substantially greater distances, indicating higher levels of dissimilarity. Threat factor (T8) was a “runt” (outlier) and the last to link with a cluster. The cluster membership and agglomeration schedule are located in Table 18.

*Dendrogram results.* The point at which the proximity coefficients were combined is displayed on the dendrogram for SWOT Threats factors (Figure 7), and visually illustrates how the clusters “hang” together. Thus, the markers that are closer together with lower distance indicate higher similarity of factors or likeness. Conversely, items that are farther apart indicate greater distance and increasing levels of dissimilarity. Reading from the top down and from left to right, the dendrogram shows three distinct clusters and a distant cluster formed by threats factor T8.



Table 18

*Cluster membership and Agglomeration Schedule for SWOT Threats*

Cluster Membership		Agglomeration Schedule for SWOT Threats Factors						
Case	4 Clusters	Stage	Cluster Combined			Stage Cluster First Appears		Next Stage
			Cluster 1	Cluster 2	Coefficients	Cluster 1	Cluster 2	
T1	1	1	11	12	3.500	0	0	6
T2	1	2	4	10	7.500	0	0	9
T3	2	3	1	5	11.500	0	0	8
T4	2	4	3	14	20.000	0	0	5
T5	1	5	3	7	32.167	4	0	9
T6	3	6	2	11	45.333	0	1	8
T7	2	7	6	13	62.333	0	0	10
T8	4	8	1	2	79.667	3	6	12
T9	3	9	3	4	106.600	5	2	12
T10	2	10	6	9	135.600	7	0	11
T11	1	11	6	8	167.850	10	0	13
T12	1	12	1	3	200.250	8	9	13
T13	3	13	1	6	317.214	12	11	0
T14	2							

The early pairing and linking process for the threats factors (T11 and T12, T4 and T10, T1 and T5) indicate that these are closer and therefore have a stronger degree of similarity. The dendrogram visually shows the increasingly greater distance that clusters form, indicating a high degree of dissimilarity. The factor that the most dissimilar is (T8) which does not join a cluster until near the last two stages as demonstrated by the dendrogram. The dendrogram illustrating the similarity and distances among the 14 threats factors is located in Figure 7. See also the additional dendrograms in Appendix N.

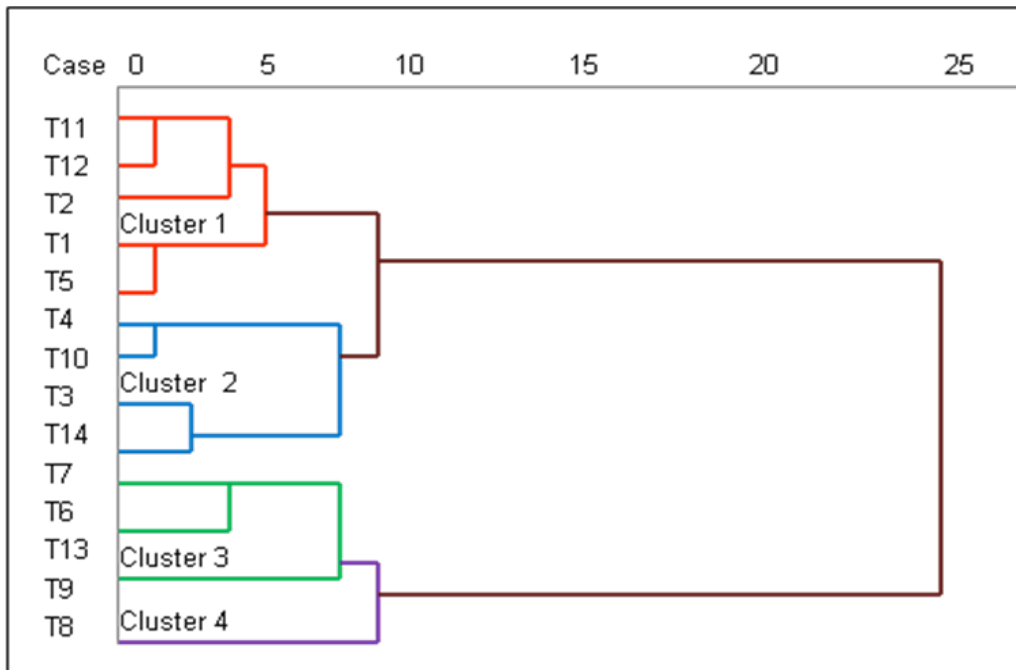


Figure 7. Cluster analysis dendrogram: Threats.

#### *Hierarchical Cluster Analysis Summary*

This section discussed the analysis of data collected from the SWOT Analysis phase of the focus group with six parents of children with special needs between the ages of 3 and 8 years old. The Ward's Hierarchical Cluster Analysis method was used to establish cluster membership for the group means of each SWOT factor obtained from the Family Support Survey.

The Ward's hierarchical cluster analysis established the optimal number of clusters for the group means ratings of each SWOT factor: Strengths (4 clusters), Weaknesses (4 clusters), Opportunities (6 clusters) and Threats (4 clusters). To better understand the meanings of the effects of differences between group means obtained from the analysis of data, the researcher used the IE<sup>2</sup> Matrix Analysis method developed by Leigh (2000, 2005a, 2005b, 2009).

### *IE<sup>2</sup> SWOT Matrix Analysis*

The final step for the IE<sup>2</sup> SWOT Matrix analysis consisted of plotting each SWOT factor data point into one of the four respective SWOT quadrants on the IE<sup>2</sup> Matrix Grid, a Cartesian coordinate system used to represent the relationship between and differences among each Strength, Weakness, Opportunity and Threat (Leigh, 2000, 2005a, 2005b, 2009). The magnitude and placement of each single data point is analyzed in relation to each other, as well as analyzing cluster membership and placement on the grid. Plotting the bivariate data within the two-dimensional IE<sup>2</sup> SWOT Matrix grid in this manner provides for a visual representation of the SWOT data that illustrates both individual responses as well as how these responses “hang” together in clusters (Leigh, 2000, 2005a, 2005b, 2009). The utility of using a visual depiction of data is that numerical and narrative data analysis is easier for individuals to grasp the relationship between factors. Additionally, according to Leigh (Leigh, 2000, 2005a, 2005b, 2009), it can facilitate analysis and interpretation of data in making informed decisions about elements that should be:

- Leveraged (for strengths under substantial internal control that also act as strong enhancers of performance)
- Monitored (for opportunities and threats under substantial external control but minimally enhancing or inhibiting performance)
- Confronted (for weaknesses under substantial internal control that also act as strong inhibitors of performance)
- Mitigated (for threats that are under minimal external control that substantially inhibit performance)

- Exploited (for opportunities that are under minimal external control that substantially enhance performance)

The group means ratings of each factor and each cluster has been discussed in detail in previous sections of this chapter. This discussion will examine each cluster's position in their respective SWOT quadrant on the IE<sup>2</sup> Grid to guide decision-making about how or whether to address findings that emerged from data analysis. The end result will be a better understanding of the degree to which there is agreement among families' attribution of control over identified factors as being internal (in their hands), or external (in the hands of others); as well as the extent to which there is agreement among families' perceptions of things they find helpful (enhance) or a hindrance (inhibit).

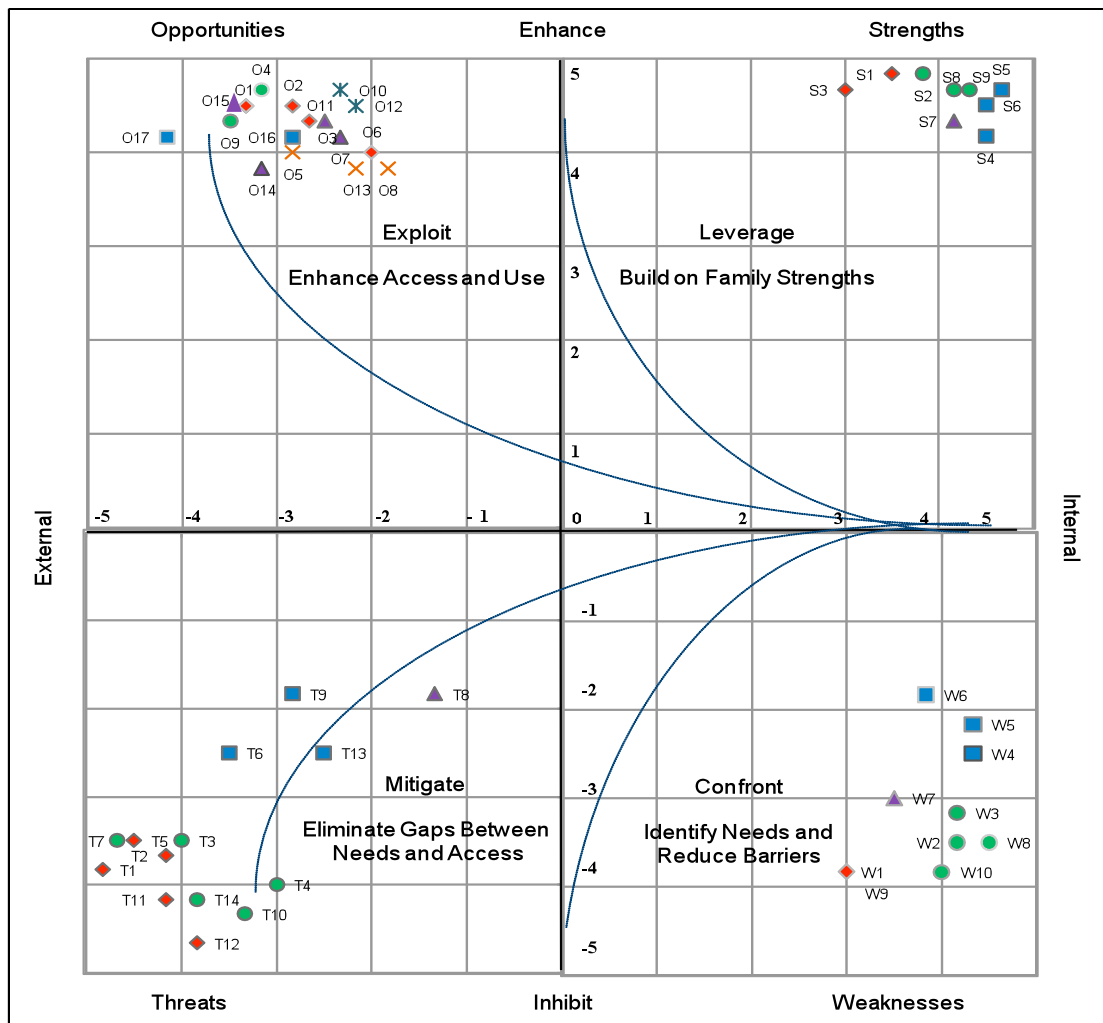
The rating scale for the IE<sup>2</sup> SWOT Matrix Grid ranges from 0 to + 5 for perceptions of internal control (to the right of the center on the *x*-axis) and for perceptions of the value of enhancing experiences (upward from the center on the *y*-axis), with +5 indicating perceptions of complete internal control or a highly valued enhancer, and zero representing neutral perceptions. Perceptions of both externally controlled and inhibiting factors are also rated from 0 to -5 with -5 indicating perceptions of complete external control (to the left of the center on the *x*-axis) or a highly inhibiting factor (downward from the center on the *y*-axis), and zero representing neutral perceptions. As participants' perceptions of having internal control increase, group means ratings (*x*-axis) extended farther to the right, and higher ratings for enhancing value (*y*-axis) are placed further towards the top.

The results of each SWOTs clusters obtained from the hierarchical cluster analysis are plotted on IE<sup>2</sup> Matrix. The IE<sup>2</sup> Grid used in this study has been modified

from the version that is conventionally used by Leigh to fit the specific needs of this study (Leigh, 2000, 2005a, 2005b, 2009). The respective placement of each bivariate data point from the Family Support Survey and clusters formed from the cluster analysis are plotted on the IE<sup>2</sup> SWOT Matrix Grid (Figure 8). In this figure, items that participants identified as strengths (internal/enhancer) on the Family Support Survey (FSS) are located in the upper right quadrant of the IE<sup>2</sup> grid and weaknesses (internal/inhibitors) are located in the lower right quadrant. Items in the upper left quadrant are opportunities (external/enhancers), and items in the lower left quadrant are threats (external/inhibitors). Within the four quadrants, cluster membership for each SWOT factor is noted by its relative symbol as follows: (diamond symbol) = cluster 1, (circle symbol) = cluster 2, (square symbol) = cluster 3, (triangle symbol) = cluster 4, (cross symbol) = cluster 5, and (star symbol) = cluster 6.

### *Strengths Clusters*

The group means ratings for each of the nine SWOT Strengths factors were plotted onto their respective data point on the SWOT quadrant labeled Strengths on the IE<sup>2</sup> Matrix Grid. Analysis of data from the hierarchical cluster analysis resulted in the formation of four clusters related to factors that parents perceived as being within their control and as enhancing their access and utilization of information, social support, and resources. Appraisals of control over factors related to SWOT Strengths factors are plotted on the *x*-axis with stronger attributions of control placed farther to the right of the *y*-axis (0 to +5). Factors perceived as enhancing access to supports are plotted on the *y*-axis, with stronger perceptions of a factors inhibiting effect plotted farther above the *x*-axis (0 to +5).



Key: ◆ Cluster 1 ● Cluster 2 ■ Cluster 3 ▲ Cluster 4 ✕ Cluster 5 ✱ Cluster 6

Figure 8. IE<sup>2</sup> Matrix Grid and plotted SWOT factors. Bivariate data of participants group means ratings are plotted into one of the four quadrants with cluster membership identified by the respective symbol.

The four clusters formed for SWOT Strengths factors identified on the Family Support Survey included:

1. Cluster 1: S1, S3
2. Cluster 2: S2, S8, S9

3. Cluster 3: S4, S5, S6

4. Cluster 4: S7

*Cluster 1.* Cluster 1, consisted of two factors represented by SWOT factors “knowledge of proper lingo to get services” (S1), and “knowledge of services available for my child” (S3). Cluster 1 is positioned at the highest point on the strengths quadrant of the IE<sup>2</sup> Grid, indicating a high degree of agreement that factors S1 and S3 were perceived as being highly valuable to families ( $M = 4.83, SD = 0.41$  and  $M = 4.67, SD = 0.52$ ). However, the degree of agreement related to attributions of control is weaker as demonstrated by the positioning of the data points spaced farther apart ( $M = 3.50, SD = 1.22$  and  $M = 3.00, SD = 1.41$ , respectively for S1 and S3).

*Cluster 2.* Cluster 2 consists of three SWOT Strengths factors, one for information and two for resources. Strengths factor S2, having “knowledge of my child’s disability and how to help my child” is positioned near the top of the  $y$ -axis of the IE<sup>2</sup> Grid, indicating a high degree of agreement that this is important to them ( $M = 4.83, SD = 0.41$ ). However, group means ratings of the degree to which they perceived control over this factor is lower ( $M = 3.83, SD = 0.75$ ), as seen by its placement to the right of other factors. The two resource factors pertain to parent advocacy for their child (S8) and involvement in getting services for their child (S9). These factors are clustered close together at the top of the IE<sup>2</sup> Matrix Grid, demonstrating strong appraisals of internal control and perceptions as being strong enhancers.

*Cluster 3.* Cluster 3 consists of three factors that are related to parents’ experiences with accessing and using social support. All items in cluster 3 received group means ratings higher than 4, with slighter higher degree of agreement related to

attribution of control. Parents perceived maintaining close friendships with others outside of the special needs community (S5) as being highly valued ( $M = 4.67$ ,  $SD = 0.52$ ) and attributed control for this as being almost completely in their own hands ( $M = 4.67$ ,  $SD = 0.52$ ). The high degree of agreement related to perceptions of control over experiences with accessing social support is illustrated by the location of these factors at the farthest right along the  $x$ -axis of the grid.

*Cluster 4.* Cluster 4 consists of a single factor concerning parents' perceptions of the value of building positive relationships with professionals (S7), and as such is a "runt" (outlier). In contrast to parents' high group means agreement of the value of this as being helpful in getting services for their child ( $M = 4.33$ ,  $SD = 0.82$ ), there is a higher degree of variability in parent scores ( $M = 4.17$ ,  $SD = 1.17$ ) for attributions of control.

*Summary of strengths clusters.* The IE<sup>2</sup> Grid shows that the strengths SWOT factors received a strong degree of agreement among parents that these factors are substantially under their control (high internal control) and are highly helpful (strong enhancer) in their efforts to access information, social support, and resources. However, factors S1 and S3 received markedly lower appraisals of control combined with perceptions of being strong enhancers of access and use of information, suggesting a need to address this so as to increase parents' perceptions of control and sense of empowerment. This will be discussed in further detail in the findings section of this paper.

#### *Weaknesses Clusters*

The group means ratings for each of the ten SWOT Weakness factors were plotted onto their respective data point on the SWOT quadrant labeled Weaknesses on the



IE<sup>2</sup> Matrix Grid. Analysis of data from the hierarchical cluster analysis resulted in the formation of four clusters related to factors that parents perceived as being within their control and as hindering their access and utilization of information, social support, and resources. The respective placement of each cluster on the IE<sup>2</sup> Grid is located in Figure 8. Appraisals of control over factors related to weakness SWOT factors are plotted on the *x*-axis with stronger attributions of control placed farther to the right of the *y*-axis (0 to +5). Factors perceived as being inhibiting are plotted on the *y*-axis, with stronger perceptions of a factors inhibiting effect plotted farther below the *x*-axis (0 to -5).

The four clusters formed for SWOT Weakness factors identified on the Family Support Survey included:

1. Cluster 1: W1, W9
2. Cluster 2: W2, W3, W8, W10
3. Cluster 3: W4, W5, W6
4. Cluster 4: W7

*Cluster 1.* Cluster 1 consisted of two factors (W1 and W9). Having a “lack of time to read or keep up with research” (W1) was perceived as being moderately within the control of parents ( $M = 3.00, SD = 0.89$ ) and moderately inhibiting ( $M = -3.83, SD = 0.75$ ). Parents’ experiences with the service delivery system (e.g., regional centers and school districts) and their trust in its capacity to provide services that have their child’s best interests in mind (W9), were likewise perceived as being moderately within parents’ control ( $M = 3.00, SD = 0.89$ ) and as hindering their access to resources ( $M = -3.83, SD = 0.98$ ). In comparison to strengths factors that were clustered relatively close together, it is visually easy to see on the IE<sup>2</sup> Grid that clusters in the weakness quadrant are more

scattered both within and between groups. Placement of these factors toward the center of the  $x$ -axis of the IE<sup>2</sup> Matrix Grid, indicate that participants view these factors as being neither completely within their control, nor completely in the hands of others, and as having a moderate degree of effect on hindering their access to information and resources.

*Cluster 2.* Cluster 2 consisted of four SWOT Weakness factors, two of which are related to information and two related to accessing resources. Each of these factors are similar, in that parents' group means ratings of appraisals of control were higher than their ratings for the extent to which they perceived these factors as hindering access to information or resources. The two factors related to information, "not accessing or using research resources" (W2), and "not knowing how to help my child" (W3) received the same group means rating and standard deviation ( $M = 4.17$ ,  $SD = 0.75$ ) for control. Ratings for the extent to which these factors were perceived as inhibiting access and use of information were moderate ( $M = -3.50$ ,  $SD = 0.84$  and  $M = -3.17$ ,  $SD = 0.75$  for W2 and W3 respectively). The difference between higher ratings of control along with lower ratings as being an inhibitor is visually observable by the positioning of these two factors (W2, W3) to the far right on the  $x$ -axis (indicating higher control) with a more mid-range placement towards the bottom (indicating a perception as being moderately inhibiting).

Near the two information factors, are the two factors related to access and use of resources (W8 and W10). As can be seen on the IE<sup>2</sup> Matrix Grid, participants also attributed control ( $M = 4.50$ ,  $SD = 0.84$ ) as being almost completely in their hands regarding the extent to which they are involved in making sure that their child gets the services he or she needs (W8). While parents also perceived a relatively high degree of

control over the extent to which they allowed others to decide what services their child receives (W10), there was greater variability for this factor ( $M = 4.00$ ,  $SD = 1.26$ ).

Perceptions of the effect of these factors on hindering access to desired resources was moderate and had a high degree of variability ( $M = -3.50$ ,  $SD = 1.38$  for W8, and  $M = -3.83$ ,  $SD = 1.17$  for W10). However, the ratings indicated a stronger perception that these factors were a slightly stronger hindrance to their access and use of resources, as can be seen by their lower position on the  $y$ -axis of the  $IE^2$  Grid.

As observed on the  $IE^2$  Grid, while not currently a threat to families, the four factors in cluster 2 (W2, W3, W8, W10) are good candidates for monitoring changes in parents' perceptions of control, as well as the extent to which these factors might become more of a hindrance to their access and use of resources.

*Cluster 3.* Cluster 3 consisted entirely of the three factors related to social supports (W4, W5, W6). Participants' appraisals of control over the extent to which they felt isolated from other parents of special needs children (W4), and seeking support from other parents (W5) were both seen as being substantially under parents' control ( $M = 4.33$ ,  $SD = 0.82$  for both W4 and W5 respectively), as observed by the position to the far right on the  $x$ -axis. However, as can be seen by the relatively high position on  $y$ -axis of the  $IE^2$  Matrix Grid, the extent to which these factors hindered experiences with obtaining social support were the lowest, and also had the highest degree of variability out of any of the other weakness factors ( $M = -2.50$ ,  $SD = 1.76$  for W4, and  $M = -2.17$ ,  $SD = 1.17$  for W5).

The other item in cluster 3 related to participant's perceptions of their experiences with getting support from their spouse (W6). Participants group means ratings for this

factor indicated parents felt that control was not entirely in their own hands ( $M = 3.83$ ,  $SD = 0.75$ ). Most notable is the placement of this factor at the highest point of the  $y$ -axis, indicating that they perceived as barriers and challenges (minimally inhibiting) in getting support from their spouse ( $M = -1.83$ ,  $SD = 1.33$ ). However, there was a very high degree of variability between parents' responses with a range of 0 to -3 (0, -1, -1, -3, -3, -3), indicating that while some parents felt this had no effect at all, others felt that it had a moderate degree of influence on their perception of feeling supported by their spouse.

In general, the position of cluster 3 (to the far right on the  $x$ -axis and mid-way down the  $y$ -axis) indicates that participant's perceived a strong degree of internal control over being able to access desired social support from other parents and their spouse, and that currently any factors that may be hindering their access are minimal.

*Cluster 4.* The final cluster consisted of just one factor (W7) that stands alone as a "runt" or outlier. This factor pertains to parents appraisals of control ( $M = 3.50$ ) over knowing what services and supports are available and the extent to which this is perceived as inhibiting ( $M = -3.00$ ) their ability to access resources for their child and family. This factor had the highest degree of variability for both appraisals of control ( $SD = 1.76$ ) and perceptions of being a hindrance ( $SD = 2.00$ ), indicating that there was less agreement among participants as to the effect of this factor on their experiences with accessing resources. One parent rated both control and hindrance as 0 while other parents rated control from a range of 4 to 5 (4, 4, 4, 4, 5) and hindrance from a range of 2 to 5 (2, 2, 4, 5, 5).

If just looking at the group means ratings, it might appear as if this factor had a relatively minimal effect on parent's access to resources. However, upon closer

examination, it is clear that most of the parents felt a strong degree of control and a strong perception that this factor hindered their knowledge of resources and services available for their child.

*Summary of weakness clusters.* The IE<sup>2</sup> Grid for weakness SWOT factors, show 4 clusters with distinct patterns of dispersion. While cluster 1 is differentiated by its moderate degree of attributions of internal control and helpfulness, cluster 3 is distinguished by a relatively high degree of agreement that control is internal, but received the lowest ratings related to perceptions of helpfulness.

In spite of parents feeling that they have a moderate to high degree of control over the extent to which they are able to access and use information, social support, and resources, their responses indicate they are not always successful. Although these factors are not currently perceived as being a threat to parents, a decrease of attributions of internal control, or increase in perceptions of having a hindering effect, could result in these factors becoming more serious threats to families access and use of desired supports. As such, experiences identified as being weaknesses with a high degree of internal control or high degree of perception as an inhibitor should be confronted to ensure that steps are taken to prevent a change in either direction.

#### *Opportunities Clusters*

The group means ratings for each of the 17 SWOT Opportunities factors were plotted onto their respective data point on the SWOT quadrant labeled Opportunities on the IE<sup>2</sup> Matrix. Analysis of data from the hierarchical cluster analysis resulted in the formation of six clusters related to factors that parents perceived as being outside of their control and as enhancing their access and utilization of information, social support, and

resources. The respective placement of each cluster on the IE<sup>2</sup> Grid is located in Figure 8. Appraisals of control over factors related to SWOT Opportunities factors are plotted on the *x*-axis with stronger attributions of control as being in the hands of others placed farther to the left of the *y*-axis (0 to -5). Factors perceived as enhancing access to supports are plotted on the *y*-axis, with stronger perceptions of a factors inhibiting effect plotted farther above the *x*-axis (0 to +5).

The Family Support Survey items related to factors identified as opportunities (external control and strong enhancer) had a wide dispersion of group means ratings resulting in six clusters (three small and three large). Furthermore, there is considerable variability within participants' responses on each of the items, that is, in addition to each parent's rating of items differently from each other, there were substantial differences in how parents rated each of their own responses. Additionally most of the variability, as well as very low ratings, are for the group means ratings for appraisals of control.

Families' ratings of the extent to which they perceive opportunities factors as being strong enhancers of their experiences with accessing and using information, social support, and resources are substantially stronger and have a greater degree of agreement than ratings pertaining to appraisals of control, and therefore exert more influence in how the clusters are grouped. One of the most noticeable features of how the clusters are grouped in this quadrant, is the dispersion of data points over a wide area of the IE<sup>2</sup> Grid for the opportunities quadrant along the *x*-axis (indicating greater variability for appraisals of control), but the rather tight clustering of data points at the top of the *y*-axis (indicating stronger agreement for helpfulness).

The six clusters formed for Opportunities factors identified on the Family Support Survey included:

Cluster 1: O1, O2, O3, O6

Cluster 2: O4, O9

Cluster 3: O5, O17

Cluster 4: O7, O11, O14, O15

Cluster 5: O8, O13, O16

Cluster 6: O10, O12

*Cluster 1.* Cluster 1 consisted of four Opportunities SWOT factors (O1, O2, O3, O6), all pertaining to families' experiences with accessing and using information.

According to the cluster analysis findings already discussed in the previous section, there is a relatively strong degree of agreement among participants that factors contributing to enhancing access and use of information includes being easy to read, understandable, filtered, and non-biased (O1), and access to resource guides prepared by professionals they trust (O2). Parents reported that other parents of children with special needs (O3), or attendance at conferences that cater to families of special needs children (O6) are important sources of information for them. Group means ratings for perceptions of control range from  $M = -2.00$ ,  $SD = 0.89$  to  $M = -3.33$ ,  $SD = 1.86$ , and  $M = 3.83$ ,  $SD = 0.75$  to  $M = 4.50$ ,  $SD = 0.84$  for perception of these factors as enhancing their access and use of information.

Interestingly, when looking at where these items are plotted on the IE<sup>2</sup> Matrix Grid, it is not readily apparent that these four factors somehow “hang” together as the cluster analysis findings would suggest. There is considerable dispersion of these four

items as can be seen in the opportunities quadrant of the IE<sup>2</sup> Grid. However, when examining participant's individual responses for these factors, it is apparent that there is a wide range of responses pertaining to their appraisals of control over these factors, with values ranging from 0 to -5 for opportunities factors O1 and O3, 1 to -4 for factor O2, and 1 to -3 for factor O6. This distinction is important because if analysis were based solely on the physical placement of the bivariate group means scores on the IE<sup>2</sup> Matrix Grid, it is possible to draw conclusions that may not take into consideration all characteristics present in the data set, as is the case with these factors related to information.

*Cluster 2.* Cluster 2 consisted of two opportunities SWOT factors. One factor pertained to participants' ratings related to perceptions of the helpfulness of experts, advocates, and others as a source of information about laws and rights that influence their ability to obtain services for their child and the extent to which they have control over accessing this information (O4). The second factor related to social supports and the extent to which parents viewed having close friendships with others who do not have a child with special needs as an important source of social support and their appraisals of control over whether or not they obtain support (O9). The group means ratings for appraisals of control were more similar for cluster 2 factors ( $M = -3.17$ ,  $SD = 2.48$  for O4 and  $M = -3.50$ ,  $SD = 1.52$ ), than cluster one. This is clearly observed by the closer proximity of factors O9 and O4 on the  $x$ -axis gridline marked -3.00 of the Opportunities SWOT chart in the IE<sup>2</sup> SWOT Matrix Grid (Figure 8).

*Cluster 3.* Cluster 3 consisted of two items, one relating to accessing information on the internet (O5), and one related to participants' perceptions that accessing resources is largely a matter of "good luck" (O17). The similar characteristic being that



participant's had a relatively strong degree of agreement that these were perceived as being important factors in families' access to information (e.g., the internet), or in whether or not they obtained desired resources (e.g., "good luck"). There was a strong degree of agreement and consistency (range = 3 to 5) among ratings of the extent to which participants' perceived these factors as enhancing their access to information and resources ( $M = 4.17$ ,  $SD = 0.75$  for O5 and  $M = 4.17$ ,  $SD = 0.98$  for O17). Similar to the four information factors in cluster 1, there was wide dispersion of participants' individual ratings related to appraisals of control over accessing information via the internet (range = -1 to -4,  $M = -2.83$ ,  $SD = 1.17$  for O5). While perception of external control was minimal for the extent to which families have access over information on the internet, just the opposite was true for attributions to factor O17, "good luck" ( $M = -4.17$ ,  $SD = 0.98$ ), which participants rated as being almost entirely in the control of others. The placement of this factor stands alone at a sizeable distance from the other opportunities factors as demonstrated by the IE<sup>2</sup> Matrix Grid.

*Cluster 4.* Cluster 4 contained four of the SWOT Opportunities factors. Two factors pertain to participants' experiences with accessing formal sources of social supports, such as the child's program providers or parent organizations (O7), or from other parents of children with special needs (O11). The other two factors relate to concerns related to experiences with having resources, such as having good schools and supportive teachers (O14), and professionals who know the type of services available and how to help families obtain these (O15).

As observed on the opportunities quadrant of the IE<sup>2</sup> Grid, factors O7 and O11 are paired together and are towards the middle of the  $x$ -axis indicating a perception of a low

to moderate degree of control as being in the hands of others ( $M = -2.33$ ,  $SD = 1.75$  and  $M = -2.67$ ,  $SD = 1.75$  for O7 and O11 respectively). Factors O14 and O15 also form a pair with slightly stronger appraisals of control ( $M = -3.17$ ,  $SD = 1.47$  and  $M = -3.33$ ,  $SD = 1.51$ , respectively). The group means ratings of these four factors indicate that participants' perceived these as being strong enhancers of their access and use of social supports and resources with a range of  $M = 4.33$ ,  $SD = 0.82$  for (O11) to  $M = 4.67$ ,  $SD = 0.52$  (O7 and 14).

*Cluster 5.* Cluster 5 contained three SWOT Opportunities factors. One factor pertains to participants' experiences with informal supports such as parent-to-parent supports (O8) and two factors refer to resources, such as formal parent support organizations, such as Autism Speaks, a national organization that funds and disseminates information about autism (O13), and having access to a parent resource room where they can do research and meet with other families (O16). Participants' group mean ratings of factor O8 received the lowest score for appraisals of control, indicating that participants perceived control over parent-to-parent support as being almost completely within their control and not in the hands of others ( $M = -1.83$ ,  $SD = 1.83$ ); however, this factor was reported as being only moderately important to families ( $M = 3.83$ ,  $SD = 0.75$ ). Parents' experiences related to more formal parent support organizations, and having a resource room were perceived as having a low degree of external control (in the hands of others) and a moderate degree of helpfulness.

Similar to other opportunities SWOT factors, there is a wide range of dispersion and variability of these three items across the  $x$ -axis on the IE<sup>2</sup> Matrix Grid. Placement of these factors' data points in the middle of the  $x$ -axis indicated that parents attribute

control as being more within their own hands than in the hands of others. However, it is also clear there is a relatively high degree of agreement among participants that these types of supports and resources are perceived as being helpful, as can be seen by the position of these factors near the top of the  $y$ -axis.

*Cluster 6.* Cluster 6 contained two SWOT Opportunities factors, one relating to social support (O10) and the other one to resources (O12). Participants appraisals of control over obtaining understanding and support from others, such as family and spouse (O10) was perceived as being more in their hands ( $M = -2.33, SD = 2.25$ ); however there was a substantial degree of variability of agreement as demonstrated by the range of responses (range= -5, 0, -1, -4, 0, -4). Parents' responses indicated a strong degree of agreement that support from their spouse and others (O10) was a strong enhancer of social and emotional support ( $M = 4.33, SD = 0.82$ ). The final item in this cluster related to parents perception of the value of having a place to meet other parents, such as in the waiting area of where their child receives therapy ( $M = 4.50, SD = 0.55$ ); furthermore, parents' ratings indicated a strong appraisal of control as being more in their own hands ( $M = -2.17, SD = 1.94$ ).

*Summary of opportunities clusters.* The most notable characteristic of Opportunities SWOT factors is the distribution of group means ratings, which are widely dispersed and highly variable for attributions of control, but a relatively strong degree of agreement that the factors in this category are perceived as being strong enhancers to parents' efforts with obtaining information, social supports, and resources. The positioning of data points indicate a relatively low degree of agreement for appraisals of external control, as represented by the wide dispersion of data points across the center of

the  $x$ -axis (-2.00 to -4.00) of the IE<sup>2</sup> Grid. Furthermore, there was as a relatively high degree of agreement that these factors substantially enhance parent's access and use of supports, as evidenced by the clustering of opportunities factors higher up the  $y$ -axis (3.00 to 5.00).

A pattern of minimal external control in conjunction with factors perceived as being strong enhancers, suggest several areas that could be exploited to further enhance parents' experiences with accessing and using information, social support, and resources, which will be discussed under findings in chapter five.

### *Threats Clusters*

The group means ratings for each of the 14 SWOT Threats factors were plotted onto their respective data points on the SWOT quadrant labeled Threats on the IE<sup>2</sup> Matrix Grid. Analysis of data from the hierarchical cluster analysis resulted in the formation of four clusters related to factors that parents perceived as being outside of their control and as hindering their access and utilization of information, social support, and resources. The respective placement of each cluster on the IE<sup>2</sup> Grid is located in Figure 8. Appraisals of control over factors related to SWOT threats factors are plotted on the  $x$ -axis with stronger attributions of control as being in the hands of others placed farther to the left of the  $y$ -axis (0 to -5). Factors perceived as hindering access to supports are plotted on the  $y$ -axis, with stronger perceptions of inhibiting effects plotted farther above the  $x$ -axis (0 to -5).

What is notable about the cluster formation for the Threats SWOT quadrant of the IE<sup>2</sup> Grid is the clustering of the majority of factors in the area that indicates a high degree of external control as well as a perception that these factors are a strong hindrance (lower

left corner of the threats quadrant. The four clusters formed for Threats SWOT factors identified on the Family Support Survey included:

1. Cluster 1: T1, T2, T5, T11, T12
2. Cluster 2: T3, T4, T7, T10, T14
3. Cluster 3: T6, T9, T13
4. Cluster 4: T8

*Cluster 1.* Cluster 1 consisted of five SWOT Threats factors. The first cluster includes two factors related to information, such as having inadequate information that is not parent friendly (T1), and misinformation and misconceptions about their child's disability (T2). These two items were rated by parents as being almost completely in the hands of others, as well as being a moderate inhibitor to the access and use of information. Parents' appraisals of control related to information that is inadequate or not usable (T1) was rated with the highest attribution of control as being almost completely in the hands of others ( $M = -4.83, SD = 0.41$ ) and as being moderately hindering to their access and use of information ( $M = -3.83, SD = 0.75$ ). The threats factor T1 is the data point positioned on the  $x$ -axis that is farthest left of the  $y$ -axis on the IE<sup>2</sup> Matrix Grid, indicating high degree of external control.

Participants perceptions of their experiences with the reactions of others when they take their child out into the public (T5) is the only social support factor in cluster 1. Parents reported a high degree of external control ( $M = -4.50, SD = 0.55$ ), and as having a moderately inhibiting effect on their ability to feel confident about taking their child out into the community ( $M = -3.50, SD = 0.84$ ). The remaining two factors, T11 and T12, pertain to resource related factors at the macro level (e.g., inflexible, inconsistent system

rules related to services available). Participants' ratings of the extent to which system policies and rules for deciding who gets what services (T12) received a high degree of agreement that this was the strongest inhibitor of their access to services for their child. The placement of factor T12 at the bottom of the  $y$ -axis of the IE<sup>2</sup> Matrix Grid illustrates that this was perceived as being substantial hindrance.

*Cluster 2.* Cluster 2 consisted of five factors, two of which relate to information (T3, T4), one relates to social supports (T7), and two relate to resources (T10, T14). Group means ratings indicate that an emphasis on cure and recovery in the media (T3) and programs that fail to keep families up to date about new services available (T4) are perceived as being mostly under the control of others, as well as hindering their access to the type of information that would help them with their child. Parents experiences with unsolicited advice from others (T7), such as managing their child's behavioral outbursts when in public was viewed as being a moderate hindrance ( $M = -3.50, SD = 1.52$ ) and as being almost completely in the hands of others ( $M = -4.67, SD = 0.52$ ).

Resource related factors in the second cluster pertain to issues at a macro level that hinder families access to information about services, such as case managers who do not provide information to parents (T10), and legislative factors that threaten the availability of services for their child (T14). The location of these two factors towards the center of the  $x$ -axis of the IE<sup>2</sup> Grid indicates that parents perceive control as being neither completely in the hands of others nor themselves ( $M = -3.33, SD = 1.86$  for T10, and  $M = -3.83, SD = 1.60$  for T14). Additionally, participants perceived these two factors as being highly hindering ( $M = -4.33, SD = 1.86$  for T10, and  $M = -3.83, SD = 1.60$  for T14).

*Cluster 3.* Cluster 3 consisted of three factors (T6, T9, and T13). The location of Cluster 3 in the center of the IE<sup>2</sup> grid reflects participants' ratings of these factors as being the least hindering of all threat factors and as having the lowest appraisals of external control. With the exception of one factor pertaining to the comfort of program facilities (T13), factors in this cluster pertain to experiences with obtaining social support, such as lack of awareness or understanding from family and friends (T6), and having responsibilities other than their child with special needs (T9).

*Cluster 4.* Cluster 4 consisted of a single “runt” or outlier (T8) as seen by the placement of this factor at a considerable distance from any of the other threats factors on the IE<sup>2</sup> Grid. Parents group means ratings related to a lack of opportunities to meet and connect with other parents (T8), received the lowest group means rating for both external control ( $M = -1.33, SD = 1.51$ ) and as an hindrance ( $M = -1.83, SD = 1.72$ ). These ratings indicate that parents perceived control as being almost completely in their own hands, and as having a minimal impact of their ability to obtain social support from other parents.

*Summary of threats clusters.* The four clusters pertains to factors perceived as threats are widely dispersed with cluster one weighted more towards appraisals of external control and cluster two weighted more towards factors that are perceived as being highly inhibiting. Cluster 3 is located in the center of the grid, reflecting a lower degree of perceived threat for factors in this cluster. A single “runt” that received the lowest rating for both control and effects as an inhibitor represents cluster 4.

SWOT Threats factors that have a low degree of external control and perceived as being a strong enhancer are targets for further examination of areas where programs can

take direct action to mitigate the hindering effects, and/or identify ways to shift as much control as possible into the hands of families. This will be discussed under findings in chapter five.

*Summary of IE<sup>2</sup> SWOT Matrix Analysis*

The process of furthering exploring the meaning of quantitative results with conventional methods (hierarchical cluster analysis) and methods not commonly used to investigate parent perceptions of experiences (plotting the bivariate group means data on the IE<sup>2</sup> Matrix grid), provided a means to triangulate and cross check the meaning of the qualitative data obtained from the focus group interview with parents. While the hierarchical cluster analysis offered a means to quantify the qualitative data obtained from families of children with special needs, the plotting of data using the IE<sup>2</sup> Matrix provided an additional method for aiding in the interpretation of the meaning of the data. The meanings and conclusions of the qualitative and quantitative data collection and analysis, as well as the utility and efficacy of the IE<sup>2</sup> Matrix approach as another tool to use in conjunction with analysis of qualitative data will be further discussed.



## CHAPTER 5: DISCUSSION

### Findings

Having a child with special needs presents an unexpected and unique challenge for parents. While many families readily accept and adapt to having a child with developmental challenges, others may experience some degree of stress that may trigger a state of crisis for the family system (Bailey & Powell, 2005; Goodman & Gottlieb, 2002; Guralnick, 2005b). A wide body of research in the field of early childhood intervention/special education indicates that access to and utilization of supports, such as information, social support, and resources, can mediate the family crisis and help families attain healthy coping and adaptation (Armstrong et al., 2005; Dunst et al., 1994; Gray, 2006). However, families of children with special needs often report a considerable discrepancy between the type of supports they desire and the type of supports that are available, and report both helpful and hindering experiences related to accessing and utilizing supports and services for their child and family. This is particularly true for families of children over 3 years of age (Allen, 2007; Connelly, 2007; Freedman & Boyer, 2000; Seligman & Darling, 2007).

The purpose of this phenomenological and mixed methods study was to gain a deeper understanding of families' lived experiences with accessing and using family supports and the meanings they make of these experiences. Specifically, the aim of this study was to explore family perceptions about the type of experiences that either enhance (help) or inhibit (hinder) their ability to access informational, social, and resource supports and the extent to which they appraise control as being completely in their hands (internal control) or completely in the hands of others (external control). The presumption

being that the study's findings could lead to a greater understanding of the psychological and environmental factors that families perceive as enhancing or inhibiting their access and use of supports, as enabling and empowering them to advocate for their child, as well as supporting their sense of competency and confidence in parenting their child with special needs.

In order to capture the richness of participants' stories, both qualitative and quantitative data was obtained during a semi-structured focus group interview and administration of the Family Support Survey, a tool designed for this study. Analysis included content analysis of qualitative data, comparison of group means from the survey responses, and using hierarchical cluster analysis to explore similarities and differences. An IE<sup>2</sup> SWOT Matrix analysis was used as a final step to organize data collection and analysis and interpretation of the meanings of families' experiences.

The information study's findings of families' experiences and stories yielded valuable information to assist the investigated program in making decisions about program practices that are working, and therefore should be maintained or improved, those practices that are not working and should be reduced or eliminated, and those practices that are desired and need to be developed (Leigh, 2000, 2005a, 2005b, 2009).

The phenomenological and mixed methods research design using qualitative and quantitative data obtained from families participating in a focus group addressed the following research questions:

RQ 1: What are the lived experiences of families whose children with special needs participate in early intervention or special education services and what meanings to they make of these experiences?

RQ 2: What are families' lived experiences with accessing and utilizing information, social support, and resources?

RQ 3: What are families' appraisals of control over their experiences with accessing and utilizing information, social support, and resources?

RQ 4: What are families' perceptions of the type of experiences that enhance or inhibit their access and utilization of information, social support, and resources?

RQ 5: To what degree, if at all, is there agreement within families' ratings of the value of enhancing or inhibiting experiences, and their appraisals of control over these experiences?

#### *Findings for Research Question 1*

Research question 1 aimed to answer, what are the lived experiences of families whose children with special needs participate in early intervention or special education services, and what meanings do they make of these experiences?

In response to research question 1, seven clusters and related themes emerged from the data: (a) Period of Diagnosis, (b) Effects on Marriage, (c) Community Experiences, (d) Empowerment, (e) Interpersonal Well-Being, (f) Adaptation, Benefit, Hopefulness, and (g) Future Needs. The findings and implications for each of these clusters and themes are discussed in the following section. All quotes were obtained from the 6 participants of this study.

#### *Period of Diagnosis*

Findings from the focus group interview with the study's participants suggested that the period surrounding their child's diagnosis with a disability was a challenging time. Families expressed feeling overwhelmed, confused, and alone, which is consistent

with findings from previous researchers related to parent reactions to having a child with a disability (Summers et al., 1988). Naseef (1997), a parent of a child with special needs, describes in his book, *Special Children, Challenged Parents* that the impact of getting the initial diagnosis often feels like the loss of a dream (p. 342). Initially, the parents in this study were hopeful that their child would get better within a few months of beginning early intervention services, and experienced deep feelings of sadness and loss when their child was instead diagnosed with a lifelong disability (Barnett et al., 2003).

Families' experiences support research findings of Marshak et al. (1999), which found that families frequently hold out hope that their child will eventually go to typical preschool or kindergarten, and suffer tremendous feelings of loss all over again when this does not occur. Parents' statements (with participant number in parentheses) that convey this include: "I thought in few months we would be done" (P4) and "I had this specific expectation about what it would be like to have a child" (P5).

The needs of parents did not decrease just because the child grew older. In fact they reported that as new areas of concern and issues developed, they required a different type of support. When their child was younger parents reported the initial period around getting the initial diagnosis as being challenging, whereas when the child was older, they were emotionally adjusting to the realization that their child's diagnosis was not temporary, but permanent with fears about the future.

### *Effects on Marriage*

Similar to research from others related to the effects of a special needs child on the marital relationship, participants reported that parenting a child with special needs disrupts and puts stress on their relationship with their spouse (Bromwich, 1997; Bruder,

2000; Weiss, 2002). However, families in this study also expressed that their spouses were a primary source of support for them, and that communication was essential in maintaining the relationship. Parent's statement includes (with participants number in parentheses):

Having a child with special needs puts a huge strain, and you have to put that (marital relationship) together and services . . . and try to be supermom . . . without solid communication . . . I am not going to be able to get through this . . . I can't deal with it alone (P1).

### *Community Experiences*

One of the more challenging experiences for participants was being able to take their child into the community to participate in typical family routines such as shopping or going to church due to their child's disruptive behavior. Parents who participated in this study described feeling judged by others when their children exhibited tantrums in public. Weiss' (2002) study of factors related to stress in mothers of child with autism, found that the most frequently cited child characteristic that resulted in parental stress was the extent to which the child exhibited behavior challenges. According to Bernheimer and Weisner (2007), all families seek to adapt and accommodate their children into the context of daily routines; however, families of children with special needs experience additional challenges, a situation consistent with the families statements in this study (Baker et al., 2002; Erickson & Upshur, 1989). Parents reported experiences in which they felt guilt and shame as a result of their child's behavior as illustrated by the following statements (with participants number in parentheses):

They are staring at me, thinking, what are you going to do about it (child's behavior)? (P3)

There is this constant thing that . . . my child is really disrupting. (P5)

### *Empowerment*

Self-efficacy, or parent's perception of competence, has been described in the literature as an important construct related to successful adaptation for parents of children with special needs (Desjardin, 2005). Furthermore, Dunst et al. (2007) found that families who felt a stronger degree of internal control were more likely to report feeling capable, confident, and empowered. Findings from this study show that parents achieved greater feelings of confidence and sense of competency as their child got older, enabling them to feel more comfortable advocating for their child. An area that seemed to be important to parents was being able to reply more assertively to strangers, who they considered unkind and rude. Participant's statement include (with participant number in parentheses):

The longer you are in this world (related to special needs), the better you get at dealing with onlookers. (P6)

Given the magnitude to which the comments of others was bothersome to the parents in this study, being able to stand up for themselves and/or their child was perceived as being important.

### *Interpersonal Well-Being*

While the majority of parents in this study whose children presented with milder symptoms reported that their situation got better over time, two parents of children with greater needs expressed that as their child got older their situation got worse. Mirroring the findings of Weiss (2002) and her study on stress and coping among parents of children with special needs, parents expressed feeling burned-out and exhausted, due to relentless caregiving demands and having to monitor their child constantly.

However, in spite of these challenges, parents reported that as their child got older they could see how their situation was a benefit to them in terms of personal growth. This finding is similar to Wikler's (1983) study of 27 parents of children with developmental disabilities, in which 75% of parents felt it made them stronger and 46% reported much stronger.

### *Adaptation, Benefit, Hopefulness*

One of the most positive findings of this study was how families adapted to their child's disability and were able to find meaning in the experience. Taylor's theory of cognitive adaptation states that individuals adapt to unexpected situations, such as having a child with a special need, when they are able to re-frame the event as having a positive interpersonal or familial benefit (Taylor, 1983), a finding supported by later research of others on families of children with disabilities (Hassall, 2005; Judge, 1997). Parents' experiences demonstrated that as their child got older, they could see how the situation was a benefit to them in terms of personal growth. One feeling expressed by all parents was the benefit of being able to make friends with people they would otherwise never have known (with participant's number in parentheses):

I learned to take it one day at a time. (P1)

I can now say it is a blessing. (P2)

I have met the most incredible people in my life. (P4)

### *Future Needs*

Families' concerns and anxieties for the future centered on issues related to services for their child. Concerns seemed to revolve around fears of losing services as their child got older, or in services being severely limited due to changing policies and

budget constraints. Especially problematic for families were policies driven by funding and not by the individual needs of their child and family. Additionally, because they are aware that their child's disability is life long, some of the parents were already contemplating what services would be available for their child when they become an adult. Gray's (2006) findings in his 10 year longitudinal study of families with children who have autism, found that as children got older, they were receiving fewer services and supports, in spite of having greater needs. His study found a decline in the use of problem-focused vs. emotion-focused coping strategies. The experiences of families in this study echo the findings of Gray's (2006) (participant's number in parentheses):

We (thought) we would need less support as time goes on . . . but sometimes the further you get into it, the more you don't know . . . there is this idea that once your child does get services for a limited period of time, that he/she will be cured, and parents will know what to do . . . it is really about the long-term and when he is 22 years old and if he still needs a tremendous amount of support. (P5)

#### *Conclusions and Implications for Research Question 1*

The findings from the focus group interview both supports and adds to the body of literature related to how parents experience a child with special needs and the meanings they make of these experiences. Families' experiences are consistent with other research findings related to effects of a child's diagnosis on the marital relationship (Seligman & Darling, 2007) and the stress they experience because of behaviors associated with their child's disability (Baker et al., 2002). A positive finding from the study was that families were able to achieve a sense of empowerment and to make meaning of the experience as an event that had a positive impact, such as making new friends, or becoming a better person (Hebbler, Spiker, Bailey, Scarborough, Mallik et al.,



2007; McCubbin & McCubbin, 1987; Summers et al., 1988; Taylor, 1983; Whitaker, 2002).

Issues related to changing and inflexible policies and decreasing services creates a high degree of anxiety for families that seemed to negatively affect their perception of being able to meet the needs of their child and family (Barnett et al., 2003; McWilliam, 2005). The literature is clear that support is essential for families, and in particular, information, social support and resources (Bailey & Powell, 2005; Guralnick, 2005b). Furthermore, without these supports, families are at increased risk of experiencing prolonged stress, failing to develop sufficient coping strategies, and delaying adaptation (Boyd, 2002; Marshak et al., 1999; Weiss, 2002). In contrast, studies show that parents who obtain desired and needed services and supports, report higher levels of personal well-being, better coping strategies, and provide more nurturing, and responsive parenting (Bromwich, 1997; Desjardin, 2005; Guralnick, 1997; Hebbler, Spiker, Bailey, Scarborough, Mallik et al., 2007).

### *Findings for Research Question 2*

Research Question 2 aimed to answer, what are families' perceived experiences with accessing and utilizing information, social support, and resources?

#### *Information*

Parent's experiences with obtaining information resulted in two primary themes, (a) access to information and (b) type of information. These are discussed in more detail.

*Access to information.* Difficulty accessing information was a common theme that predominated parent's experiences, and it crossed over into the other two areas addressed in research question two, social support and resources. Hebbler et al.'s (2007)

National Early Intervention Longitudinal Study found that the most frequently mentioned supports needed by families were information. Bailey and Powel (2005) further supported this finding in their review of 11 studies utilizing the Family Needs Survey, which showed that families identified the need for information as being substantially higher than other domains assessed (e.g., family and social support or resources).

Families who participated in this study reported frustration with not being able to get information about services that were available, as well as how to get these services, especially in the beginning when they were just starting services for their child (Guralnick, 2001). A universal theme among participants was frustration with professionals and representatives of funding agencies, who were not always forthcoming about services that were available for their child (Freedman & Boyer, 2000). Additionally, parents felt that the system was constantly changing the rules and that they could not keep up with the proper “lingo” they needed to use in order to obtain services, as expressed by one participant’s comments: “I did not know anything . . . what to look for . . . what to ask for . . . and how to go about finding things” (P1).

Social support is consistently identified in the literature as being critical to families (Seligman & Darling, 2007; Whitaker, 2002) and a powerful influence in reducing perceptions of stress and increasing feelings of self-efficacy and empowerment (Spiker et al., 2005). Parents expressed strong agreement that their best source of information, especially about services available, was from other parents. Additional sources of information they found useful included resource guides, books related to their child’s disability, the internet, conferences, and experts, such as advocates.

We got all of our information from us (parents in the room). (P5)

Nobody told me anything except other moms. (P6)

*Type of information.* The information most desired by parents in this study included knowing about services available, about their child's disability, and about various treatment approaches. This finding is supported by Bailey and Powell (2005) who reported that families seek information to understand the nature of their child's needs and the types of supports and services available.

One of the biggest challenges for parents in this study was not a shortage of information, but the overwhelming volume of information available. They expressed a desire for information that was vetted, abbreviated, non-biased, and in a format that was easy for parents to understand. Similar to the findings in this study, Wesley et al.'s (1997) qualitative study using a focus group with 13 parents about their experiences with parenting a child with special needs, found that the parents in his study also had a strong need for information about services and family supports. Furthermore, they wanted information to be centralized and to be provided in a format that was easy to understand and use (Wesley et al., 1997).

There is so much information . . . almost too much. (P4)

We need a reader's digest version . . . I don't have time to read anything more than a magazine. (P3)

A complaint that all parents agreed with was too much emphasis in the media about cures promoted by celebrities whom they did not see as being credible even though they were widely known. Furthermore, they expressed feeling guilty if they did not try new approaches being promoted.

So many people say it's (treatment) is the magic pill or cure . . . is it proven? We are basing this on a celebrity (name omitted) . . . just a lot of misinformation that gets your hopes up . . . this worked for kid "A" and so it is going to work for kid "B." (P2)

Every T.V. thing you saw about it (autism) was a recovered child . . . if you do it right, you too will have that . . . I feel now they sometimes try to show kids on various parts of the spectrum . . . I am happy to see that. (P5)

### *Social Support*

Two types of social support emerged from participant's statements, (a) informal support, and (b) formal support. Informal support refers to the type of supports that parents develop on their own and primarily involves their spouse, family and friends. Formal supports are typically related to support accessed through their child's intervention/education programs, caseworkers and organized parent groups/organizations.

*Informal support.* Participants in this study believed that relationships with other parents of children with special needs were the most meaningful and important to their emotional well-being. They described the program's waiting area as a critical source of support to them, even describing it as a "lifeline." The parents identified the program lobby as a central place where they could meet and share resources and information with one another. This area also served as an important source of emotional support and a place where they could have a shared experience with other parents of children with special needs, which helped them to feel as if they are not alone.

Dunst et al.'s (1997) review of research related to the effects of social support on parents of children with special needs, demonstrated that social support offers several benefits for families. These benefits include better parental psychological well-being, positive attitudes toward their child, reduced stress, and more satisfactory marital

relationships. Other sources of support families found helpful were friends outside the special needs community and faith-based organizations. More recently, Armstrong et al. investigated the effects of social support on parental well-being, parenting skills, and child resiliency (2005). Their results support the experiences of the families in the study, that social support is identified consistently by parents as one of the most important supports desired, as well as contributing to parent coping and well-being. One of the participant's express it simply, "I do rely a lot on my friends and family" (P1).

*Formal supports.* Participants in the study perceived formal supports to be important, though not to the extent of informal supports. All families in the study participated in organized parent groups and found these to be very helpful in providing what one parent described as "logistical support" related to information about treatment approaches, the educational system, or accessing services. Marshak et al. (1999) also found that parent support groups provide families a place to connect with other families and both give and receive emotional, informational, and social support.

### *Resources*

Two themes emerged from parents' statements related to resources, (a) access to resources, and (b) type of resources available. These are discussed in more detail.

*Access to resources.* The majority of families in this study were capable of meeting their families' material needs and as such, they were focused more on experiences with obtaining supports and services for their child. They reported that getting services prior to their child's third birthday was relatively easy, but that as their child got older, services were more scarce and difficult to access, a finding also reported on by Connelly (2007). All families in the study were fearful that their child would lose

services as their child got older, especially due to the current fiscal climate in the State of California at the time of this writing.

Even with everything I have now, I am at the edge a lot of the time, so if I lost services, it would be really, really, hard. (P1)

In particular, parents expressed frustration with service coordinators who appeared to be more concerned about complying with policy rather than helping them access individualized services for their child. In contrast to the experiences of the parents in this study, Spiker et al. (2005) reported that professionals should be helpers that link families to community resources. Similarly, McWilliam (2005) found that families need more than services from case managers and other professionals, but that they also need access to providers who are responsive and sensitive to the needs of families.

*Type of resources.* Families reported that respite care was an essential resource, and referred to it as a “lifesaver.” However, the topic that was discussed most regarding resources was the difficulty families experienced in accessing supports and services that meet the unique and individualized needs of their child and family. The parents in this study expressed similar experiences as reported elsewhere in the literature, namely that the service system is inflexible and fails to meet their needs (Allen, 2007; Freedman & Boyer, 2000). One parent seemed to sum up the sentiment among families in saying, “support is not a one-size-fits-all” (P6).

### *Conclusions and Implications for Research Question 2*

At the core of early intervention/early education services for children, is recognition of the family as the context within which young children develop, and as such, the developmental, educational, or social-emotional needs of children cannot be

adequately addressed without also supporting the needs of the family (Bruder, 2000; Dunst et al., 2002; Guralnick, 2006). Current models of early intervention/early education call for the use of family-centered approaches to service delivery, which is based on the belief that the families' concerns, needs and priorities should direct intervention planning and services (Bailey, 1987; Bailey et al., 1998; Blue-Banning et al., 2004; Bruder, 2000; Dunst et al., 2002; Trute & Hiebert-Murphy, 2007). Services should also provide information, social supports, and resources so that families can effectively parent their child (Bernheimer & Weisner, 2007). Research and practice within the field of early intervention/early education show that families who receive needed and desired supports are more likely to establish adaptive and supportive family interaction patterns (Bromwich, 1997; Guralnick, 2005b; Turnbull et al., 2007).

Although the number of participants in this study was small ( $n = 6$ ), their experiences mirror the experiences of other families reported on in the literature for families of children with disabilities. The families in this study confirmed that all of these supports are essential in helping them meet the needs of their child, as well as to attain a sense of well-being. Interestingly, there was a substantial amount of overlap between each of the three areas of support addressed in research question 2. For example, families reported using networks of informal social support to both give and share information related to services that are available, as well as strategies for obtaining desired supports.

However, in spite of the abundant body of research and years of collective wisdom gained from practitioners and families about the importance of support (Barnett et al., 2003), there is a wide disconnect between what is known to be good practice and what is actually provided. A common theme shared among the study's participants, and

reported on in the literature, was the lack of services available as their child got older and the constantly changing rules around who gets what, a situation that created stress and anxiety for families (Allen, 2007; Connelly, 2007).

A key goal of family support is to enable and empower families by providing supports that help them develop competency and confidence in their ability to meet their children's developmental needs (Dunst et al., 2002). If this is indeed the goal, the experiences shared by the families in this study seem to show that they find the informal supports they create for themselves as being the most valuable and most accessible. In contrast, families appear to experience a great amount of frustration with a service delivery system they perceive as being inflexible and unsupportive.

A current trend in the field of early intervention/early childhood education services for children with special needs is the provision of supports in natural settings (e.g., home, park, day care, or preschool). Additionally, there is an explicit movement towards reduction and/or elimination of services in center-based settings such as the one where these families participated. Given the value that these families placed on having a place to meet other parents where they could get information, social support, and strategies for accessing resources, there are implications for how this shift in practice will affect families' coping and adaptation process. These parents reported that many of the individuals they met while bringing their child to the center have continued to be close friends they rely upon for support. The findings from this study would suggest that developing places where families can gather with other parents who share their experiences has value over and above the value of direct services provided to their child.



Qualitative data obtained from participants during the semi-structured interview during a focus group, resulted in findings that added to understanding parent's perceptions of their experiences with obtaining supports for their child and family. However, one weakness of focus groups is that some perspectives may be overstated (e.g., individuals who tend to talk more or have stronger opinions) and other viewpoints may be underrepresented (e.g., individuals who are quieter and less likely to speak up). Additionally, while qualitative data provides a rich description of what it means to experience a particular phenomenon, such as parenting a child with special needs, it does not conventionally lend itself to ranking the relative strength or agreement of various perspectives. Thus, the risk is always that results may unintentionally represent more extreme perspectives.

#### *Findings for Research Question 3 and 4*

Using the procedures described in Chapter 3 and reported on in Chapter 4, the researcher further evaluated families' experiences to answer Research Question 3 and Research Question 4. Research Question 3 aimed to answer, what are families' appraisals of control over their experiences with accessing and utilizing information, social support, and resources? Research Question 4 aimed to answer, what are families' perceptions of the type of experiences that enhance or inhibit their access and utilization of information, social support, and resources?

The goal of Research Question 3 was to gain a better understanding from families' perspectives of who or what they believed to have control over whether they get the supports they desired and needed for their child and family. Perception of control, as being either internal (within parent control) or external (control by others), is reported on

in the literature as an important factor that influences parental coping, adaptation, and a sense of empowerment (Behr et al., 1992; Taylor, 1983). Internal control has been shown to promote self-efficacy and confidence in parent's belief that their efforts and early intervention supports will make a difference in their child's developmental outcomes and family well-being (Bandura, 1989; Desjardin, 2005).

The purpose of Research Question 4 was to gain a better understanding of parent's perceptions about experiences they believed to be helpful or to be barriers to accessing and utilizing information, social support, and resources related to their child's disability and family needs. This questions draws upon principles associated with family-centered practices, which emphasize provision of services that originate from a family's expressed concerns, priorities, and resource needs (Dunst et al., 2002).

While research question 1 and 2 asked questions that were open-ended and semi-structured, questions asked during the second half of the focus group were organized around one of four SWOTs (strengths, weaknesses, opportunities, and threats). This information was used to develop the Family Support Survey (FSS) tool (a Likert-type questionnaire) developed for this study. The information gathered from research question three and four and analyzed using quantitative measures, enhanced the value of the qualitative data collected during the focus group interview and added greater reliability and validity to the results. The findings from the Family Focus Survey are summarized for each of the SWOTs and the implications and the specific action to take are discussed.

### *Strengths*

In this study, strengths (internal enhancer) refer to family strengths that support or help them access and use information, social support, and resources. (See Table 10 for

individual and group means ratings and standard deviations for the SWOT Strengths factors).

Group means ratings from the Family Support Survey (FSS) related to strengths factors showed a relatively high average degree of agreement among families that control is perceived as being in their hands. Factors such as knowing the right words used to get services and knowledge about their children's disability, and how to help him or her were perceived as being highly valuable enhancers, but as being only moderately within parents' control.

An interesting finding was that parents perceived maintaining friendships outside of the special needs community as being slightly more valuable than connecting with other parents who share their experience, and as being more within their control. Families' perceived being actively involved in advocating for services and building positive relationships with professionals as being helpful to their access and use of resources, however appraisals of control were slightly lower than other factors in this cluster.

Having a quantifiable measure of participant's individual responses helps to pinpoint with a greater degree of confidence those areas that are most important to families, and thus areas should be priorities of the program. In particular, the areas related to information should be directly addressed to ensure that families have greater control over obtaining the information they need about their child's disability and services available to help their child.

### *Weaknesses*

In this study, weaknesses (internal inhibitor) refer to family challenges that hinder their access and use of information, social support, and resources. (See Table 11 for individual and group means ratings and standard deviations for SWOT Weaknesses factors).

For the most part, families perceived a high degree of control over factors that presented challenges to their ability to access and use supports. Inhibiting factors, such as not getting support from their spouse or not reaching out to other parents were perceived as having a very low impact; while not having enough time to keep up with the research, or letting others decide about services for their child was perceived as presenting a slightly higher degree of challenge.

The participants in this study expressed a strong degree of control over getting support from their spouse, family, and friends. Furthermore, this factor was perceived as having a minimal hindering effect. Although families perceived control over accessing information, moderate group means ratings indicate that factors such as a lack of time to read or keep up with research or not being able to access information about their child's disability is a moderate hindrance.

In order to reduce the impact of this on families, it would be important to identify those specific barriers and challenges that impede families' access and use of research and the extent to which these factors affect their knowledge of how to help their child and the type of services that are available.

### *Opportunities*

In this study, opportunities (external enhancer) refer to factors outside of the family's control that support or help them access and use information, social support, and resources. (See Table 12 for individual and group means ratings and standard deviations for SWOT opportunities factors).

Families' perceptions of factors that are outside of their control and are helpful showed a high degree of variability among ratings, and this is particularly true for appraisals of control, which were perceived as being neither completely in the hands of others, nor in the hands of parents for most opportunities factors. Group means ratings indicated a relatively strong average degree of agreement of the value of factors perceived as enhancing their experiences with accessing supports. An interesting belief that emerged was a strong perception that "good luck" was a factor related to obtaining resources and services, and was perceived as being almost completely in the hands of others.

Findings from families' responses showed that the quality of information and the extent to which it was easy to read and parent friendly influenced a strong enhancer for helping them access information, but that this was moderately in the hands of others. Support groups, places to meet other parents and share experiences, and good schools and supportive teachers were areas that emerged as factors that helped them with accessing and using information, social support, and resources. An encouraging finding was the degree to which families' perceived control as shared between themselves and outside factors and the degree to which these factors were helpful.

Similar to the discussion of the strengths and weaknesses SWOTs, several areas can be explored for further action. Specifically, families' responses indicated a desire for information that is understandable, filtered, and non-biased. Additionally, access to information, such as resource guides was identified as being helpful. Families identified having access to good schools and supportive teachers as being highly valued, and moderately outside of their control. Providing access to information that is both accessible and usable to families is something that is directly within control of the program and should be addressed to increase families' sense of control over this. Additionally, given that families view the waiting room area as an important place they meet and support other parents, maintaining access to a comfortable and inviting area is a small, but apparently important action that can make a big difference for families.

### *Threats*

In this study, threats (external inhibitor) refer to factors outside of the family's control that hinders access and use of information, social support, and resources. (See Table 13 individual and group means ratings and standard deviations for SWOT Threats factors).

In contrast to opportunities, several items perceived as threats to access and use of supports were rated as being almost completely in the hands of others and as being moderately to highly inhibiting. Families perceived the service delivery system and its lack of flexibility as being the most serious threat to their family. Along these same lines, they perceived their case managers as withholding information about services that might be available for their child. A thread brought up repeatedly was the fear families felt about losing services and feeling as if they had no control over this.

The strongest threat to families was the inadequacy of information, which they perceived as being biased, overwhelming, and too clinical. The recurrent theme related to information indicates that this is the most influential factor that either helps or hinders their experiences with parenting their child, and as such should be prioritized as a primary target for addressing.

#### *Conclusions and Implications for Research Questions 3 and 4*

When all four of the SWOTs are considered together, it is more likely that the correct action can be taken. For example, families indicated that having access to information was important to them. However, in spite of the high value of information, it was an area identified with some consistency as being moderately under the control of others. Furthermore, several areas that hindered their access to information showed up, such not being available in a format they could easily read and understand. Additionally, information was perceived as being overwhelming because of its volume and misinformation. Families stated that they wanted information that they could trust and presented in an abbreviated format they could easily understand. Given the high value information to families, this should be a top priority for determining the appropriate action to take to ensure that families have access and use of information, social support, and resources that are desired.

Because the purpose of this study was to obtain a broad range of perspectives about the meaning of families experiences with accessing and using information, social support, and resources, the researcher used additional quantitative measures that could more objectively explore the extent to which parents agreed with the statements derived from the focus group discussions. The Family Support Survey tool, developed from

information obtained from parents during the open-ended focus group interview, enabled all participants, including those who may have been less vocal, the opportunity to validate the degree to which they agree with the statements that emerged from the interview discussion. The value of using participant's own statements as the items to be rated, is an increased level of confidence that the results accurately reflect the meanings of families' lived experiences.

The Family Support Survey was analyzed to identify group means ratings and variability of SWOT factors related to participants appraisals of control as being either in their hands (internal) or in the hands of others (external), as well as their perceptions of the extent to which these factors either enhance or hinder their access to information, social support, and resources. While this is valuable information, it provides limited utility in helping the investigated program prioritize areas that are candidates for direct action. The researcher conducted two additional steps for data analysis using the results obtained from the Family Support Survey (FSS). The purpose of these steps was to explore more closely how participant's responses grouped together and to better understand factors that families identified as strengths (internally controlled enhancers that should be leveraged), weaknesses (internally controlled inhibitors that should be confronted), opportunities (externally controlled enhancers that should be exploited), and threats (externally controlled inhibitors that should be mitigated).

#### *Findings for Research Question 5*

Research Question 5 aimed to answer, to what extent, if at all, is there agreement within families' ratings of the value of enhancing or inhibiting experiences, and their appraisals of control over these experiences. In order to obtain this information, the



researcher conducted a hierarchical cluster analysis using the Ward's Method option available in SPSS software to identify how the group means ratings SWOT factors clustered together, and plotted the bivariate data obtained from participants' group means ratings on the IE<sup>2</sup> Matrix Grid developed by Leigh (2000, 2005a, 2005b, 2009). The findings from the cluster analysis and the meanings derived from the data are discussed for each of the SWOT factors in the order of strengths, weaknesses, opportunities, and threats. Each of these will be discussed within the context of the extent to which participants perceived these factors as enhancing or inhibiting their access to information, social support, and resources, and the extent to which they attributed control as being internal (in their own hands) or external (in the hands of others).

#### *Cluster Analysis and IE<sup>2</sup> Matrix*

In order to more closely examine the extent to which there was a relationship or interaction effect among participants' ratings on the Family Support Survey, the researcher conducted a hierarchical cluster analysis using the Ward's Method option available in SPSS software. Although, a cluster analysis approach identifies how individual variables cluster (e.g., SWOT factors from the survey) or group together based on similarities and differences, it does not explain the meaning of the group membership. Thus an additional analysis approach referred to as the IE<sup>2</sup> Matrix Grid was used in this study to plot bivariate data obtained from the group means ratings to further explore the meaningfulness of each cluster as plotted on the IE<sup>2</sup> Grid (Leigh, 2000, 2005a, 2005b, 2009). The findings from the hierarchical cluster analysis and the IE<sup>2</sup> Matrix approach were used to answer research question 5 and are discussed.

### *Strengths*

The hierarchical cluster analysis for SWOT Strengths factors resulted in four clusters that were plotted on the IE<sup>2</sup> Grid in the top right quadrant of the matrix. The positioning of clusters in this quadrant represent factors which parents perceive as being enhancers of their ability to access and use information, social support, and resources as well as the degree of agreement related to parent's attribution of internal control.

According to Leigh, items plotted in top right corner of the strengths quadrant indicates a perception of high internal control and a perception that factors which cluster in this location are strong enhancers of something desired (e.g., information, social support, and resources) according to Leigh (2000, 2005a, 2005b, 2009).

Parents perceived factors related to access and use of information as being strong enhancers, but also perceived a lower degree of control over these factors. Without looking at numerical data, this is visually observable by the position of the three information strengths factors at the highest data point on the IE<sup>2</sup> Matrix Grid (see Figure 8), but dispersed in the direction toward the y-axis, indicating lower appraisals of internal control. Parents' experiences with social supports and access to resources reflected perceptions of high internal control as well as being strong enhancers of their experiences.

Factors related to parents' perceptions of control illustrate the value triangulating the data from multiple perspectives. For example, the group means ratings for one factor (building positive relationships with professionals) was not as robust as the other two resource factors, which is reflected in its position on the IE<sup>2</sup> Matrix Grid (moderate degree of control and strong enhancer). However, upon closer examination of individual

responses in the data, there is a lower outlier rating by one participant for control and helpfulness, which reduced the overall group means rating. This is identified as a “runt” in a separate cluster and is positioned at a greater distance from the other two resource factors on the IE<sup>2</sup> Matrix Grid.

Factors identified as being strong enhancers and high internal control represent areas of family strengths can be used as the foundation to improve areas that are perceived as being more in the hands of others and as hindering their experiences with accessing desired supports and will be discussed in greater detail later in this section.

### *Weaknesses*

The hierarchical cluster analysis for Weaknesses SWOT factors resulted in four clusters that were plotted on the IE<sup>2</sup> Grid in the bottom right quadrant of the matrix. The positioning of clusters in this quadrant represent factors which parents perceive as being inhibitors of their ability to access and use information, social support, and resources as well as the degree of agreement related to parent’s attribution of internal control.

According to Leigh, items plotted in bottom right corner of the weaknesses quadrant indicates a perception of high internal control and a perception that factors which cluster in this location are strong inhibitors of something desired, such as information, social support, and resources (Leigh, 2000, 2005a, 2005b, 2009).

The four clusters identified by the hierarchical cluster analysis as weakness factors are more widely dispersed on the IE<sup>2</sup> Grid than the clusters for the strengths factors. In general, parents attributed control as being more in their own hands than in the hands of others, and a moderate to low effect on hindering their access to information, social support, and resources. When looking at the IE<sup>2</sup> Grid, it is easy to observe that

social support factors have a high degree of internal control and a minimal inhibiting effect (placement midway down and to the far right on the grid). One of the clusters, located in the bottom right corner of the IE<sup>2</sup> Grid, pertains to parents' attribution of control (high internal) and hindrance (moderately inhibiting) to access and use of information and resources.

Parents' ratings of two factors (i.e. lack of time to keep up with research and not trusting the school system) located at the bottom of the IE<sup>2</sup> Grid were identified as having the strongest inhibiting effect, and moderate appraisals of internal control. The findings from the cluster analysis and IE<sup>2</sup> Grid substantiate the findings from analysis of the survey data, in which parents expressed difficulty with having enough time to read or keep up with research related to their child's disability. Factors perceived by parents as having a high degree of internal control, and a high degree of influence over hindering access to supports should be confronted so that barriers and challenges can be reduced or eliminated.

### *Opportunities*

The hierarchical cluster analysis for Opportunities SWOT factors resulted in six clusters that were plotted on the IE<sup>2</sup> Grid in the top left quadrant of the matrix. The positioning of the cluster indicates in this quadrant represent factors which parents perceive as being inhibitors of their ability to access and use information, social support, and resources as well as the degree of agreement related to parent's attribution of external control. According to Leigh, items plotted in top left corner of the opportunities quadrant indicates a perception of high external control and a perception that factors which cluster

in this location are strong enhancers of something desired, such as information, social support, and resources (Leigh, 2000, 2005a, 2005b, 2009).

There were six clusters identified by the hierarchical cluster analysis as being outside of their control and as enhancing their access to information, social support, and resources. Clusters grouped in the opportunities quadrant of the IE<sup>2</sup> Matrix show a pattern of wide dispersion of data points across the *x*-axis, indicating a considerable variability of responses related to appraisals of external control; conversely, clusters also group within a relatively high and narrow range of responses related to factors perceived as enhancing access to supports. The location of opportunities' clusters (top and center of the quadrant) indicate that parents perceived these factors as being minimally under the control of outside factors, and as being strong enhancers of access to supports. The only factor that participants rated with a strong degree of external control related to perceptions of "good luck" as helping them obtain supports.

In contrast, most opportunities factors were rated by parents as being strong enhancers, as being minimally low to moderately in the hands of others. Given the low degree of external control, and the strong degree of helpfulness, the factors identified in this quadrant, such as having access to quality information, support and understanding from spouse, family, and friends, and places to meet other parents suggest several opportunities for further exploration of factors that should be exploited to enhance parents' sense of control.

In particular, factors that emerged with a low degree of external control and a strong enhancer, such increasing parent access and use of resource guides, and

opportunities to meet other parents through both formal and informal parent support groups.

### *Threats*

The hierarchical cluster analysis for Threats SWOT factors resulted in four clusters that were plotted on the IE<sup>2</sup> Grid in the bottom left corner of the matrix.

According to Leigh (2000, 2005a, 2005b, 2009), items plotted in the bottom left corner of the threats quadrant indicates a perception of high internal control over factors and a perception of being strong enhancers of something desired (e.g., information, social support, and resources).

The four SWOT factors related to threats are widely dispersed both in terms of appraisals of external control as well as perceptions of factors parent's view as being inhibitors to the access and use of supports. The pattern of dispersion reflects the numerical data associated with these factors and provides a visual way to ascertain where each cluster "hangs" in the quadrant. The cluster located at the far left bottom of the matrix is noteworthy because of its high degree of agreement among parents that these factors were largely in the hands of others, and perceived as being moderately or strongly inhibiting. These factors include perceptions related to the inhibiting effect of inadequate information, misconceptions, lack of tolerance from others, and a service delivery system that is inflexible, and insensitive to their child's unique needs. In contrast, the cluster consisting of factors related to perceptions of a lack of understanding from others about how their experiences affect them, having responsibilities other than children with special needs, and program facilities that are not comfortable, indicate reflected appraisals of external control as being low to moderate, and the inhibiting effect of these factors as

being minimally inhibiting. The threats factors identified as having the strongest appraisals of external control and hindering effect should be examined to determine priorities and action to take to mitigate negative impacts on families' experiences.

There are numerous areas identified in the SWOT, cluster analysis, and IE<sup>2</sup> Matrix analysis related to factors families perceive as being strengths or assets, barriers or challenges, opportunities or threats to families' access to information, social support, and resources. These areas are potential targets for direct action and will be discussed in the section Implications for Family Support.

#### *Conclusions and Implications for Research Question 5*

The use of a hierarchical cluster analysis in combination with the IE<sup>2</sup> Matrix approach enhanced understanding of the meaning of families lived experiences with accessing and using family supports related to their participation in services for their special needs child between 3 and 8 years of age. Within the context of a SWOT approach, experiences perceived as being under control of participants and helpful are strengths (internal enhancer), those under their control but hindering are weaknesses (internal inhibitors), those outside of their control and helpful are opportunities (external enhancers), and those outside of their control and hindering are threats (external inhibitors). Although a cluster analysis method does not make a distinction between dependent and independent variables (in this case the SWOT factors), it does explore all factors as having a meaningful relationship and groups these factors into smaller sets of clusters. For the purposes of this study, factors were examined for interaction effects within each SWOT quadrant of strengths, weaknesses, opportunities, and threats.

By exploring the data in this manner, the researcher was able to obtain a better understanding of those SWOT factors that have the strongest agreement or similarity. Furthermore, when analyzed using both qualitative and quantitative measures, data can guide decision making about which factors should be priorities for action and those that should be monitored for change.

*Findings About the Utility of the IE<sup>2</sup> SWOT Matrix Analysis*

The IE<sup>2</sup> Matrix Analysis provides useful format for organization and analysis of data collected during the focus group interview. Using an iterative process that reduces data into smaller, units that are more meaningful, data can be analyzed using quantitative measurements and exploration of qualitative data to measure the extent to which parents agree with the responses given during the focus group (Tashakkori & Teddlie, 1998). Data analysis using the IE<sup>2</sup> SWOT Matrix Grid provides visual representation of data that illustrates both individual responses as well as how these responses “hang” together in clusters (Leigh, 2000, 2005a, 2005b, 2009).

The utility of using a visual depiction of data is that numerical and narrative data analysis is easier for individuals to grasp the relationship between factors. Additionally, according to Leigh (2000, 2005a, 2005b, 2009) it can facilitate analysis and interpretation of data in making informed decisions about elements that should be:

- Leveraged (for strengths under substantial internal control that also act as strong enhancers of performance)
- Monitored (for opportunities and threats under substantial external control but minimally enhancing or inhibiting performance)



- Confronted (for weaknesses under substantial internal control that also act as strong inhibitors of performance)
- Mitigated (for threats that are under minimal external control that substantially inhibit performance)
- Exploited (for opportunities that are under minimal external control that substantially enhance performance)

An important aspect to keep in mind in relation to the possible actions listed above is that the influence of a factor, as well as the most appropriate action to take, is dependent on the perspective of the parties involved. For example, a factor identified by families as being externally controlled and an enhancer (e.g., the quality and format of information), might be considered a weakness when viewed from the perspective of the program conducting the SWOT analysis (e.g., something the program has control over but is not doing). Under such circumstances it would be advisable for a program to conduct further probes to identify what is desired (e.g., factors identified as opportunities by parents) or what should be mitigated (e.g., factors identified as threats by parents), thus changing a program weakness into a potential opportunity that can enhance rather than a potential threat that inhibit parent's experiences. The ultimate outcome being that the program has an opportunity to turn a weakness into a strength not only for the program, but for the family as well. The value of such an approach is that programs and families can take a more collaborative approach to program evaluation where each can share in not only identifying potential areas for improvement and change, but can also share in the solutions for how to best address areas perceived as being problematic.

Application of a SWOT approach using the IE<sup>2</sup> Matrix Grid, facilitates knowledge of factors that families perceive as either enhancing or hindering their experiences, and the extent to which they attribute control as being in their own hands or in the hands of others. The use of the IE<sup>2</sup> Matrix Grid Analysis added richness and depth to the qualitative data in order to gain a better understanding of families' lived experiences and the meanings they make of these experiences. Furthermore, the use of a SWOT approach for creating the Family Support Survey provided added depth to their perceptions of factors that enhance or inhibit their access and utilization of information, social support, and resources, and the extent to which families perceive control over these factors. The implications of this study for family support are discussed in the following section.

#### *Findings About Implications for Family Support*

The purpose of this study was to gain a better understanding of families' lived experiences with parenting a child with special needs between the ages of 3 and 8 years of age. As already discussed, many, if not most, families of children with special needs experience considerable stress that triggers a substantial need for information, social support, and resources related to caring for their child. The purposes of family support, is to enhance parent's capacity to provide optimal family interaction patterns as identified in the literature related to cognitive theory of adaptation and coping; family systems, socio-ecological systems, developmental systems perspectives, and normative child development.

#### *Meanings of Lived Experiences*

All families strive to make meaning of their experiences, and this is just as true for families of children with special needs. A valuable finding in this study is the

importance families placed on their friendships with other parents of children with special needs and the instrumental role of early intervention/education service delivery programs in facilitating opportunities for families to connect with other families. For the families in this study, participation in services where they brought their child to a center was a critical factor in obtaining social support, which in turn enhanced their access to and use of information and resources. Social support from their spouse, family and friends both within and outside of the special needs community were essential in helping participants gain a sense of confidence in their abilities to meet their child's needs. However, as important as this was to families, they also identified the importance of maintaining connections with friends outside of the special needs community as a means to maintain a sense of normalcy.

Similar to studies conducted by others, the study participants' worries about their children persisted, as they got older. Many expressed concerns about their own well-being, such as feeling burned out from the day-to-day responsibilities and lack of relief. Additionally, many expressed fears that their child and family would lose much needed services and family supports; a factor heightened by the State budget crisis that was unfolding at the time of the focus group interview.

An encouraging finding was that the families in this study had all reached a level of coping and adaptation in which they were able to see a personal benefit to their situation. Most notably, participants felt that having a child with special needs enabled them to make friends with individuals they otherwise would never have known, and that they were a better person because of their experiences.

The findings obtained from families lived experiences provides new information that strengthens the body of research pertaining to the importance of family support as key factor related to successful coping and adaptation of families experiencing events that may trigger a potential crisis. The findings also illustrate the importance of using multiple data collection and analysis methods for gaining an in-depth understanding of how families make meaning of their experiences, as well as the factors that either enhance or inhibit their ability to achieve successful coping and adaptation.

#### *Access and Utilization of Information*

Information about services and their child's disability was one of the most important factors that contributed to participants' sense of feeling competent and empowered. Many of the barriers identified by families pertained to not having access to information in a format that was credible, unbiased, abbreviated, and parent friendly. In particular, families perceived that professionals and funders of services were not always knowledgeable about resources and services available for their child. In some instances, families expressed frustration that these individuals were not as forthcoming with this information as they could have been. The two most frequently mentioned types of information desired pertained to services for their child, and information about their child's disability and how to help them.

In the context of this study, parents perceived their experiences with accessing and using information as being strong enhancers, but also expressed comparatively lower appraisals of control. Parents' responses indicated a strong need for the proper words to use for getting services for their child as well as knowing about their child's specific needs related to their disability and their child's unique developmental profile.

These findings are consistent with prior research conducted with parents using focus groups, which showed that families have a continued need for information and a desire for understanding how to navigate a complex interrelated system of service programs and agencies (Summers et al., 1990). Additionally, six families in this study echoed experiences reported on from other families concerning their desire to have access to research in a format they could understand and use. (Wesley et al., 1997).

These findings also suggest the importance of explicitly creating program practices which systematically ensure that parents have access to desired information, especially for families with newly diagnosed children or who are transitioning from one system of direct services to another (e.g., from infant/toddler to preschool to kindergarten). Optimally, this information would be available in a format that is readily accessible to parents, thus increasing their own sense of empowerment in being able to take steps towards helping their child, thus increasing their sense of confidence in their competency as a parent. This need for information about where and how to access services and resources is even more critical now due to the increasing scarcity of desired and needed supports. This places greater responsibility on service providers and other professionals to ensure that parents have access to relevant information in a format that is “parent friendly.”

The program could take direct action to leverage parents’ desire for information by creating opportunities for parents to obtain information that is readily available and accessible. Information could be provided in multiple formats, such as through resource guides, parent education and training workshops, access to the internet, vetted compilations of current research and through one-to-one supports from their direct

service provider. In doing so, the program can play an instrumental role in strengthening parent's knowledge and understanding, thus shifting control of information from outside others, to themselves.

#### *Access and Utilization of Social Support*

Participants' responses showed a high degree of agreement that maintaining friendships outside of the special needs community was highly valuable to them, followed by support from their spouse and other parents of children with special needs.

Participants shared that they took the initiative to learn about their child's disability and services by talking to other parents, reading research, and attending conferences or parent support groups. Additionally, participants felt that having positive supportive relationships with other parents, with and without children with special needs, was something they could control by maintaining relationships they had prior to having their child, or by actively reaching out to parents they met at locations where their child received therapeutic services. Without exception, participants felt that these relationships created an emotional lifeline for them. Most importantly, families shared that their relationship with their spouse was essential for their sense of well-being and ability to cope with and manage their child's disability related needs.

By far, the greatest perceived threats to families were the reactions from others or the unsolicited advice they encountered when they took their child into the community, a finding consistent with prior research related to the effects of children's behavior on their stress and well-being (Baker et al., 2002). This was a contributing factor to feelings of isolation, especially when their children were younger and had more frequent outbursts of challenging behaviors. However, participants reported that as they grew more competent

in their ability to manage their child in public and felt more empowered, the negative impact of this lessened.

Knowing the importance of social supports, a program would want to examine more closely the types of activities it offers that provides opportunities for parents to support each other, but also the extent to which it supports families in maintaining their connections with friends in the community. It would be important for programs to create maximum opportunities for both informal social supports such as parent-to-parent groups, and formal supports, such as scheduled parent events where they can come together, such as to hear experts or other guest speakers discuss a topic of interest.

#### *Access and Utilization of Resources*

Families' responses indicated they perceived being actively involved in advocating and obtaining services, as well as building positive relationships with professionals as strong enhancers that influence their access and use of resources for their child. Parents concurred that their own advocacy efforts and involvement helped them to get services for their child, as illustrated by the comment, "It is up to you, how involved you want to be in getting services for your child."

In response to probing questions about experiences that are perceived as being outside participants' control and helpful, several themes emerged. Families felt that others, such as experts, professionals, other parents, or the internet, generally controlled the quality and accessibility of information they sought. Formal and informal support groups were perceived as outside experiences that families relied upon for information and support about resources and services available. An area that was mentioned frequently by parents was the availability of a parent resource room as a place they could

access information and meet with other parents. Interestingly, parents felt that “good luck” played a significant role in determining whether they obtain resources or services they desire for their child and family.

An unanticipated finding from this study was the empowering effect of the focus group itself on the parents who participated. These families expressed feeling supported and validated by the process of being able to share their story with others who have a similar shared experience. This might suggest that using focus groups can not only obtain important information useful for guiding decision making and action, but that the process has an inherent value itself.

#### Limitations

The results of this study are limited to a single program and are not intended to be generalized beyond the small number of participants in study. Furthermore, this study did not use an experimental design that attempted to control for variables to which group differences can be attributed. The research methods selected for this study used qualitative/descriptive methods to analyze data obtained from comments made by family members who were recruited purposively to examine their personal lived experiences with accessing and utilizing information, social support, and resources related to their child with special needs. As such, the findings of this study provide a richer degree of depth not breadth (Wesley et al., 1997).

Furthermore, the researcher is employed by the investigated program, which has the added limitation of introducing researcher-bias as well as the potential for affecting the extent to which participants would be honest and forthcoming in their responses. Additionally, the researcher is a parent of an adult with special needs, which introduces a



degree of bias into interpretation of results. However, as a parent of an individual with special needs, there is also the added benefit that families may have felt a shared experience and therefore been more comfortable and open with their experiences.

Another area that may have influenced this study's findings relate to the current place where families were on their journey as parents of a special needs child. As discussed in the literature review, periods of transition, in particular when children transition from one service system to another, can trigger anxiety and renewed feelings of loss and uncertainty (Connelly, 2007). The parents in this study had older children who were nearing transition from their current services at the program they had been with for several years, and no replacement services were offered or available, thus leaving families feeling abandoned and on their own. This raises the possibility that families' perceptions reflected a heightened state of anxiety about what comes next or what services would be available for their children, as they got older. This concern of parents is reflected by their responses on the Family Support Survey for Threats SWOT factors, where items perceived as being strongly inhibiting and with a high degree of external control related to the service delivery system (e.g., lack of information from case managers, inflexible services, changing rules and terms, services based on policy rather than need, etc.).

Additional limitations relate to the challenge of averaging participants' ratings of locus of control, as this is highly subjective from one parent to another. However, the use of the IE2 SWOT Matrix protocol and plotting group means ratings on the IE<sup>2</sup> Grid can facilitate parents' identification of those areas over which they have the most control and those areas where they have the least amount of control. This can in turn be used to make

decisions about what should be prioritized for the appropriate action (e.g., accessible and parent friendly information, support from other parents, or flexible services).

## Contributions

### *Early Intervention/Education Field*

The findings from this study support the current literature related to families' perspectives that informational, social, resource support is not as readily available as desired or needed, and this is especially true regarding the need for information about their child's disability. In particular, the families who participated in this study expressed a strong need for information about services available and how to access these services, as well as credible, non-biased, vetted, and parent friendly information about their child's disability and how to help their child.

Additionally, the families who participated in this study supported findings from other researchers that the need for support is not limited to any one particular period, such as early diagnosis or during transitions, but rather that the need for support is ongoing. However, there are substantial shifts in how services are delivered to families once their child turns three. The resources and supports that were readily available while their child was under three are dramatically reduced, and continue to decrease incrementally as their child gets older. This was an area that study participants perceived as being one of the more substantial threats to their ability to meet their child's needs.

An important finding of this study was the extent to which these parents used social support as a means to gain information they deemed to be valuable and as a tool for learning how to navigate the system in order to access resources and services for their child. This would suggest, that opportunities for parents to come together not only

enhance their perceptions of feeling socially and emotionally supported by one another, but is also a valuable tool for networking that helps them become better informed about services and resources available for helping their child. For these families, support from other parents of children with special needs was instrumental in helping them to cope, but also contributed to enhancing their sense of confidence and competency in parenting their child, ultimately leading to feelings of empowerment and adaption. One parent's comment seemed to sum this up when stating, "I can do this" (P1).

Finally, the mixed methods and phenomenological research approach used in this study contributed to a much richer understanding of these families lived experiences and the meanings they make of these experiences, than could have been attained through the use of either of these alone. This researcher found that most studies involving families of children with special needs are quantitative and survey based, and to a lesser extent, many are qualitative. However, few studies have used a mixed methods approach that combines both qualitative and quantitative measures.

To the best of this researchers knowledge, there have been no studies to date that have applied the SWOT-like IE<sup>2</sup> Matrix analysis to studies related to family experiences with parenting a child with special needs. In particular, there appears to be no prior research that specifically seeks to better understand families' perceptions of the type of experiences that either enhance or hinder their access to information, social support and resources, and the extent to which they perceive control over these experiences.

The use of families' own statements obtained during the focus group interview as the content for the Family Support Survey tool provided an opportunity for parents who might have been less vocal within the group, an opportunity to validate the extent to

which they agreed with statements made by other parents. This procedure serves as a built-in validation and reliability check, as parents are verifying their own statements.

Furthermore, this method increases opportunities for parents to be active partners in designing and implementing program evaluation, so that what is evaluated are those areas perceived as being meaningful and relevant to families. Thus, families not only participate in program evaluation, but when evaluation is used to enhance program performance, they also become authentic collaborators in program design and development. In this way, parents and professionals can work together to create the type of services that are desired by families, who are the ultimate users of these services (Wesley et al., 1997).

A modification to consider in future applications of this approach would be to give each parent their own IE2 Matrix and sticky dots that they could place then the researcher could enter the bivariate data from each participant's matrix into a spreadsheet to obtain an average score for all responses. Another configuration might be to create a web-based program where participants could drag-and-drop each factor into the matrix as they desire and then submit to the researcher, who could then analyzed individual and group means ratings.

### *Investigated Program*

The study findings yielded valuable information about services and supports desired and needed by the parents who participated in this study and the factors that either helped or hindered their attainment of information, social support, and resources. The analysis of the focus group qualitative data through the additional use of quantitative measures, the cluster analysis, and the IE<sup>2</sup> Matrix Analysis provided a rich and in-depth

understanding of families' experiences with obtaining supports. Specifically, the results helped to show the type of supports families' value most, where they get support from, and how they get support. Just as important is a greater understanding of the factors families perceived as either enhancing or inhibiting their experiences, as well the extent to which families attribute control over these factors to themselves (internal control) or to outside others (e.g., program, funding systems, or "good luck").

The value of this process is that parents can be meaningful participants in the long-range strategic planning of the program practices to ensure that these meet the desired needs of the families it serves, including the nature of services desired, the intensity of services needed, and the location of where services are most meaningful and relevant to the family. Furthermore, the findings are useful in helping the program make important decisions about what services and activities should be leveraged (strengths), confronted (weaknesses), mitigated (threats), exploited (opportunities), or monitored.

By approaching program evaluation in this manner, there can be greater confidence that valued services will be maintained or enhanced, and those that are not will be reduced or eliminated, thus making changes based on factors that families perceive as important, not just those that the program believes to be so (Wesley et al., 1997).

### *Family Support*

In spite of the limitations discussed earlier, the study offers important insights about how families perceive their experiences as parents of a child with special needs and confirms much of the research previously conducted on family experiences. Most germane to the purpose of this study, is the use of families' statements from the focus

group interview as the content for the Family Support Survey. This offered a means to quantify their statements, thus providing a greater depth of understanding of the meanings they make of these experiences. While the information for the qualitative data could have been obtained through individual interviews with participants, the value of the focus group process itself was evident in how parents' responses triggered one another's memories of experiences, thus enriching the meaningfulness of each of their statements. As one parent put it when asked if there was anything else they could think of that they wanted to add:

It was very helpful to be able to see everybody's viewpoints, and things I have not thought about in a long time. . . . I am not alone. . . . We know it, but to hear 5 other strong females say that, it validates me as a person. . . . I have these feelings, I am not alone. We all feel this; it is very empowering. (P1)

#### Recommendations

This study represents six parents from a single program and the findings are not intended to be generalized outside of this specific setting and population. It is recommended that additional research be expanded to a wider range of families from multiple programs, as well as with different ages of children who receive services from a variety of different funding sources to examine the effects of these variables on parents' experiences.

The Family Support Survey tool was developed for use in this study and therefore has not been validated for reliability; this is something that should be considered in future research using this method. Additionally, in order to examine in more depth the interactions between the SWOTs, an analysis of variance (ANOVA) should be considered when using larger samples and populations. Furthermore, the Ward's method

hierarchical cluster analysis approach utilized in this study is appropriate for small sample sizes (< 250); however, when larger samples are used, it would be appropriate to use other cluster approaches (e.g., K-Means clustering).

Data can also be disaggregated by information, social support, and resources within each SWOT, thus comparing the relative ratings of information-to-information across each SWOT and so on for each factor being analyzed. Finally, while data from the Family Support Survey (a Likert-type scale) was treated as if it were interval data, the actual nature of the data is ordinal. That is, participants rated survey statements using numerical values (continuous scale); however, the implicit meaning of the rating pertained to perceptions of strength of agreement (word scale) according to McCall (2001).

This study did not examine participants' perceptions of the process, which is important to know if the method is to be expanded outside of this study. It is also suggested that further studies investigate service providers to examine how they perceive they facilitation of family access and use of information, social supports, and resources. Comparison studies of professionals from different levels of service delivery such as administrators, direct care providers, service coordinators/case managers, or teachers are also recommended.

As is true for education in general, there is a trend the field of early intervention/education toward greater accountability and use of evidenced based practices. In order to achieve these requirements, it is important to capture both quantitative means to measure effectiveness, but also to capture the meanings that families make of their experiences, so as not to lose sight of the reason we provide these

services in the first place, namely to support families caring for children with special needs.

In spite of the emphasis on evidence-based practice and accountability, service providers are slow to adopt the regular practice of implementing high quality and meaningful evaluation of program practices. There are many reasons cited for this including lack of experience, knowledge, and time. However, failure to conduct in-depth evaluations of families' perspectives prevents providers and professionals of having an objective means to determine the extent to which their services are perceived by families as enhancing or hindering their experiences with parenting a child with special needs. The method used in this study is an approach that might have utility as an approach that provides in-depth understanding of families' experiences and a quantifiable means to guide program decision making and action. Further studies could explore the utility of this approach on a larger scale and the extent to which it is useful and practical for programs with minimal evaluation experience.

#### Concluding Comments

In the time between beginning this study and collecting and analyzing data obtained from families' responses during the focus group interview, there have been substantial changes in the service delivery system in the State of California, where this research occurred. Many of the types of services identified by families in this study as being helpful, have been discontinued or severely limited, and would not be available to their children had they been diagnosed under the new criteria. As of the writing of this study, nearly 50% of children under the age of three with early risk factors, or mild to moderate delays, who would otherwise have qualified for early intervention services, are



no longer eligible. Additionally, due to cost saving measures mandated by state legislative changes, entire categories of services (e.g., recreational programs, camps, respite care) for children over three have been eliminated or severely limited, resulting in service decisions being driven by these new policies rather than the individual needs of the child and family.

This is an unfortunate turn of events for these young children and their families. As shown by the stories of the families in this study, the services they have received for their children have been instrumental in helping them successfully cope with and adapt to their child's special needs. Participants expressed experiences with funding agencies where personnel informed families that they are expected to learn therapeutic strategies from professionals and should be able to independently implement these without professional therapeutic supports. However, as stated one by of the study's participants:

This connects with our fears about dropping services. . . . I am at the edge a lot of the time, so if I lost that (services) it would be really, really hard. . . . It is not just getting through the next year or years after, it is really about that long-term and what happens when he is not going to school and he is 22 years old, and if he still needs a tremendous amount of support. . . . As you see the changes going on, there is another generation of services. . . . What others were able to accomplish years ago is not going to hold now because there are people out there ready to take away (services) . . . they are chipping away at it, and this whole notion that we need an exit plan, and don't keep coming up with new things to work on . . . it is very frustrating. (P5)

Parenting a child with special needs is one of the most challenging, but also one of the most rewarding tasks a parent will ever do. As can be seen from the families in this study, support from their spouse, family, friends, and professionals are a critical factor that can either enhance or hinder their experiences.

Within the context of an ecological systems perspective of human development, children require responsive, nurturing, and growth enhancing interactions from their primary caregivers and their environment, who in turn need support from professionals with expertise related to their children's needs, and a larger system of community services committed to the well-being of children and families. As the sphere of support moves outward from the family, the support available is determined more by public policy, rather than what is known to be developmentally in the best interests of children and their family. Over the past 40 years, United States public policy has been committed to a strong system of supports for children with special needs and their families.

In 1973, California enacted the Lanterman Act, an entitlement program that established a commitment to persons with disabilities and their families, which states that individuals should be able to live at home and in the community with the supports they need to sustain independence and a satisfying quality of life. However, this promise is severely threatened due to persistent cuts that have substantially reduced supports available for families. Furthermore, there are more children than ever being diagnosed with Autism Spectrum Disorder (1 in 100), according to the Centers for Disease Control and Prevention (2008). Autism is a disorder that requires comprehensive and intense services and places higher levels of chronic stress for families of children with autism than parents of children with other disabilities. As such, support is essential, and a lack of these supports has the potential threat to diminish the capacity of families to provide responsive, nurturing caregiving for their children. However, in the current atmosphere of economic scarcity, this is trending downwards, with unknown consequences.

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## APPENDIX A

### Research Questions

Research Question	Data Source	Data Analysis
RQ1- What are the lived experiences of families whose children with special needs participate in early intervention or special education services, and what meanings do they make of these experiences?	<i>Qualitative Data</i> Focus Group: Open-ended, semi-structured Interview	Content Analysis of themes and categories  (Modified Stevick-Colaizzi-Keen method, Moustakas, 1994)
RQ2- What are families' lived experiences with accessing and utilizing information, social support, and resources?	<i>Qualitative Data</i> Open-ended, semi-structured Interview	Content Analysis of themes and categories  (Modified Stevick-Colaizzi-Keen method, Moustakas, 1994)
RQ3- What are families' appraisals of control over their experiences with accessing and utilizing desired information, social support, and resources?	<i>Qualitative Data</i> IE <sup>2</sup> SWOT Matrix Protocol  <i>Quantitative Data</i> Family Support Survey	Measures of Central Tendency  Means, Range, Standard Deviations
RQ4- What are families' perceptions of the type of experiences that enhance or inhibit their attainment of desired information, social support, and resources	<i>Qualitative Data</i> IE <sup>2</sup> SWOT Matrix Protocol  <i>Quantitative Data</i> Family Support Survey	Measures of Central Tendency  Means, Range, Standard Deviations
RQ5- To what extent, if at all, is there agreement among families' ratings of the value of enhancing or inhibiting experiences, and appraisal of control over these experiences?	<i>Quantitative Data</i> Family Support Survey IE <sup>2</sup> Matrix Grid	(SPSS) Hierarchical Cluster Analysis-Ward's Method Cluster Membership, Agglomeration Schedule, Dendrogram  IE <sup>2</sup> Matrix Analysis  (Leigh, 2000, 2005a, 2005b, 2009)

APPENDIX B

Informed Consent

INFORMED CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES

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

Participant: \_\_\_\_\_

Principal Investigator: Joannie Busillo-Aguayo

Title of Project: *Parent Experiences with Accessing Supports as Participants in Services for Their Special Needs Child after Age Three*

Dear \_\_\_\_\_,

Thank you for your willingness to participate in this study. In the course of my doctoral program at Pepperdine University, I am performing research on parent perspectives of their experiences with obtaining family supports as participants in services for their special needs child between three and eight years of age.

Your name has been selected because you are a parent and/or guardian of a child with special needs between three and eight years of age and are a participant in services provided by the investigated program, Child Development Institute (CDI). Your contribution will provide important information to the field of early intervention/early childhood special education as well as improve family support services at CDI. Your participation is voluntary and you are free to withdraw from participation at any time without any prejudice or negative effects on you or your child's further participation in any programs offered by CDI.

You will be participating in a discussion group of 6-10 other parents and/or guardians that will occur at the agency at a time that is convenient to all participants. During this time, you will be asked several questions regarding your experiences with obtaining family support services related to your child's special needs. Your responses will be recorded on large wall sized poster paper, and will be tape recorded. Additionally a research assistant will enter these responses into a computer generated survey instrument that will be used during the final phase of the focus group.

You have the right to refuse to answer any questions and request that the tape recorder be turned off during any part of the interview. The discussion is expected to be completed during a single 1 ½ to 2 hour session and will consist of the following:

- Collection of data obtained from open-ended, semi-structured group interview and completion of a brief survey. Data will be recorded through a combination of field notes, audio tape, and entry of responses into a computer database. Comments will not be recorded with any identifiable information and each participant will receive a code number.
- Data will be transcribed into written text and analyzed by the researcher for common themes
- While not planned at this time, data may be used at a later time in future publications
- Data will be maintained in a secure, locked file cabinet for a period of 5 years and destroyed thereafter

You will be notified regarding significant findings revealed by the study upon your request. The identities of all participants will remain confidential to the researcher, research assistant, and fellow participants, as the names are replaced through coding. As standard practice, all transcripts, notes, and recordings will be maintained in a locked cabinet, accessible solely by the principle investigator, and will be destroyed after a five year period. The confidentiality of the records will be maintained in accordance with applicable state and federal laws.

This study does not present more than a minimal risk to participants. The potential risks may include mild fatigue due to completion of a survey tool and mild anxiety with discussing experiences within the context of a group setting. In the event that you should desire consultation with a mental health specialist following participation, the researcher will arrange for this to be provided to you at no charge. Additionally, there is no monetary compensation for participation.

This study is directed toward benefiting scholars, practitioners, and parents of children with special needs. Your willingness to share your experiences is sincerely appreciated. If you have any questions, please feel free to contact me at [REDACTED] or email me at [joannie.busillo-aguayo@pepperdine.edu](mailto:joannie.busillo-aguayo@pepperdine.edu). This research is conducted under the guidance of Dr. Doug Leigh, Dissertation chair. Dr. Leigh can be contacted at [REDACTED] or through email at [doug.leigh@pepperdine.edu](mailto:doug.leigh@pepperdine.edu) and is available to answer any questions. If you have any further questions regarding your rights as a participant, you may contact Jean Lee, Manager of Graduate and Professional School IRB at (310) 568-5753 or through email at [jean.lee@pepperdine.edu](mailto:jean.lee@pepperdine.edu)

Pepperdine University requires that you be apprised of, understand, and agree to the terms stated in the letter. Signing and returning the consent form in the enclosed stamped envelope, will indicate your agreement to participate in this study.



SIGNATURE OF RESEARCH SUBJECT

I understand that my participation is voluntary and that I may refuse to participate and/or withdraw my consent and discontinue participation in the project or activity at any time without penalty or loss of benefits to which I am otherwise entitled.

I understand that the investigator will take all reasonable measures to protect the confidentiality of my participation and my identity will not be revealed in any publication that may result from this project. Under California law, there are exceptions to confidentiality, including suspicion that a child, elder, or dependent adult is being abused, or if an individual discloses an intent to harm him/herself or others.

I understand, to my satisfaction, the information in the consent form regarding my participation in the research project. All of my questions have been answered to my satisfaction. I have received a copy of this informed consent form which I have read and understand. I hereby consent to participate in the research as described above.

---

Participant's Name

---

Participant's Signature

---

Date

SIGNATURE OF RESEARCHER

It is my evaluation that the subject has voluntarily agreed to participate and possess the legal capacity to make such a decision. I have explained and defined in detail the research procedure in which the subject has agreed to participate. Having explained this and answered any questions, I am cosigning this form and accepting this person's consent.

---

Principle Investigator

---

Signature of Principle Investigator

---

Date

## APPENDIX C

### Site Consent

To: Joannie Busillo-Aguayo

From: Joan Maltese

As the Executive Director of the Child Development Institute, I agree to have our agency serve as a study site for your project to determine parent perspectives of informational, social, and resource support as participants in services for their special needs child after age three. I recognize that you will be conducting a focus group with parents as well as using a survey tool developed for the purpose of this study.

I understand that participation by any parent is voluntary and any parent who participates will not be revealed and all information will be strictly confidential. All data will be displayed in such a way as to protect the confidentiality of all participants. Additionally, participation or non-participation in this study will in no way affect the status of any parent and/or child who received or is receiving services from the agency.

I agree to the above protections for participants. I prefer that the name of our agency be kept confidential in all dissertation uses unless indicated by me otherwise.

---

Joan Maltese, Ph.D.  
Executive Director

Date

## APPENDIX D

### Institutional Review Board (IRB) Approval

# PEPPERDINE UNIVERSITY

Graduate & Professional Schools Institutional Review Board

March 17, 2009

**Protocol #:** E0209D06

**Project Title:** *Parents Perspectives of Experiences with Accessing Family Supports as Participants in Services For Their Special Needs Child Between the Ages of Three and Eight*

Dear Ms. Busillo-Aguayo:

Thank you for submitting your application, *Parents Perspectives of Experiences with Accessing Family Supports as Participants in Services For Their Special Needs Child Between the Ages of Three and Eight*, for exempt review to Pepperdine University's Graduate and Professional Schools Institutional Review Board (GPS IRB). The IRB appreciates the work you and your faculty advisor, Dr. Doug Leigh, have done on the proposal. The IRB has reviewed your submitted IRB application and all ancillary materials. Upon review, the IRB has determined that the above entitled project meets the requirements for exemption under the federal regulations (45 CFR 46 - <http://www.nihtraining.com/ohsr/site/guidelines/45cfr46.html>) that govern the protections of human subjects. Specifically, section 45 CFR 46.101(b) (2) states:

(b) Unless otherwise required by Department or Agency heads, research activities in which the only involvement of human subjects will be in one or more of the following categories are exempt from this policy:

**Category (2) of 45 CFR 46.101**, research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: a) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and b) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

Your research must be conducted according to the proposal that was submitted to the IRB. If changes to the approved protocol occur, a revised protocol must be reviewed and approved by the IRB before implementation. For any proposed changes in your research protocol, please submit a **Request for Modification Form** to the GPS IRB. Because your study falls under exemption, there is no requirement for continuing IRB review of your project. Please be aware that changes to your protocol may prevent the research from qualifying for exemption from 45 CFR 46.101 and require submission of a new IRB application or other materials to the GPS IRB.

A goal of the IRB is to prevent negative occurrences during any research study. However, despite our best intent, unforeseen circumstances or events may arise during the research. If an unexpected situation or adverse event happens during your investigation, please notify the GPS IRB as soon as possible. We will ask for a complete explanation of the event and your response. Other actions also may be required depending on the nature of the event. Details regarding the timeframe in which adverse events must be reported to the GPS IRB and the appropriate form to be used to report this information can be found in the *Pepperdine University Protection of Human Participants in Research: Policies and Procedures Manual* (see link to "policy material" at <http://www.pepperdine.edu/irb/graduate/>).

6100 Center Drive, Los Angeles, California 90045 ■ 310-568-5600

Please refer to the protocol number denoted above in all further communication or correspondence related to this approval. Should you have additional questions, please contact me. On behalf of the GPS IRB, I wish you success in this scholarly pursuit.

Sincerely,



Jean Lee  
Manager, GPS IRB & Dissertation Support  
Pepperdine University  
Graduate School of Education & Psychology  
6100 Center Dr. 5th Floor  
Los Angeles, CA 90045  
W: 310-568-5753  
F: 310-568-5755

cc: Dr. Lee Kats, Associate Provost for Research & Assistant Dean of Research, Seaver College  
Ms. Ann Kratz, Human Protections Administrator  
Dr. Doug Leigh, Chair, Graduate and Professional Schools IRB  
Ms. Jean Lee, Manager, Graduate and Professional Schools IRB  
Ms. June Schmieder-Ramirez  
Ms. Christie Dailo

## APPENDIX E

### Recruitment Procedures

1. The researcher recruited participants from a list of all families currently enrolled in, or enrolled within the previous 6 months, to screen for those families meeting the eligibility criteria for participation in the study.

The criteria used for selection is:

- a. Parents whose children are older than 3 and under 8 years of age, and
  - b. Currently participate in services provided by the investigated program or,
  - c. Have participated services provided by the investigated program within the past 6 months.
2. The researcher initially contacted all eligible families by a phone interview.
  3. During the initial interview, the researcher explained her role in the study and how potential participants were selected for consideration as participants. In addition, the following information was provided (a detailed script for the initial phone interview is in Appendix F ):
    - a. The purpose of the study and families interested in participating
    - b. Further details about the nature of the focus group and a general description of how the focus group would be conducted.
    - c. Assured parents that their names and any information provided would be kept confidential, known only to the researcher, research assistants, and participants of the focus group.
    - d. Informed parents that their responses would be audiotapped to facilitate data collection and analysis; and that tapes will be kept by the researcher in a locked cabinet for a period of 5 years and then destroyed.
    - e. Informed parents that their participation in the study is voluntary and they may withdraw at any time.
    - f. Explained that if they should decline to participate, that this would not affect their future participation in the investigated program.
    - g. Confirmed if the parent was still interested in participating in the study.
    - h. Parents who no longer wished to participate in the study were thanked for their time, and removed from the list of prospective participants.
    - i. The initial interview was concluded and potential candidates were informed that the research assistant would mail additional information within one week. (See item #5 below)

4. Families contacted were coded and categorized according to whether they agreed or disagreed to participate, or were undecided. Parents and/or guardian who were undecided were contacted within one week to determine their final decision of whether or not they wished to participate.
5. The research assistant mailed a packet of materials to each potential participant that either had agreed or was undecided. The packet included the following:
  - a. A cover letter providing information about the study
  - b. Informed consent form
  - c. Self-addressed stamped envelope to increase the return rate
6. The research assistant followed-up with parents who did not return their informed consent agreements within two weeks.
7. As informed consent forms were returned, the research assistant contacted families to get days and times that were convenient for scheduling the focus group.
8. The researcher made every attempt to ensure that the date was accommodating to all selected participants, individuals who were not able to make the date that worked for the majority were thanked and excused.
9. There were six parents who agreed to participate, thus one (2-hour) focus group was conducted with all participants present.
10. The research assistant mailed confirmation of the scheduled date and time of the focus group to participants and an agenda outlining the focus group procedures.

## APPENDIX F

### Phone Interview Script

*(General introductions, ask if this is a good time to talk, if not, make arrangements to call at a more convenient time)*

I am conducting research on gaining an understanding of families' experiences with getting and using supports related children's special needs between the ages of three and eight years. I know that you are very busy and this phone call will not take more than a few minutes. Is this a good time to talk with you about this?

Your participation in this research is voluntary and everything we discuss during this phone interview is confidential, known only by myself. If you agree to participate in this study, I will be asking you questions concerning your experiences with seeking and using desired supports such as information, support from other parents, and resources; as well as the type of experiences that have either enhanced or hindered your access to desired supports. Additionally, the study is interested in identifying your beliefs about who controls whether or not you are able to access and use these supports.

Your participation would consist of being part of a discussion with 6 to 10 parents and/or guardians of children with special needs between ages of three and eight years. The discussion is expected to last from 1 ½ to 2 hours and will be located at the agency. The focus group interview will involve the researcher, research assistants and other parents and/or guardians. While your participation will not be anonymous due to the nature of a group interview process, your privacy is of utmost consideration. Therefore, in order to maintain a maximum level of confidentiality, your identity will be known only to the researcher, research assistants, and other parents.

Would you like to participate in this study?

*If yes, then the researcher will inform them that the research assistant will mail additional materials, including an explanation of the study, informed consent form, and a self-addressed stamped envelope, as well as scheduling of the focus group date and time.*

**If not**, then the researcher will thank the parent and/or guardian for their time, and end the call.

*If undecided, then researcher will inform them that the researcher will follow-up with them in one week to determine whether or not they have decided to participate*

*If at any time a parent and/or guardian seem uncomfortable, the interview will be stopped, and apologies provided to the parent.*

APPENDIX G

Focus Group Interview Protocol

Date: \_\_\_\_\_  
Time of Focus Group: \_\_\_\_\_  
Location: \_\_\_\_\_  
Participants: 1. \_\_\_\_\_  
2. \_\_\_\_\_  
3. \_\_\_\_\_  
4. \_\_\_\_\_  
5. \_\_\_\_\_  
6. \_\_\_\_\_  
7. \_\_\_\_\_  
8. \_\_\_\_\_  
9. \_\_\_\_\_  
10. \_\_\_\_\_

I. Introduction

1. Thank participants and confirm voluntary participation
2. Clarify the confidentiality and use of field notes, audiotapes and computer
3. Clarify the purpose of the study
4. Describe planned procedures that will be used
5. Obtain Signed Informed Consent Forms
6. Define the following terms related to the research questions:
  - a. Support- can mean information, social support, or resources that relate to child’s special needs
  - b. Internal Control- a parent’s sense of having control in accessing something desired or needed
  - c. External Control- a parent’s sense that control in accessing something desired or needed is in the hands of professionals or others
  - d. Enhancer- a factor that enhances parent’s access to get something desired or needed
  - e. Inhibitor- a factor that inhibits parent’s access to getting something desired or needed
7. Explain the general nature of the SWOT procedure that will be used for the study- (more detailed description of process is provided in the next section)
8. Provide the opportunity for questions and comments.



## II. Qualitative Data Collection: Focus Group Interview Protocol

1. Research question 1: The researcher used open-ended, semi-structured questions to gain a better understanding of participants' experiences related to parenting a child with special needs, and in particular their experiences with getting supports when children are between the ages of three and eight years of age. Probing questions were used to elicit information related to effects on interpersonal and relationship well-being, perceived positive or negative effects, and experiences with the early intervention/special education system. The researcher and two research assistants recorded statements through field notes and audio tape.
  
2. Research question 2: The researcher used open-ended, semi-structured questions to gain a better understanding of parent's experiences with accessing and utilizing information, social supports, and resources. Probing questions were used to elicit experiences related to the type of information, social support, and resources they have needed, as well as how they have attempted to get these supports. The researcher and two research assistants recorded comments through field notes and audio tape.
  
3. Research question 3 and 4: The researcher conducted the IE<sup>2</sup> SWOT Matrix protocol to gain a better understanding of parents' appraisals of control over their ability to access desired or needed information, social support, and resources; as well as their perception of factors they identify as either enhancing or inhibiting their access. Following the steps described in Chapter 3, the process for conducting the IE<sup>2</sup> SWOT Matrix Analysis, as well as the purpose for using this approach was explained to the participants.
  - a. The Researcher interviewed participants using the questions related to research question 3 and 4 as per procedures outlined in Chapter 3 to obtain:
    - 1) Participants' appraisals of control (internal or external)
    - 2) Participants' perceptions of experiences that enhance access and utilization of information, social support, and resources
    - 3) Participants' perceptions of experiences that inhibit access utilization of information, social support, and resources
    - 4) Probing questions were used to gather detail related to their experiences
  - b. Research assistant #1 recorded responses on Large Post-it™ paper (18"X24") as the researcher asked questions (\*See sample form for recording SWOTs on next page).

- c. Research assistant #2 typed participants' responses into a computer template\*. Statements were recorded as close to verbatim as possible in order to reduce introducing bias through use of different language or terms used by participants.
- 4. The Researcher asked participants if they had anything they wanted to add to the list of SWOTs. When consensus was reached that the list is complete, the focus group was concluded.

III. Conclusion

- 1. The Researcher informed participants that their responses would be analyzed for statements that related to each of the four SWOT categories (strengths, weaknesses, opportunities, threats), and that their verbatim (or paraphrased) statements would be used to generate the survey items for the Family Support Survey that would be mailed to them within two weeks.
- 2. The Researcher thanked participants for their time and participation.

\* Sample Recording Form for SWOTs

	Internal Factors (Strength/Weakness)	External Factors (Opportunity/Threat)
1		
2		
3		
4		
5		
6		

Participant Response		
	Enhancers (Strength/Weakness)	Inhibitor (Opportunity/Threat)
1		
2		
3		
4		
5		
6		

## APPENDIX H

### Family Support Survey Protocol

#### I. Quantitative Data Collection: Family Support Survey Development

1. Research Question 3 and 4: Content for the survey instrument was derived from the qualitative data collected during the focus group interview for research question 3 and 4. The Likert-type Family Support Survey tool was developed using the following procedures:
  - a. The Researcher transcribed verbatim and paraphrased responses from the SWOT's generated during the focus group interview that were coded and numbered then entered into the Family Support Survey tool.
  - b. Survey based on IE<sup>2</sup> SWOT Matrix which organizes statements around categories of influence referred to as SWOTs (strengths, weaknesses, opportunities, and threats). Tool developed to measure participants' appraisals of control (internal/external) and perception of factors that enhance (help) or inhibit (hinder) access to supports.
  - c. Statements were further classified within each SWOT into factors that related to access and use of information, social support, and resources.
  - d. The Family Support Survey tool used an 11-point Likert-type rating scale that ranged from -5 (high external or inhibitor) to +5 (high internal or enhancer), with a value of (0) in between. (\*See sample survey at end of protocol description)
2. Sample Template for Family Support Survey

<b>The factor listed below ...</b>	<b>... is under my control (+):</b>	<b>... and is helpful (+):</b>
SWOT Strengths Factors Statements . . .	0 1 2 3 4 5	0 1 2 3 4 5
<b>The factor listed below ...</b>	<b>... is under my control (+):</b>	<i>... and is a hindrance (-):</i>
SWOT Weakness Factors Statements...	0 1 2 3 4 5	0 1 2 3 4 5
<b>The factor listed below ...</b>	<i>... is outside my control (-):</i>	<b>... and is helpful (+):</b>
SWOT Opportunities Factors Statements....	0 1 2 3 4 5	0 1 2 3 4 5
<b>The factor listed below ...</b>	<i>... is outside my control (-):</i>	<i>... and is a hindrance (-):</i>
SWOT Threats Factors Statements...	0 1 2 3 4 5	0 1 2 3 4 5

3. Research Question 5: The Researcher administered the Family Support Survey (FSS), a Likert-type tool, developed for this study to answer research question 5 examining the degree to which, if at all, there was agreement among families' ratings of the value of enhancing or inhibiting experiences with accessing and utilizing information, social supports, and resources, and their appraisals of control over these experiences.

II. Quantitative Data Collection: Family Support Survey Protocol Administration Procedures used to obtain data using the Family Support Survey Tool and Demographic Information Questionnaire (See Appendix ??).

1. The researcher mailed the Family Support Surveys, along with a demographic information questionnaire to each of the six participants with instructions for completion of the survey:
  - a. Ratings of Control: Each participant was instructed to independently rate the focus group responses for the degree to which they perceived a SWOT factor as being completely within their control (strengths, weaknesses) or completely outside of their control (opportunities, threats).
2. The *strengths and weaknesses* sections of the questionnaire used a Likert-type rating scale for appraisals of internal control, with 0 indicating absence of internal control to +5 representing appraisals of control as being completely in their own hands.
  - a. The *opportunities and threats* sections of the questionnaire used a Likert-type rating scale for appraisals of external control, from 0 indicating absence of control as being in the hands of others to -5 representing appraisals of control as being completely in the hands of others.
  - b. Enhance/Inhibit: Each participant was instructed to independently rate the degree to which each statement was perceived as either enhancing their experiences with accessing and utilizing supports (for strengths and opportunities) or inhibiting access (for weaknesses and threats).
    - 1) The *strengths and opportunities* sections of the questionnaire used a Likert-type rating scale for perceptions of factors that enhanced their access and use of supports, with 0 representing a neutral perception, and +5 indicating that the factor was highly enhancing.
    - 2) The *weaknesses and threats* sections of the questionnaire used a Likert-type rating scale for perceptions of factors that enhanced their access and use of supports, with 0 representing a neutral perception and -5 indicating that the factor was highly inhibiting.

### III. Conclusion

1. The Researcher instructed participants to return the completed survey at their soonest convenience in the self-addressed stamped envelope.
2. An individual not associated with the study opened and separated the surveys from the demographic information in order to de-identify participants' responses.
3. Responses from surveys were coded (randomly) and results were entered into a spreadsheet for analysis.

## APPENDIX I

### Expert Panel Review Procedures

Date

Expert Address

Dear Expert,

My name is Joannie Busillo-Aguayo and I am a doctoral student of Organizational Leadership at Pepperdine's School of Education and Psychology. I am conducting a research study of parents participating in a single program related to their child's special needs. I am seeking your assistance in validating (1) my research questions, (2) the proposed focus group interview questions, and (3) a rating scale developed by the researcher for this study. Your review will help to ensure that the research questions, focus group interview questions, and rating scale will provide the data that will lead to the completion of my study.

I have provided an abstract of my dissertation as an overview of the study. The purpose of the study is to gain a better understanding of parent perspectives regarding their experiences with obtaining information, social support, and resources for their child and family after the child is 3 years old. I will conduct a single focus group with 6 to 10 parents whose children participate in an adaptive skills and social skills program. The total length of time for participation is expected to last from 1½ to 2 hours.

Your feedback will ensure the quality and validity of the focus group questions and the utility of the rating scale and thus contribute to the overall quality of my research. Please note your cooperation and feedback is strictly voluntary and you may elect to withdraw at any time. I have enclosed the Abstract, research questions, focus group questions and the rating scale. I have also attached a Review Form for the focus group questions, and the rating scale. Please rate each question for the focus group as (1) the question is relevant, (2) the question needs modification as shown, (3) the question is not relevant to the study. For the rating scale, please rate the form using the following criteria of (1) acceptable, (2) needs modification, (3) not acceptable.

I have included space for additional comments on each question for your feedback. Upon completion, please mail back the form in the self-addressed stamped envelope provided. Your time and participation is greatly appreciated. If you need to contact me, please email me at [REDACTED] or call at [REDACTED]

Sincerely,

Joannie Busillo-Aguayo

## Experts Review of Focus Group Questions

Please check the appropriate number in the rating scale indicating the relevance of the (1) focus group questions, and (2) Rating Scale.

Focus Group Question #1: How would you describe your experiences as a parent of a child with special needs?

### *Probing Questions*

- a. . . . experiences with your child's intervention or education program?
- b. . . . experiences with transitioning from early intervention to preschool or from preschool to kindergarten?
- c. How have these experiences affected you and your family?

(1) Relevant \_\_\_\_ (2) Needs Modification \_\_\_\_ (3) Not Relevant \_\_\_\_

Modify as follows: \_\_\_\_\_

---

Focus Group Question #2: What has it been like for you to get *information* related to your child's special needs or the needs of your family?

### *Probing Questions*

- a. What type of information have you sought for your child and family?
- b. How do you typically get information?
- c. What has helped you to get the information you wanted or needed?
- d. What has interfered with your getting information?
- e. What or whom do you believe has control over your attainment of information?
- f. What type of information has been most valuable to you?

(1) Relevant \_\_\_\_ (2) Needs Modification \_\_\_\_ (3) Not Relevant \_\_\_\_

Modify as follows: \_\_\_\_\_

---

Focus Group Question #3: What has it been like for you to get *social or emotional support* related to your child's special needs or the needs of your family?

*Probing Questions*

- a. What type of social support have you sought for your child and family?
- b. How do you typically get social or emotional support?
- c. What has helped you to get the social and emotional support you wanted or needed?
- d. What has interfered with your getting social or emotional support?
- e. What or whom do you believe has control over your attainment of social or emotional support?
- f. What type of social or emotional support has been most valuable to you?

(1) Relevant \_\_\_\_ (2) Needs Modification \_\_\_\_ (3) Not Relevant \_\_\_\_

Modify as follows: \_\_\_\_\_

---

Focus Group Question #4: What has it been like for you to get resources related to your child's special needs or the needs of your family?

*Probing Questions*

- a. What type of resources have you sought for your child and family?
- b. How do you typically get resources?
- c. What has helped you to get the resources you wanted or needed?
- d. What has interfered with your getting resources?
- e. What or whom do you believe has control over your attainment of resources?
- f. What types of resources have been most valuable to you?

(1) Relevant \_\_\_\_ (2) Needs Modification \_\_\_\_ (3) Not Relevant \_\_\_\_

Modify as follows: \_\_\_\_\_

---



Experts Review of Family Support Survey Protocol

1. Clarity of instructions

(1) Acceptable \_\_\_\_\_ (2) Needs Modification \_\_\_\_\_ (3) Not Acceptable \_\_\_\_\_

Modify as follows: \_\_\_\_\_

\_\_\_\_\_

2. Understandable and free from jargon

(1) Acceptable \_\_\_\_\_ (2) Needs Modification \_\_\_\_\_ (3) Not Acceptable \_\_\_\_\_

Modify as follows: \_\_\_\_\_

\_\_\_\_\_

3. Layout is easy to read

(1) Acceptable \_\_\_\_\_ (2) Needs Modification \_\_\_\_\_ (3) Not Acceptable \_\_\_\_\_

Modify as follows: \_\_\_\_\_

\_\_\_\_\_

4. Rating scale is explained and easy to understand

(1) Acceptable \_\_\_\_\_ (2) Needs Modification \_\_\_\_\_ (3) Not Acceptable \_\_\_\_\_

Modify as follows: \_\_\_\_\_

\_\_\_\_\_

Additional Comments: \_\_\_\_\_

\_\_\_\_\_

## APPENDIX J

### Focus Group Interview Question and Administration

*(Note: Each question will be on a separate page to leave room for notes)*

#### Qualitative Data Collection: Focus Group Procedure

Research Question 1: What are the lived experiences of families whose children with special needs participate in early intervention or special education services and what meanings do they make of their experiences.

1. How would you describe your experiences as a parent of a child with special needs and what effect has this had on you and/or your family?

#### Probe for Experiences

- a. . . . interpersonal- stress, anxiety, depression, overwhelmed and so on.
- b. . . . relationships- marital, siblings, friends, professionals and so on.
- c. . . . positive effect- closer family, stronger, sense of purpose, joy, able to cope and adapt, purpose in life and so on.
- d. . . . experiences with service delivery system, early intervention programs, special education, therapists, teachers and so on.
- e. . . . negative effect- financial, child's behaviors, disrupt family routines, community involvement, working, child care and so on.

Research Question 2: What are families' perceived experiences with obtaining (a) information (b) social support (c) resources?

2. What has it been like for you to get supports related to your child's special needs or the needs of your family?
  - a. Probes for Information:
    - What type of information have you sought for your child and family? (e.g., child's disability, managing behaviors, parenting strategies, services, resources)
    - How do you typically get information? (e.g., family, friends, professionals, books, internet)
  - b. Probes for Social Support:
    - What or who do you rely on for support? (e.g., friends, family, program, therapist, parent group)
    - How do you typically get social support? (e.g., hear about it from others, ask from funding agency, find other parents, join groups)

c. Probes for Resources:

- What resources have you needed for your child and family? (e.g., services, therapy, doctors, financial, housing, respite, childcare, )
- Where do you go to get resources? (e.g., family, friends, funding agency, community resource, early intervention program, social services agency)

Research Question 3: What are families' appraisals of control over their experiences?

3. Who do you think has control over whether you get the supports you desire and/or need for your child and family?

a. Probes for internal control

- To what extent do you believe that you have control over your ability to get supports?

b. Probes for external control

- To what extent do you believe that control is in the hands of professionals, other family members, agencies, policy, "powerful others," etc.?

Research Questions 4: What are families' perceptions of the type of experiences that enhance or inhibit their attainment of (a) information (b) social support (c) resources?

4. When you are trying to get supports for your child or family, what do you find to be helpful? What type of barriers do you face?

a. Probes for Information:

- What are some ways that have helped you to get information?
- What are some barriers that you have faced?

b. Probes for Social Support

- What are some ways that you have been helped to get support? (e.g., family, friends, professionals)
- What obstacles have you encountered when trying to get support? (e.g., relational factors, demands on time, not available)

c. Probes for Resources

- What helps you get the resources you need?
- What are some obstacles that make it difficult to get resources?

## APPENDIX K

### Family Support Survey Administration

#### I. Child Characteristics Questionnaire

1. Parents are instructed to complete the Child Characteristics Questionnaire (Appendix L) and to return with completed Family Support Survey.
2. Please provide the following information regarding your child's diagnosis and education placement. This information is used for descriptive purposes only, and is not connected or linked with any of your responses. Your identity will remain confidential and will not be linked with any of your responses.

#### II. Quantitative Data- Family Support Survey

1. Research Question 5: To what extent, if any, is there agreement with or among families' appraisals of control over factors that affect their access to desired or needed supports and their ratings of the value of factors that enhance or inhibit their access?
2. Rate each statement for the degree to which it is perceived as being within or outside of your control.
  - a. A score of [0] is perceived as being complete absence of control over internal factors (strengths and weaknesses) and external factors (opportunities and threats)
  - b. A score of [5] is perceived as being completely within your control (strengths/weaknesses and opportunities/threats)
  - c. A score of [-5] is perceived as being completely outside of your control (strengths/weaknesses and opportunities/threats)
3. Rate each statement for the degree to which it is perceived as being an enhancer or inhibitor of your access to desired and needed supports.
  - a. A score of [0] is perceived as having little to no added value as an enhancer or inhibitor
  - b. A score of [5] is perceived as having the highest degree of added value as an enhancer
  - c. A score of [-5] is perceived having the highest degree of subtracted value as an inhibitor

APPENDIX L

Child Characteristics Questionnaire

Please provide the following information regarding your child’s diagnosis and education placement. This information is used for descriptive purposes only, and is not connected or linked with any of your responses. Your identity will remain confidential and will not be linked with any of your responses.

How old is your child now? \_\_\_\_\_

How old was your child when you first began receiving services? \_\_\_\_\_

What is your child’s diagnosis? \_\_\_\_\_

What is your child’s current school placement? *(please check)* \_\_\_\_\_

Grade

\_\_\_\_\_ Kindergarten

\_\_\_\_\_ 1<sup>st</sup> Grade

\_\_\_\_\_ 2<sup>nd</sup> Grade

\_\_\_\_\_ 3<sup>rd</sup> Grade

Type of Placement

\_\_\_\_\_ Full Inclusion

\_\_\_\_\_ Partial Inclusion

\_\_\_\_\_ Special Education

What services does your child currently receive, in addition to attending school?  
(check all that apply)

	Service	# of hours and frequency per week
<input type="checkbox"/>	Speech	
<input type="checkbox"/>	OT	
<input type="checkbox"/>	PT	
<input type="checkbox"/>	Behavioral Therapy	
<input type="checkbox"/>	Floortime Based therapy	
<input type="checkbox"/>	Adaptive Skills	
<input type="checkbox"/>	Social Skills Group	
<input type="checkbox"/>	Other (please specify)	

Are there any services and/or activities that you would like your child to participate in, that he/she is not able to because of his/her special needs? \_\_\_\_\_

What would help your child to be able to participate in these activities? \_\_\_\_\_

Do you have any other comments or suggestions? \_\_\_\_\_

## APPENDIX M

### Family Support Survey

#### Instructions:

The purpose of this survey is to get a better understanding of the type of experiences that either enhance (supports) or inhibit (prevents) your access to supports that you desire and/or need for your child and/or family. Each of the following statements represents the responses you provided during the previous group discussion about your experiences with accessing and using supports for your family related to your child's special needs.

*The survey will provide you with the opportunity to individually rate the relative benefit of each statement to YOU and/or YOUR FAMILY.*

You will be asked to answer each question with 2 different responses:

1. First you are asked to rate the extent to which you individually believe that the experience is currently within yours and/or your family's control or in the control of others.
2. Second you are asked to rate the extent to which you individually agree that the stated experience is currently or has previously enhanced (supports) or inhibited (prevents) you and/ your family from getting the desired and/or needed supports.

Thank you for taking the time to complete the survey. Your responses will help our program provide family supports that match the needs of you, your family, and child.

Sincerely,

The Child Development Institute

## STRENGTHS SWOT FACTORS

**Instructions:** For each factor listed below, indicate your sense of the degree to which it is under (+) your control. Also, indicate the extent to which you believe it is a helpful (+) to accessing and utilizing desired information, social support, and resources.

The factor listed below . . .	. . . is <i>under (+)</i> my control:	. . . and is <i>helpful (+)</i> :
1. Knowledge of the proper “lingo” needed to get services for my child.	0 1 2 3 4 5	0 1 2 3 4 5
2. Knowledge of my child’s disability and how to help my child.	0 1 2 3 4 5	0 1 2 3 4 5
3. Knowledge of services available for my child.	0 1 2 3 4 5	0 1 2 3 4 5
4. Connecting with other parents who share my experience.	0 1 2 3 4 5	0 1 2 3 4 5
5. Maintaining friendships outside of the special needs community.	0 1 2 3 4 5	0 1 2 3 4 5
6. Maintaining good communication with my spouse and a supportive marital relationship.	0 1 2 3 4 5	0 1 2 3 4 5
7. Building positive relationships with professionals.	0 1 2 3 4 5	0 1 2 3 4 5
8. Advocating for services for my child.	0 1 2 3 4 5	0 1 2 3 4 5
9. Being involved in getting services for my child.	0 1 2 3 4 5	0 1 2 3 4 5

## WEAKNESSES SWOT FACTORS

**Instructions:** For each factor listed below, indicate your sense of the degree to which it is under (+) your control. Also, indicate the extent to which you believe it is a hindrance (-) to accessing and utilizing desired information, social support, and resources.

The factor listed below . . .	. . . is <i>under (+)</i> my control:	. . . and is <i>a hindrance (-)</i> :
1. Lack of time to read or keep up with research.	0 1 2 3 4 5	0 1 2 3 4 5
2. Not accessing or using research resources.	0 1 2 3 4 5	0 1 2 3 4 5
3. Not knowing how to help my child.	0 1 2 3 4 5	0 1 2 3 4 5
4. Being isolated from other parents who have children with special needs.	0 1 2 3 4 5	0 1 2 3 4 5
5. Not reaching out to other parents who share my experience.	0 1 2 3 4 5	0 1 2 3 4 5
6. Not getting support from my spouse.	0 1 2 3 4 5	0 1 2 3 4 5
7. Not knowing what services and supports are available.	0 1 2 3 4 5	0 1 2 3 4 5
8. Not being involved in making sure that my child gets services he/she needs.	0 1 2 3 4 5	0 1 2 3 4 5
9. Not trusting that the system (e.g., school or regional center) has my child's best interests in mind.	0 1 2 3 4 5	0 1 2 3 4 5
10. Letting other's decide what services my child will receive.	0 1 2 3 4 5	0 1 2 3 4 5



## OPPORTUNITIES SWOT FACTORS

**Instructions:** For each factor listed below, indicate your sense of the degree to which it is *outside (-)* your control. Also, indicate the extent to which you believe it is a *helpful (+)* to accessing and utilizing desired information, social support, and resources.

The factor listed below ...	<i>... is outside (-) my control:</i>	<i>... and is helpful (+)</i>
1. Information that is parent friendly (e.g., easy to read, understandable, abbreviated, filtered, non-biased, accurate, up-to-date).	0 1 2 3 4 5	0 1 2 3 4 5
2. Resource guide with information about books, websites, phone numbers of resources available.	0 1 2 3 4 5	0 1 2 3 4 5
3. Professionals, teachers, experts, advocates, others who share information about laws, rights, services.	0 1 2 3 4 5	0 1 2 3 4 5
4. Books, TV, Internet	0 1 2 3 4 5	0 1 2 3 4 5
5. Professionals who know what services are available and how to get them.	0 1 2 3 4 5	0 1 2 3 4 5
6. Formal support groups (e.g., emotional/logistical support from program or parent organizations; therapy from licensed therapist).	0 1 2 3 4 5	0 1 2 3 4 5
7. Parent-to-parent support (e.g., Mom's Club, Parent Advisory).	0 1 2 3 4 5	0 1 2 3 4 5
8. Close friends with others who do not have children with special needs.	0 1 2 3 4 5	0 1 2 3 4 5
9. Understanding and support from others (e.g., spouse, family, friends, neighbors).	0 1 2 3 4 5	0 1 2 3 4 5
10. Other parents of children with special needs.	0 1 2 3 4 5	0 1 2 3 4 5
11. Parent support groups offered by the program.	0 1 2 3 4 5	0 1 2 3 4 5
12. Places to meet other parents and share experiences (e.g., program lobby/waiting area).	0 1 2 3 4 5	0 1 2 3 4 5
13. Parent support organizations (e.g., TACA, KEN, Autism Speaks)	0 1 2 3 4 5	0 1 2 3 4 5
14. Good schools, supportive teachers and vice-principals.	0 1 2 3 4 5	0 1 2 3 4 5
15. Conferences for parents of special needs children.	0 1 2 3 4 5	0 1 2 3 4 5
16. Parent Resource Room	0 1 2 3 4 5	0 1 2 3 4 5
17. Good Luck	0 1 2 3 4 5	0 1 2 3 4 5

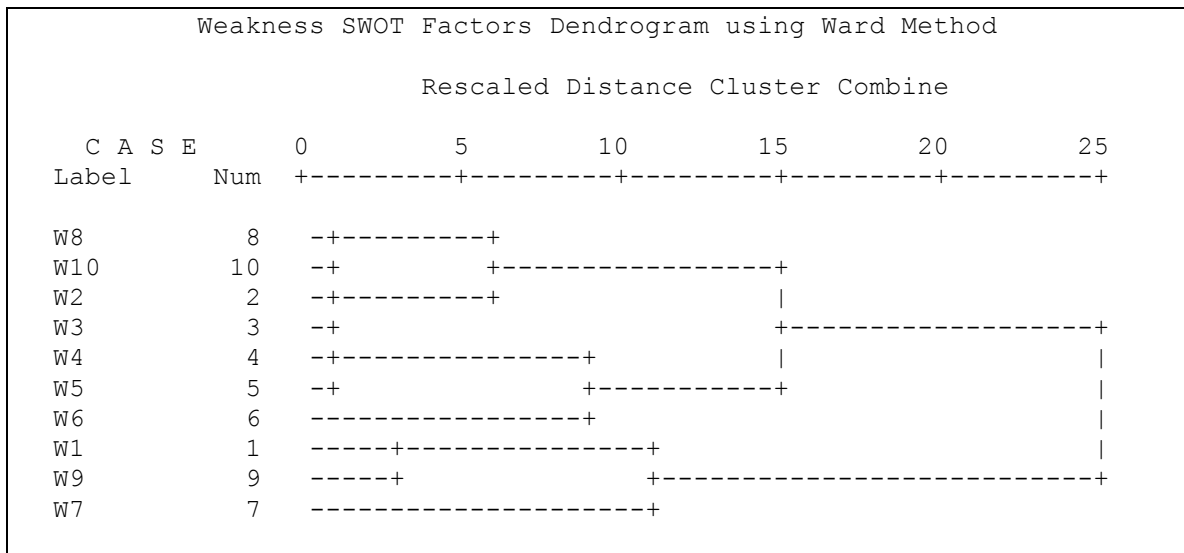
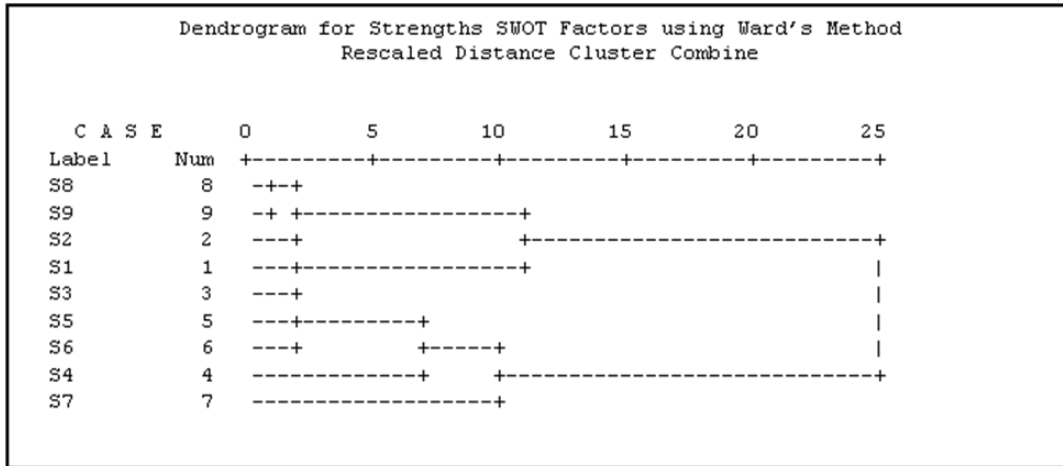
## THREATS SWOT FACTORS

**Instructions:** For each factor listed below, indicate your sense of the degree to which it is *outside (-)* your control. Also, indicate the extent to which you believe it is a *hindrance (-)* to accessing and utilizing desired information, social support, and resources.

The factor listed below ...	... is <i>outside (-)</i> my control:	... and is <i>a hindrance (-)</i>
1. Inadequate information (e.g., biased, not usable, too much, clinical and dry, depressing, negative, not about my child's unique needs).	0 1 2 3 4 5	0 1 2 3 4 5
2. Misinformation and misconceptions about disabilities.	0 1 2 3 4 5	0 1 2 3 4 5
3. Emphasis on cure and recovery in media.	0 1 2 3 4 5	0 1 2 3 4 5
4. Program doesn't keep families up to date about new services available.	0 1 2 3 4 5	0 1 2 3 4 5
5. Reactions from others (e.g., lack of tolerance, being judgmental).	0 1 2 3 4 5	0 1 2 3 4 5
6. Lack of awareness or understanding from family and friends of what it is like to parent a child with special needs (e.g., "sit in my shoes").	0 1 2 3 4 5	0 1 2 3 4 5
7. Unsolicited advice about how to raise my child.	0 1 2 3 4 5	0 1 2 3 4 5
8. Lack of opportunities to meet and connect with other parents who share my experience.	0 1 2 3 4 5	0 1 2 3 4 5
9. Responsibilities other than my child who as special needs (e.g., other children, family, work).	0 1 2 3 4 5	0 1 2 3 4 5
10. <i>Case Managers/Service Coordinators</i> : do not provide information about services available and how to get them.	0 1 2 3 4 5	0 1 2 3 4 5
11. <i>Services Offered by System</i> : time limited, not sensitive to my child's individual needs or preferences (e.g., diapers), or a "one-size-fits-all" approach to providing services.	0 1 2 3 4 5	0 1 2 3 4 5
12. <i>System Policies/Procedures</i> : inflexible, changing rules and terms about who gets what, services are allocated on policy rather than need.	0 1 2 3 4 5	0 1 2 3 4 5
13. <i>Program Facilities</i> : not comfortable, too small, not appropriate for my child's age.	0 1 2 3 4 5	0 1 2 3 4 5
14. Legislative factors that influence funding or cuts in services for my child.	0 1 2 3 4 5	0 1 2 3 4 5

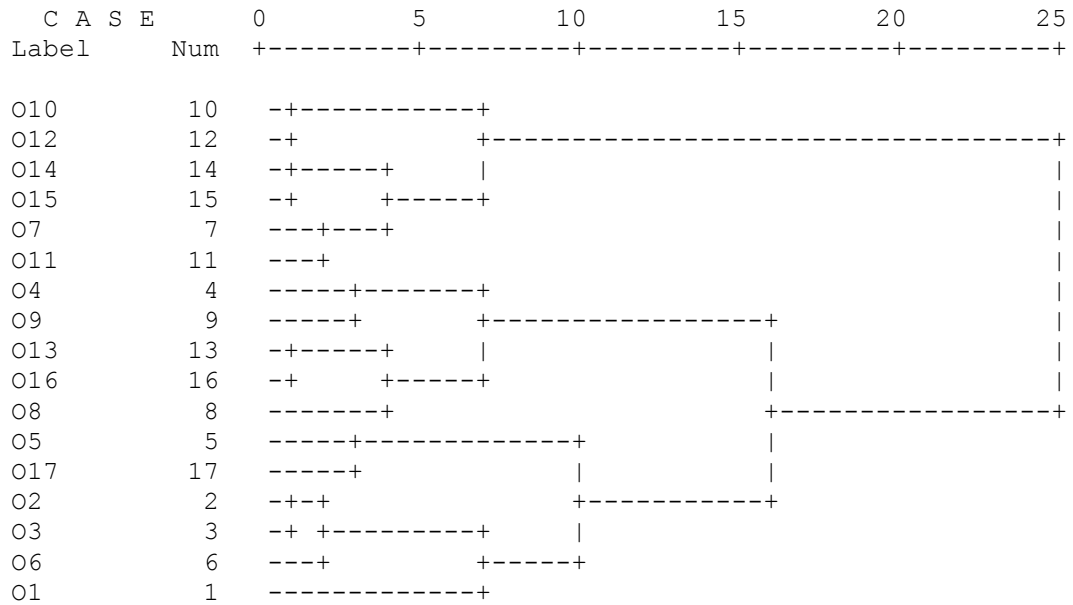
## APPENDIX N

### Additional Dendrograms



SWOT Opportunities Factors Dendrogram using Ward Method

Rescaled Distance Cluster Combine



Threats SWOT Factors Dendrogram using Ward Method

Rescaled Distance Cluster Combine

