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Parent-to-parent peer support for diverse low-income families of children with disabilities: A qualitative interview study of a self-help program as part of a medical home model

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

by

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Parent-to-Parent Peer Support for Diverse Low-Income Families of Children with Disabilities: A Qualitative Interview Study of a Self-Help Program as Part of a Medical Home Model

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DEDICATION

I dedicate this work to the five most important men in my life: my husband and my children. To my four boys, Owen, Alexander, Miles and Henry– you all give me tremendous joy, and great exhaustion, every time I wake up to you crawling into my bed way too early in the morning. Being your mother has truly made me understand the importance of love, family, and support. Your father and I are so excited to watch you grow into exceptional young men. I look forward to spending more mom time with each of you now that this study is complete. And to my husband, John– I cannot possibly describe how much I appreciate you and everything you have done to support me through, what felt like, a thousand years of school. I know how much we both have sacrificed to get to this final point and I will always be grateful to you for giving me the courage to continue, even when I wanted to quit– multiple times. I love you so much and I owe you the world. Thank you my dear. Now it is time for us to move on to the next exciting adventure of our lives together.

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Wood, L. B. & Singer, G. H. S., Parent-to-parent support for diverse low-income families: A study of the voice of the lifeworld in a medical context.

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2011-Present	Statewide Program Evaluator and Grant Writer Family Voices of Minnesota, Parent-to-Parent Program Minneapolis, MN
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ABSTRACT

Parent-to-Parent Peer Support for Diverse Low-Income Families of Children with Disabilities: A Qualitative Interview Study of a Self-Help Program as Part of a Medical Home Model

by

Louisa Bancroft Wood

ABSTRACT

Nearly one in five children in the United States has a special healthcare need and/or disability today. Families of children and youth with special needs can be vulnerable to weaknesses within the healthcare system, as services and supports for families are often uncoordinated, inaccessible, and lacking social supports. Currently, there are few organizations that help guide families of children with special needs in accessing healthcare systems and supports within the United States. This dissertation focused on the impacts of integrating a parent-to-parent peer support program to primary care medical home clinics along with outreach specialty clinics serving low-income, diverse families, including underserved and unrepresented families, of children and youth with special healthcare needs and disabilities. The program was granted to improve medical clinics for children in urban and rural areas from a Midwestern state of the United States. Peer support is a topic of interest in research on disability, and medical and mental health. It may represent an adjunct to professional services, and could offer a unique and supplemental form of helping. The purpose of this study was to identify the social exchanges that take place in a parent-to-parent support program, and investigate how they are understood and valued by the participants when parents acting as support providers join with medical personnel within the medical home model of care to serve families with children with special needs who are traditionally underrepresented and underserved. The parent-to-parent support movement has traditionally been organized by Caucasian, middle-class women throughout the United States and abroad. Recently, however, parent-to-parent programs are beginning to transform by working collaboratively with more culturally and linguistically diverse populations, which is more representative of the population of the United States than in the past. Data were collected from 24 interviews with key stakeholders taking part in the parent-to-parent support program in the Midwest. Data were systematically analyzed in multiple rounds and resulted in six themes including trust and empathy; resources and accessibility; awareness and understanding; cultural competence; mutual respect and partnerships; and empowerment and advocacy. These findings suggest that parent-to-parent support can provide culturally competent, family-centered support to families of children and youth with special healthcare needs and/or disabilities that help serve as an adjunct to traditional medical services to help achieve a medical home model of care for families.

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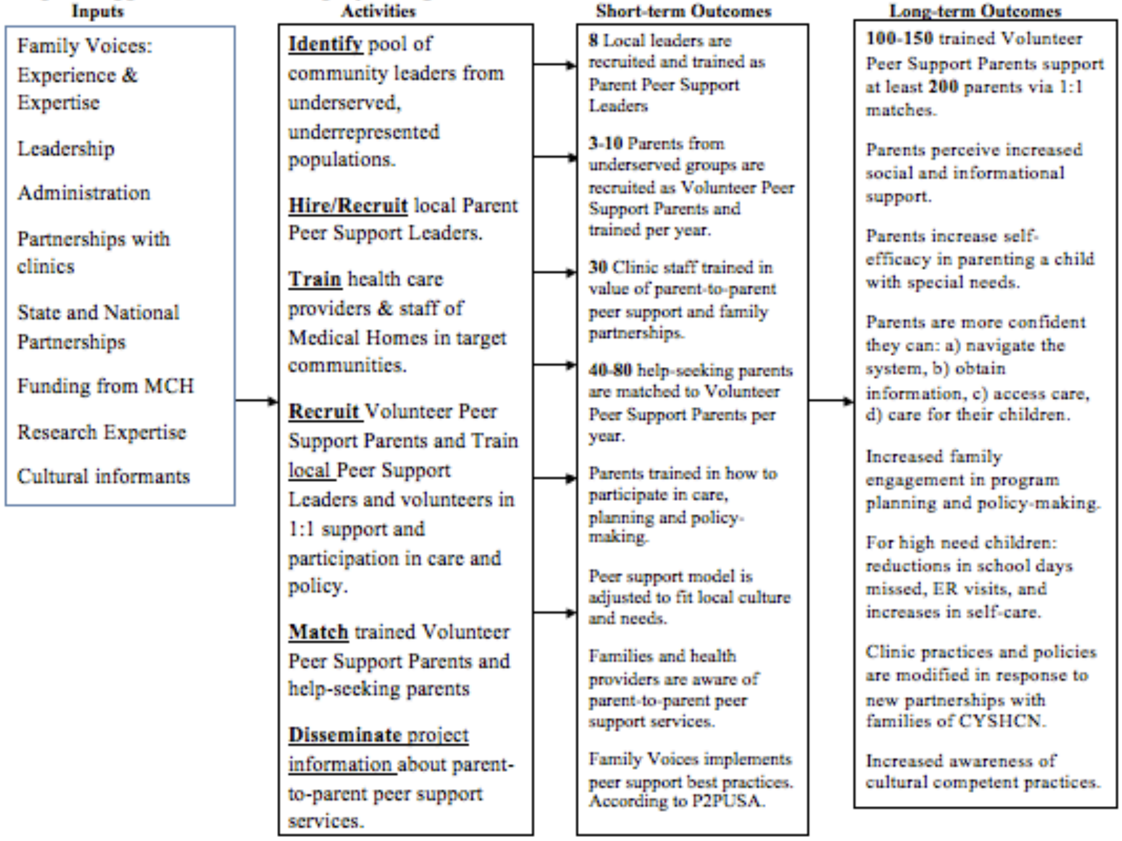
CHAPTER I: INTRODUCTION

This study served as an evaluation of a model program that integrated parent-to-parent support programs within the framework of comprehensive medical systems in order to help achieve a medical home model of care for families of children and youth with special healthcare needs and/or disabilities. The aim of this model was to address a number of issues that many families of children with special needs face including but not limited to 1) barriers in accessing a family-centered, culturally competent healthcare system; 2) isolation due to an inaccessibility of understanding peer and family supports; 3) obstacles in accessing community resources related to their family member's illness and/or disability or others; 4) stress and anxiety related to child's and families' needs; 5) challenges of economic pressures; and 6) loneliness due to remoteness of living location. The parent-to-parent peer support medical home project was created to help contend with some of these barriers that family members face, often daily, when raising a child with a special healthcare need and/or disability. Figure 1 below shows the logic model that was created at the start of this project.

Figure 1

The peer support medical home project logic model



Inputs

Family Voices: Experience & Expertise

Leadership

Administration

Partnerships with clinics

State and National Partnerships

Funding from MCH

Research Expertise

Cultural informants

Activities

Identify pool of community leaders from underserved, underrepresented populations.

Hire/Recruit local Parent Peer Support Leaders.

Train health care providers & staff of Medical Homes in target communities.

Recruit Volunteer Peer Support Parents and Train local Peer Support Leaders and volunteers in 1:1 support and participation in care and policy.

Match trained Volunteer Peer Support Parents and help-seeking parents

Disseminate project information about parent-to-parent peer support services.

Short-term Outcomes

8 Local leaders are recruited and trained as Parent Peer Support Leaders

3-10 Parents from underserved groups are recruited as Volunteer Peer Support Parents and trained per year.

30 Clinic staff trained in value of parent-to-parent peer support and family partnerships.

40-80 help-seeking parents are matched to Volunteer Peer Support Parents per year.

Parents trained in how to participate in care, planning and policy-making.

Peer support model is adjusted to fit local culture and needs.

Families and health providers are aware of parent-to-parent peer support services.

Family Voices implements peer support best practices. According to P2PUSA.

Long-term Outcomes

100-150 trained Volunteer Peer Support Parents support at least **200** parents via 1:1 matches.

Parents perceive increased social and informational support.

Parents increase self-efficacy in parenting a child with special needs.

Parents are more confident they can: a) navigate the system, b) obtain information, c) access care, d) care for their children.

Increased family engagement in program planning and policy-making.

For high need children: reductions in school days missed, ER visits, and increases in self-care.

Clinic practices and policies are modified in response to new partnerships with families of CYSHCN.

Increased awareness of cultural competent practices.

Integrating Programs: Parent-to-Parent and the Medical Home

Parent-to-parent programs and the medical home model of care have a number of overlapping and compatible values that could, when combined together, have an even greater impact in supporting families. Integrating parent-to-parent programs within medical clinics may be able to help contribute in part to establishing family-centered care and may help to achieve a medical home for families of children and youth with special needs.

Positive Impacts. According to Dennis (2003), within the dynamic medical environment of disease treatment and health promotion, peer support has become a significant element in the delivery of quality health care. First of all, the basic principles of the parent-to-parent program itself subscribe to the philosophy of family-centered care in that it: a) regards the child and family as the main focus of care; b) involves parent and professional collaboration and partnership; c) addresses the needs of the families; d) provides family-specified support; e) relies on family decision making; f) emphasizes the strengths of the family; g) attends to families' individual needs; and h) empowers families (Allen & Petr, 1996).

Incorporating parent-to-parent support within medical clinics can also help establish a medical home within the daily practice of healthcare professionals with families of children and youth with special healthcare needs and/or disabilities by encouraging families to advocate for and to train healthcare providers in incorporating the values of family-centered care mentioned above as a part of comprehensive care. Moreover, parent-to-parent programs can help to establish a medical home by promoting the philosophy that care should be accessible, continuous, comprehensive, family centered, compassionate, and culturally effective (American Academy of Pediatrics, 2015) when training healthcare providers and other professionals.

Parent-to-parent programs can also help to establish a medical home within medical practices because families can have access to the parent support during times of the day that traditional support is not available. This is an important part of the medical home concept. Availability of technology (i.e. cell phone, computers, etc.) can provide access to social media that links families together from anywhere at any time. In addition, in their study, Wood and Singer (2014) reported that healthcare providers and other professional stakeholders in the medical field perceive that parent-to-parent programs can help promote partnerships with families of children and youth with special healthcare needs and disabilities. Further, healthcare providers may also benefit by helping to coordinate care by providing a unique referral resource for parents of patients to parent-to-parent programs in their area to help increase communication and compassion through others with shared experiences (DiMatteo, 2004).

At the same time, parent-to-parent programs may benefit from taking part in medical clinics because research has shown that there is more family member buy-in when a professional refers the family to the support program. Mandell and Salzer (2007) found that family members were more likely to access social support networks when referred by their physician. Moreover, parent-to-parent programs can link families together of similar cultural backgrounds, which can help increase a medical clinic's cultural competence, another component of a medical home as defined by the American Academy of Pediatrics (Banerjee, Watt, Gulati, Sung, Klassen, & Klassen, 2011; McCabe, 2008; Frazier, Abdul-Adil, Atkins, Gathright, & Jackson, 2007; Musser-Granski & Carillo, 1997). In their study, Munson, Hussey, Stormann, and King (2009) interviewed 16 African American women as parent advocates within a system of care model service of delivery. Results showed that parent advocates value their own experience and can: help families translate medical jargon (medical world vs. lifeworld discourse); provide navigation to families through the medical system; empower parents and their children; and provide links to other sources of information. Further, Munson and associates also found that parent advocates differ from regular medical team case managers in that: the support is not a billable service for the medical clinics (which can help decrease costs and paperwork for clinics); advocates have much more flexibility with their work; and advocates can help develop non-traditional therapies catered towards the unique needs of families.

Barriers. Despite the growing body of literature supporting the use of the parent-to-parent support within the medical home model of care, research has shown challenges with implementing the model (Carrier, Gourevitch, & Shah, 2009; Nolan, Orlando, & Liptak, 2007). Perhaps one reason for these challenges with program implementation may be the focus of professionals and health clinics on the few ways in which parent-to-parent programs are incompatible with the medical home model of care. These incompatibilities may include, but are not limited to: differences in the levels of training of participants; lack of quality guidelines and empirical research to facilitate program implementation; added paperwork and processes over and above traditional care; misconceptions regarding the responsibilities and roles of participants; and different cultural belief systems (Palfrey, et al., 2004).

Although the current knowledge about the benefits of integrating parent-to-parent peer support into comprehensive medical care and integrating it within the medical home is beginning to emerge, further research is needed. Building partnerships through collaborative efforts with healthcare professionals may improve care, cost effectiveness and health outcomes, as well as increasing the parent's ability to be able to speak for their child and advocate for change for families of children with disabilities. Further, partnerships with health professionals and families may also impact families from underrepresented and underserved populations, including families from culturally and linguistically diverse backgrounds and with low socio-economic status. Research is needed to determine if such outcomes can in fact be attained.

Statement of Problem

This research study will begin with, and continue to maintain throughout, the assumption that a child with a disability and/or special healthcare need positively impacts families. Many families of children and youth with special healthcare needs and/or disabilities report experiences of enjoyment and satisfaction when caring for a child with a special healthcare need and disability. Although many parents of children with disabilities acknowledge positive effects on their lives (Hastings & Taunt, 2002), these experiences have received limited documentation in the professional literature. A small body of research has indicated that most parents reported a number of positive changes in their lives as a result of parenting a child with a disability, which included 1) a stimulus for personal growth, 2) a contribution to family strength, 3) improved relations with others, 4) changes in philosophical or spiritual values, 5) a pathway to learning through experience and challenges, etc. (Behr, 1988; Behr, Murphy, & Summers, 1992; Scorgie & Sobsey, 2000).

Families of children and youth with special healthcare needs and/or disabilities do experience the typical demands of family life; however, family members may also encounter a number of challenges that are unique to their child's needs. (Ainbinder, et al., 1998). Meeting the personal, medical, educational and social needs of a child with a disability or chronic illness within the context of public attitudes that habitually are negative, based on common misconceptions of disability and stigma, and within a non-collaborative and often inaccessible service delivery system, may be physically exhausting and financially draining for some parents (Green, 2007).

Regardless of the positive impacts described above, disability and special healthcare needs have been, and continue to be, presented in the research from a tragedy-based perspective which has, until recently, accentuated only negative outcomes. However, there has been a recent shift in relation to how disability is presented and the issues of how best to characterize the impact of children with special healthcare needs and/or disabilities on family, and how families adapt to the role as caregivers over time (Singer & Wang, 2016). According to Glidden (2003), researchers and service coordinators must be cognizant of the way in which family support designs are examined:

> An almost monolithic conception of the inevitability of distress, crisis, and pathology has been replaced by recognition of extreme variability of family response and an understanding of the importance of identifying the antecedent causes of that variability. (Glidden, 2003, p. 3)

That is, successful adaptations in parenting a child with a special need are prevalent within families, but are rarely identified in the current literature. There is great variability in the way in which families are able to successfully manage daily living responsibilities. In fact, contemporary research suggests that families adapt, love and care for their child with special needs, and enjoy parenting a child with a special healthcare need and/or a disability (Hastings & Beck, et al., 2002).

There are multiple ways in which parents or family members may be able to adjust positively in caring for a child or relative with a special need (Singer & Wang 2016). In fact, many families of children with disabilities are in fact able to cope well and even thrive with having a child with a special need. According to the small body of literature that currently exists in regards to positive outcomes of having a child with a disability, family members with positive perceptions associated with a child with a special need may help individual family members adapt or cope, and may assist with adaptation to a child with a disability. (Hastings & Taunt, 2002). Furthermore, family members may attend to positive experiences and emphasize growth and development of the self and the family unit while minimizing limitations of the child and the challenges caused for the family (Patterson, 2004). Family members often report range of positive perceptions and, although some family members may report more stress than other families with children who do not have disabilities, families of children do not seem to report fewer positive perceptions of their children (Hastings & Beck, 2002). That is, there are a sizeable number of families that are able to enjoy their families and lead fulfilling lives with all of their children, despite what disabilities and/or healthcare needs may or may not exist (Hastings, Allen, McDermott, & Still, 2002).

While many families cope and thrive with a family member with a special need, other families may find the challenges related to caring for a child that has a special healthcare needs and/or disability overwhelming and stressful (Hastings & Beck, 2002). In her 2007 study examining the impacts of having a child with a disability, Bayat surveyed parents of children with Autism to determine how parents described their parenting experiences. Data suggest that one-third of family members described their experiences of parenting a child with a disability as beneficial, 2) one third described a combination of positive and negative experiences, and 3) one third of families described their experiences as negative. These data imply that more than half of the families caring for families of children with special needs experience positive outcomes. This is to say, there seems to be great variation in the way families view and adapt to their role as a parent of child with a special need. The causes of successful adaptations of families of children with a special needs may be naturally occurring within the family itself or exogenous.

There may be myriad forces responsible for the negative experiences reported by some families described above in Bayat's research (2007). Research has indicated that some parents may experience feelings of grief, loss, and guilt, while other families report sometimes encountering psychological, social, and political consequences such as isolation and social marginalization, stigmatization, and disempowerment (Byrne, Cunningham, & Sloper, 1988; Pahl & Quine, 1987). Other family members that experience the responsibilities of caring for a child or youth with special healthcare needs or disabilities could also be at an increased risk to experience stress, anxiety, financial worries, and ill health in addition to the challenges of completing everyday tasks as compared to family members with typically developing children (Diehl, Moffitt & Wade, 1991; Glendinning, 1983; Pahl & Quine, 1987; Parker, 1985; Singhi, Goyal, Pershad, Singhi, & Walia, 1990; Singer, Irvin & Hawkins, 1988). In addition to the pressure of ensuring quality care for their child, some parents may feel isolated which could lead to depression and hopelessness (Seligman & Darling, 2009; Winch & Christopher, 1988). Nevertheless, there is emerging literature that indicates that, although challenging events may produce negative results in some families initially, the positive outcomes typically may not be as immediate to be realized, but are lasting and of a higher order (Palus, 1993; Scorgie & Sobsey, 2000). In fact, research of survivors of even extremely challenging events has shown that for many individuals, the crisis ultimately results in positive change and personal growth (Aldwin, 1994; Davis & Watson, 2002; Frankl, 1984; Janoff-Bulman, 1992; Moos & Schaeffer, 1986). Despite the benefits of the positive outcomes of having a child with a disability described above, some parents report feelings of isolation and loneliness throughout their familial journeys due to the few social and emotional supports that are available (Santelli, 2002; Seligman & Darling, 2009).

Nearly one in five children in the United States has a special healthcare need or disability today (National Survey of Children with Special Healthcare Needs, 2010). Some families of children with special needs who may have more challenges with coping and may be at more of a risk of experiencing stress and anxiety due to a lack of supports in the healthcare system and community supports. That is, some families of children and youth with special healthcare needs and/or disabilities may be vulnerable to weaknesses in the healthcare system (Weller, Minkovitz, & Anderson, 2003) and services and supports for these types of families are often fragmented, uncoordinated, and confusing for stakeholders (Huang, et al., 2005). Research suggests that families consistently stumble on unforeseen barriers in an effort to access information, services and supports that are needed in order for the families to be engaged and empowered partners when working with healthcare providers (Wagner, et al., 2001). Although meeting the complex and specialized needs of a child with disabilities requires collaboration between parents and professionals, many parents rarely experience an equal relationship with professionals, and often parents may be lacking the knowledge, expertise or power to influence decisions, participate in interventions, or negotiate the services affecting the child (Brett, 2002; Case, 2000; Dale, 1996). Caregivers have reported the feeling of a lack of understanding and empathy from their child's healthcare providers in regards to the families' individual needs and wants (Case, 2000; Dale, 1996), and even their cultural beliefs (Harry, 2008). In fact, some caregivers report professionals often exclude family members completely in the healthcare decision-making process for their child (Case, 2000). In addition, research has shown that healthcare providers often use a technical "voice of medicine" when discussing a child's diagnosis and treatment plans with family members. According to Mishler (1984), the voice of medicine reflects a medical professionals' technical interest and is often expressed with a seemingly unsympathetic scientific attitude, which can leave families feeling uncomfortable and isolated (Barry, Stevenson, Britten, Barber, & Bradley, 2001). This lack of ability to communicate more naturally and lack of ability to collaborate from healthcare providers towards families of children with disabilities can lead to misdiagnosis due to missed symptoms and inability to elicit information from the child or parents, poor quality healthcare treatments, lack of compliance with the provider's recommendations, further health complications for the child, and greater stress on the family (Bhasale, 1998). Moreover, families often must learn about their child's diagnosis on their own recognizance and discover on their own what the diagnosis may mean for their child, as well as for their family as a whole (Hummelinck & Pollock, 20062). Parents must learn the language of the medical, legal, financial, and special education worlds and find their way in a service system that may or may not provide appropriate support (Avila, 2009). These challenges may be magnified for families who are underserved and underrepresented, including families who are living in poverty, those from various cultural and linguistic groups and families living in extremely rural areas of the country (Harry, 2002; Markey, Markey, Quant, Santelli, & Turnbull, 2002).

The current literature suggests that, when asked about services in their healthcare and within their communities, parents of children and youth with disabilities identified several unmet needs including information and support for parents and support navigating the complex systems and services (Farmer, Marien, Clark, Sherman, & Selva, 2004). Parents report that connecting with other parents of children with similar conditions can be invaluable, especially when the other parents were able to provide needed information and support, particularly advice and information about navigating the health and insurance systems (Farmer, et al., 2004). A small body of research indicates that for some parents peer support can be helpful in adapting to the challenges of family care giving (Ainbinder, et al., 1998; Corcoran, 1981; Ireys, Chernoff, DeVet, & Kim, 2001). According to Mead, Hilton, and Curtis (2001), peer support is defined as a system giving and receiving of help founded on key principles of respect, shared responsibility, and mutual agreement on what is helpful. Mead, Hilton, & Curtis (2001) showed that peer support providers attempt to think creatively and not judgmentally about the way individuals experience and make meaning of their lives in contrast to having all actions and feelings diagnosed and labeled. The primary types of support provided by peer support are emotional support (i.e. offers esteem, attachment, and reassurance), instrumental support (i.e. offers material goods and services); and informational support (i.e. offers advice, guidance, and feedback) (Solomon, 2004).

Parent-to-parent programs can provide emotional and informational support to parents of children with special healthcare needs and disabilities through trained peer supports (Santelli, Turnbull, Marquis, & Lerner, 2000). Parent-to-parent is a program that matches families of children or youth with special health care needs or disabilities with an experienced Volunteer Support Parent who has received specialized training (Parent-to-Parent, USA, 2014). Parent-to-parent programs maintain the capacity to match families with diverse experiences including but not limited to ethnicity, culture, race, language, socio-economic status, disability, special health need, and other child/family related factors.

Parent-to-parent programs differ from other types of formal support in that parent-to-parent support has the capacity to provide meaningful, experiential empathy (i.e. sensing or feeling another’s inner experience based on one’s personal experiences) (Corcoran, 1981; Meissner, 1996). Family members of children and youth with special healthcare needs and disabilities who are newly referred to a parent-to-parent program by healthcare providers or other professionals, are intentionally linked with trained and experienced veteran parents who provide one-to-one emotional and informational support. Trained veteran parents share what they have learned from their experience of both the joy and the challenges when parenting a child with special needs and may be able to provide a more encouraging life picture to other parents who may be struggling currently (Ainbinder, et al., 1998).

Research on the efficacy of peer-support programs has shown that parent-to-parent can be successful and families consider their linked parent a reliable ally when there is perceived sameness, there are comparable situations for learning relevant skills and gathering useful information, the support is easily accessible, and there is mutuality of support (Ainbinder, at al., 1998). This research demonstrates that perceived sameness of lived experience is a fundamental reason why parents trust other parents (Ainbinder et al., 1998). In addition, parents provide support to help-seeking parents through the voice of the lifeworld, the use of narrative and story telling. Mishler (1984) described the voice of the lifeworld as the way an individual reports and describes the world of everyday life that is expressed from the perspective of a natural attitude. This ability to communicate in a more natural manner can help families feel comfortable, which can decrease feelings of isolation (Barry, Stevenson, Britten, Barber, & Bradley, 2001).

Previous research indicates that parent run organizations providing structured training and follow-up are successful in preparing experienced parents as volunteer mentors (Singer et al., 1999). Parents from the same ethnic and linguistic groups facing similar challenges are likely to have information and emotional support that is highly salient to help-seeking parents (Banerjee, 2011). After receiving emotional and informational support, parents have shown increased confidence in parenting children with special needs (Singer et al., 1999). Increases in self-confidence, in turn, are associated with a variety of improvements in health care utilization and participation at all levels of planning from individual medical planning for a child to organizational planning for a clinic (Wagner, Austin, & Von Korff, 1996).

Linking trained peer supports with families of children and youth with special healthcare needs and disabilities through a parent-to-parent program can potentially provide caregivers with emotional and social supports that may lead to a decrease in the levels of stress, anxiety, and feelings of isolation (Ireys et al., 2001) and an increase in engagement, empowerment (Ainbinder, et al., 1998), access to community resources and better healthcare (Bhasale, 1998). In a study completed by Ireys et al. (2001), data revealed that peer support reduced symptoms of anxiety in parents of children with special healthcare needs and disabilities. Moreover, some individuals who provide social support through volunteering experience less depression, heightened self-esteem and self-efficacy as well as improved health behaviors and health outcomes (Walker, 2000). Furthermore, data has shown that parent-to-parent peer support programs can provide opportunities for parents to build on their strengths by offering training for emerging leaders in policy, healthcare financing, advocacy and other areas of leadership development (Ainbinder et al., 1998).

An emerging body of literature has shown the potential benefits of adding parent-to-parent programs to traditional medical practice as a part of comprehensive medical care to help achieve family-centered care within a medical home (Gabovith & Curtin, 2009; MacKean, Thurston, & Scott, 2005). The medical home is an approach to healthcare that provides comprehensive primary medical care through the facilitation of partnerships between patients, physicians, and families. There has been a movement within the field of pediatric medicine to disseminate the medical home as a model. Over the past fifteen years, the American Academy of Pediatrics has been at the forefront of numerous initiatives to promote the adoption and spread of patient- and family-centered care in a medical home (Hagan, Shaw & Duncan, 2008). A medical home is an approach to medical care in which the primary pediatric care team works in partnership with a child and a child's family to assure that all medical and non-medical needs of the patient are met (Pettoello-Mantovani, Campanozzi, Maiuri, & Giardino, 2009). The dimensions of a medical home include accessibility, continuity, coordination, comprehensiveness, communication and compassion, and cultural competence of medical care providers (Briton, Martin, & Landon, 2003). According to Frazier, Abdul-Adil, Atkins, Gathright, & Jackson (2007), involving family members in the design and delivery of services for children and youth with special healthcare needs and disabilities would provide perspective that reflects the daily experiences of families and that offers clinicians a window into their cultural world. According to Barry, et al. (2001), physicians may have to change their notions of success from purely technical considerations to include family members of children with disabilities feeling understood, listened to and treated like whole and unique human beings. If doctors could be sensitized to the importance of dealing with the concerns of the daily life for families of children with disabilities it might be possible to obtain better care for patients.

Adding a peer support component to comprehensive medical care may be a method of achieving a medical home for many families. Parent-to-parent programs are intended to add to and augment the help provided by professionals and their assistants, not to replace them. Family-centered care can be defined as placing the needs of children, in the context of their families and community, at the center of medical care. Then the medical team designs an individualized and dynamic model of care in collaboration with the child and family that will best meet these needs based on each individual family's wishes, strengths, and needs. (Allen and Petr, 1996; Eckle & MacLean, 2001). Although the current knowledge about the benefits of incorporating parent-to-parent peer support into comprehensive medical care and integrating it within the medical home is beginning to emerge, further research is needed. Building partnerships through collaborative efforts with healthcare professionals may improve care, cost effectiveness and health outcomes, as well as increase the parent's ability to be able to speak for their child and advocate for change for families of children with disabilities.

Asking what are the benefits of peer support programs in diverse communities is a socially valuable question for both practical and theoretical purposes in that it a) may focus on the current change in demographics in the United States, and the challenges that both increased poverty and increased diversity pose for medical service providers, b) may help address how peer support can help to offset the current shortages in professional helpers in the medical field through paraprofessionals, particularly trained peer supporters, and c) may offer a unique form of support for both families of children and youth with special healthcare needs and healthcare providers, which can further amplify the benefits from traditional professional medical services (Denboba, et al., 1999). This present study examined the impacts of integrating a parent-to-parent support program within comprehensive medical care as part of the medical home. The program was granted to enhance medical services for families of children and youth in urban and rural areas of a region from the Middle Northwest of the United States.

Emerging literature in the field of parent-to-parent support and disability research is beginning to demonstrate some positive impacts on families of children and youth with disabilities. Currently, however, few studies examine the impacts of adding peer support programs, such as parent-to-parent support, to traditional medical care within the medical home model of care.

Many of the peer-reviewed studies examining family support, however, have not been able to incorporate representative data from families of low-income status and of culturally and linguistically diverse populations (Harry, 2008; Montgomery, Kunik, Stanley, & Weiss, 2010). In order to ensure validity and rigor of qualitative research, a sample of the population that includes culturally and linguistically diverse participants being served a program like parent to parent must be utilized.

Purpose of Study

In light of the problems defined above, there is a need to determine the effectiveness of parent-to-parent programs for families of children with special needs when they serve in conjunction with the medical home model within comprehensive medical care. The purpose of this dissertation study is to examine the impacts of adding this parent-to-parent peer support program to primary care medical home clinics along with outreach specialty clinics serving low-income, diverse families of children with special health care needs and disabilities. The impacts of interest in this study will be the effects of the parent-to-parent program on culturally and linguistically diverse consumers of clinical medical services for children with disabilities and/or chronic illnesses. Research will focus on data collected from families of culturally and linguistically diverse backgrounds because currently there is little evidence regarding the effects of family support programs on these populations (Harry, 2008;

McCabe, 2008; Castro, Barrera, & Martinez, 2004; Markey, Santelli, & Turnbull, 1998; Thorp, 1997). Individuals presently being served by this parent-to-parent program include families living in urban and rural communities and families from both majority populations and from culturally and linguistically diverse populations living in a state in the Midwest.

This study could potentially make a useful contribution to the field of disability and family support research. Data could help identify and examine if integrating parent-to-parent support programs and the medical home model of care provides effective support to families of children and youth with special healthcare needs and/or disabilities, especially focusing on families from culturally and linguistically diverse backgrounds. Asking what are the benefits of peer support programs in diverse communities is a socially valuable question for both practical and theoretical purposes in that it may focus on the current changes in demographics in the United States, and the challenges that both increased poverty and increased diversity pose for medical service providers, and b) may offer a unique form of support for both families of children with special healthcare needs and disabilities from traditionally underrepresented and underserved communities and healthcare providers, which can further amplify the benefits from conventional professional medical services (Denboba, et al. 1999). The author believes that this study will make a meaningful contribution to the field of peer support research and could present an important step in understanding how to address the current lack of social and informational supports for families. This study may also contribute to the field of research in the medical home model of care as it seeks to determine ways in which to achieve family-centered practice, a major component of the medical home model of care as outlined by the American Academy of Pediatrics.

The parent-to-parent program has added a peer support component to pediatric outreach clinics and medical home clinics. It has involved people from two very different concepts of care and support, namely volunteer peer support and professional medical care. These are nested in two major organizational contexts with very different orientations, a relatively small non-profit organization and a large medical organization. Volunteer support programs, such as the Family Voices project, tend to be nonprofessional and volunteer based, whereas medical programs, such as traditional care within a medical facility, tend to be highly professionalized and formally structured along bureaucratic lines.

Participants with various roles in the parent-to-parent program were interviewed for this study to obtain multiple perspectives on the process of implementing the program and its early outcomes. The roles of the interview participants include healthcare providers, Program Coordinators, referred family members, and trained support family members from the pool of those individuals who had been connected with the parent-to-parent program taking place throughout a state in the Midwest.

Research Questions

The research questions in this study are related to the overarching pragmatic goals of examining the efficacy of integrating parent-to-parent within the medical home concept of care for diverse families of children and youth with special needs. The central questions that will be addressed in this study are:

1. Do parent volunteers trained under the auspices of a structured Parent-to-Parent program help outreach medical clinics realize a major value that has been widely agreed upon by stakeholders in the system establishing a medical home where families receive family-centered care?
2. What are parents' perceptions of the differences in the kinds of social and

informational support provided by trained peer supporters as compared to other sources of support?

3. Are there similarities between the perceptions of culturally and linguistically diverse families compared to those perceptions from the white Anglo majority culture regarding the type and effectiveness of the parent-to-parent support?
4. How do family members of children with special needs perceive, if any, the differences in discourse when speaking to professionals in the medical field as opposed to speaking to another parent with shared experiences?
5. In what ways, if any, do parent-to-parent programs contribute to establishing family-centered care for families of children and youth with special healthcare needs for families?
6. What challenges do the differences in parent-to-parent and clinic functions and organizational contexts raise for implementation of a joint parent-to-parent and medical clinic service model and how have they been addressed?

CHAPTER II: LITERATURE REVIEW

Current Support Systems for Families

It is important to understand the current state of peer-to-peer support programs across the country, especially within the context of the medical care system, to properly address the gap in effective family support programs for families of children and youth with special healthcare needs and disabilities. The aim of this section of the literature review is to examine the systems of supports for families of children and youth with special healthcare needs and disabilities, especially related to healthcare.

In order to illustrate how integrating parent-to-parent support and the medical home model of care could potentially benefit families of children with special needs, current literature and theories on the developmental influences (i.e. family, empathic behaviors, and medical services) and levels of impact from the available systems of care for a child with special needs, and their family members, will be reviewed within the framework of Bronfenbrenner’s Ecological Model of Human Development (1977). This literature review will also highlight the recent empirical literature on the influences of family, as it relates to family-healthcare practitioner and family-health clinic relationships, in addition to other relevant relationships. Examining theories of developmental influences on children with special needs and family members in the literature is an important step to understanding what is already known in the field of disability research and what areas are still in need of significant study. Implications for this research study into the field of parent-to-parent support within the medical home model of care will be detailed below, especially focusing on individuals from culturally and linguistically diverse populations, as well as families with low socio-economic status.

Theoretical Framework

Understanding the multitude of factors that contribute to the development of a child with a chronic illness and/or disability can be incredibly challenging and complex. Urie Bronfenbrenner's ecological model for human development (1977) provides a constructive framework within which one can examine the major influences upon the development of a child living with a special need. Despite the complexity of the ecological model, it offers a holistic approach to analyzing multilevel and interactive influences of child development. Bronfenbrenner proposed in his original theory that, in order to understand human development, the entire ecological system in which growth occurs for a child must be considered. The ecological framework can help facilitate organizing information about children with special needs and their environment in order to understand their interconnectedness.

Simply stated, a system is a group of interacting, interrelated, or interdependent elements that together make up a complex whole. An ecological perspective on human development emphasizes both individual and contextual systems and the interdependent relations between the two. At the very center of ecological thinking is the natural ecosystem, the network of interactions among organisms and between organisms and their environment (McLaren & Hawe, 2005). Bronfenbrenner developed his ecological model to create a constructive framework within which to analyze the multifaceted system that is human development. According to Bronfenbrenner and Morris (2006), development is defined as the following:

> The phenomenon of continuity and change in the biopsychological characteristics of human beings, both as individuals and groups. The phenomenon extends over

> the life course, across successive generations, and through historical time, both past and future (p. 793).

Bronfenbrenner's ecological model is represented graphically by concentric circles nested within one another, with each circle representing a distinct socially organized subsystem. The interactions between and among the entities in these concentric circles help guide and support human growth (see Figure 2 below). Based on Lewin's theory of psychological fields (1935), each successive level of the ecological model is nested in previous levels so that units of analysis move from large historical forces down to minute social interactions (Bronfenbrenner & Ceci, 1994). These six nesting circles include the self or target individual (sitting directly at the center of the bulls-eye shape), the microsystem, the mesosystem, the exosystem, the macrosystem, and the chronosystem, which represents the final and all-encompassing layer of the model. Each of the six systems in the model establishes the contextual nature of an individual's life and offers a constantly changing set of options and sources of growth (Bronfenbrenner, 1977). Additionally, bi-directional influences occur within and between each system, which can imply that relationships have impacts both towards and away from the child (Bronfenbrenner & Ceci, 1994).

Within a hierarchically organized system, such as the ecological model for human development, activities or circumstances at one level synergistically affect those of another level. Ecological frameworks orient attention to the diverse levels of environments in which individuals are embedded. That is, the ecological framework describes the five levels of social environments that may affect a child's development, including: 1) the microsystem, in which personal environments consist of individuals with whom the focal child interacts directly; 2) the mesosystem, in which small group environments have emergent properties beyond the individual child, such as support programs and health clinics; 3) the exosystem, in which characteristics of broader social networks, such as local politics and national service organizations, subsist; 4) the macrosystem, in which broader sociocultural factors, such as laws, belief systems, and cultural values exist; and 5) the chronosystem, in which the temporal characteristics of environmental events and transitions that occur throughout a child's life, including any sociohistorical events, occur. A key insight of bioecological systems theory is that processes that occur in more distal settings influence individuals by altering aspects of progressively more proximal environments (Bronfenbrenner, 1979).

Figure 2. Bronfenbrenner's ecological model of human development

(Wood, 2014)

This study specifically centers on two units within the mesosystem and how they impact families in the microsystem.

The Child

The very first subsystem sits at the center of the model and is where the individual, in this case the child, fits. Influences within the center circle can include, but are not limited to, the age, gender, race, and health of the child. These characteristics can “place the child in a particular environmental niche that defines his or her position and role in society” (Bronfenbrenner & Morris, 2006, p. 814). It is important to note that in this literature review I will be discussing developmental influences upon a child that has a special healthcare need and/or disability, which may have a great impact on the child. That is, for a child with a special need such as cystic fibrosis, juvenile diabetes, cerebral palsy, autism, or Down’s syndrome, physical and/or intellectual functioning may be greatly impacted, which could lead to overall life course influences that other children with typical development may not necessarily have. The system of the self also can include neurological and psychological functioning (i.e. typical functioning, maladaptive functioning, etc). Such variables can also influence proximal processes, either directly or indirectly. For example, childcare practices (proximal processes) will differ based on a child’s temperament, which in turn, impacts growth and development.

Bronfenbrenner and Morris acknowledged the relevance of biological and genetic aspects of the child, but focused more on the personal characteristics that a child can bring with them into any social situation (1998). More precisely, three types of characteristics of a child were described, including: demand (age, gender, skin color, and physical appearance); resource (mental and emotional resources such as past experiences, skills, and intelligence); and force (temperament, motivation, and persistence). For instance, two children may have similar demands and resources (i.e. both are five years of age, of African American descent, and have cerebral palsy with similar intellectual functioning), but each child's developmental trajectories will be quite different if one is motivated to be successful and works hard to achieve his or her goals, while the other is not motivated and does not work as hard.

A child's development is influenced by a wide range of biological and environmental factors, some of which protect and enhance their development while others could compromise their developmental outcomes (Fernald, Kariger, Engle, & Raikes, 2009). Within this center level of the ecological framework, personal characteristics, biological factors, and behavior all impact a child's overall developmental life course (see Figure 3 below).

Figure 3. The child: The innermost circle of Bronfenbrenner's ecological model.

(Wood, 2014)

The Microsystem

The second level directly outside the center is the system in which the child lives, the microsystem. That is, it is the layer closest to the child and contains structures within which the child has direct contact. The child is actively engaged and directly influenced by this system. The microsystem encompasses the relationships and interactions a child has with his or her immediate surroundings (i.e. face-to-face contact) such as with family, school or childcare environments, neighborhood, church, sports groups, primary care pediatric doctor, etc. (Berk, 2000; Bronfenbrenner, 2007). In Bronfenbrenner's model, primary care physicians are placed in the exosystem, but I would argue that in the case of a child with a chronic illness or disability, there is a great deal of face-to-face contact between the child, the family, and the primary care physician. This continued interaction of the primary care physician with the child and the family members would greatly impact the development of a child and I would therefore place the primary pediatric healthcare provider within the microsystem.

The major variables that have been studied in the microsystem level that influence the development of children with special needs that I will concentrate on are family with emphases on stress, coping and empowerment, and social support. This variable will be discussed in detail with examples of how the empirical literature analyses these types of influences on a child's development.

Family. As discussed above, family members of a child with special healthcare needs and/or disabilities greatly influence a child's development. Much of the literature examining families of children with disabilities focuses on family functioning and parental caregiving as it relates to stress, coping, and empowerment.

Stress. In a study examining stress levels, family functioning, and social support, Dyson (1997) compared the results of surveys from 32 sets of parents of children with developmental and other disabilities with the results of surveys from 32 sets of parents of children with typical development. Dyson showed that fathers and mothers of children with special needs exhibited greater levels of stress than did fathers and mothers of children without disabilities. In their comparison study examining parental stress, Roach, Orsmond, and Barratt (1999) surveyed 41 sets of parents of children with Down's syndrome and 58 sets of parents of children with typical development. Surveys revealed parents' stress level as it relates to care giving difficulties, child-related stress, parent-related stress, and parental involvement in childcare. Results showed that that mothers and fathers of children with Down's syndrome faced care giving challenges, including perceived competence in parenting, more health problems, greater feelings of role-restriction, and higher levels of parental depression, that exceeded those faced by mothers and fathers of age-matched children without disabilities.

In their review examining the impacts of stress on families of children with chronic and prevention strategies that exist for these types of families, Perrin and MacLean (1988) found that family members face increased risk for marital and economic dysfunction, and siblings may also feel the impacts as well. The authors suggest that ongoing interventions, including education and counseling for the child and family members, use of stress management techniques, and facilitation of social support mechanisms is imperative (Perrin & MacLean, 1988).

In her study investigating family stress related to resources, parental coping, and family types, McCubbin and McCubbin (1996) surveyed 58 two-parent families who had a family member living with a chronic illness. The sample of families was divided into three groups based on whether the child had mild, moderate, or severe levels of a chronic illness. She then examined the relationship between the family characteristics and the child's level of need based on the severity of the illness. The survey results showed that families contributed an increasing amount of involvement depending with increasing levels of severity of chronic illness. That is, the severity of the child's impairment does play a role in the management of family life with a child living with a chronic illness. This study also suggests that the degree of need for extended family and other social support had a significant positive association with the child's health problems. These data indicate that, given the increase of need for a child with a chronic illness, the greater the need for positive social support to assist families with the stress they may face.

Smith, Oliver, and Innocenti (2001) examined levels of parental stress by surveying 880 families of children with disabilities. Results suggest that, although both family functioning and the severity of the child's disability were related to overall parental stress, family functioning variables were generally stronger predictors of overall support. That is, the authors' results suggest that factors such as income, time available for interactions with their child, and social support predict parenting stress much better than do aspects of the child's current level of functioning (Smith, Oliver, & Innocenti, 2001).

Coping and Empowerment. Much of the research on families of children with disabilities that exists today focuses on coping skills and on levels of empowerment of family members (Folkman & Lazarus, 1988; Folkman & Moskowitz, 2000; Horton & Wallander, 2001; Kerr & McIntosh, 2000; Summers, Behr, Turnbull, Singer, & Irvin, 1989). In her study regarding the concept of empowerment in relation to parenting children with chronic illnesses, Gibson (1995) interviewed 12 mothers of children with a chronic neurological condition. Results revealed that, despite facing the challenges and stress of parenting a child with a disability, many families were able to adapt to their situation and develop a sense of control over their lives via empowerment (i.e. developing and employing the necessary knowledge, competence, and confidence for making their voices heard). In their review of positive affect and coping in individuals facing high-stress situations, Folkman and

Moskowitz (2000) found that even individuals who reported high levels of depressed mood could retain the capacity to engage in meaning-based coping and experience positive affect.

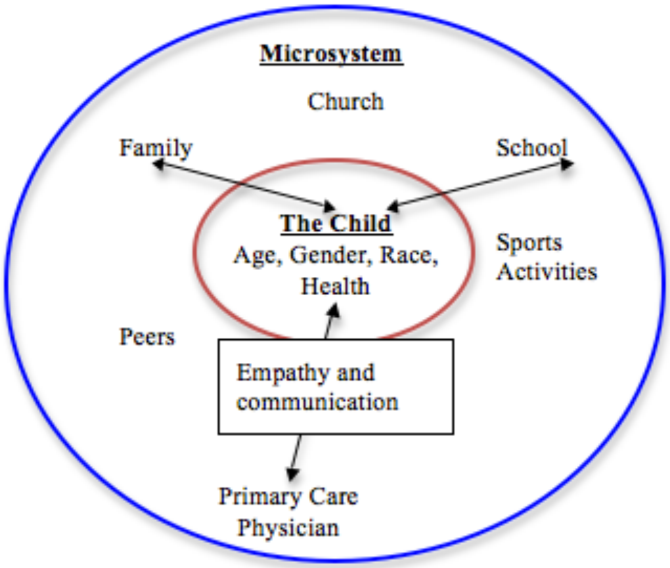
This section emphasized some of the major developmental influences upon a child with a special need within the child himself and from the child's microsystem. The following section will discuss how a child's relationships impact one another within and between the microsystem level.

The Child–Microsystem Relationship

As described above, the next concentric circle outside of the child is the microsystem, which refers to environmental contexts the child has direct contact with (family members, peers, and primary care physicians) that can act to influence the development of a child with special needs. For example, while a child's family members may directly affect his or her beliefs and behavior, the child also affects the behavior and beliefs of the parent. At the microsystem level, the term *proximal processes* refers to the reciprocal transactions between the child and persons, objects, and symbols in the immediate microsystem that directly influence a child's development (Bronfenbrenner, 2001). Throughout the first five years of a child's life, parenting is the primary proximal process (Lustig, 2010). Social roles, activities, and interpersonal relations as well as psychological and neurological functioning can be included within this system (see Figure 4 below).

At the very center of nesting circles is the relationship between the child and the microsystem. The relationship between these two levels can be the most tangible and fundamental aspect of a child's development. There are myriad forces at play between these two levels in both directions.

Figure 4. The microsystem: An example of the units of analysis and the directions of influence within the second level of an ecological model.



(Wood, 2014)

Within this section I will focus on the child-family relationship, the child-primary care physician relationship, and the child-school relationship. Further, I will examine how empathy (at the neurological, psychological, and interpersonal levels) and communication, as mediators, affect these many interactions.

Child-family relationship. The child-parent relationship is the child's primary proximal process, especially during the first five years of life. The way the child and the parent interact with one another greatly influences the development of the child. For example, factors at the microsystem level can directly affect the quality of parental caregiving for children with disabilities, which in turn can directly impact the child's development (Goldberg, Higgins, Raskind, Herman, 2003). That is, the effect of disabilities on parents and families may depend on the characteristics of the child's particular disability or current level of functioning (Algood, Harris, & Hong, 2013; Crnic, Friedrich & Greenberg, 1983).

Stress is one variable that affects the relationship between the child and his or her microsystem. In a study examining levels of stress associated with care demands and the use of social supports by Floyd and Gallagher (1997), 231 mothers and fathers of children with intellectual disability or chronic illness, or significant behavior problems, were surveyed. The researchers found that mothers and fathers of children with intellectual disabilities were uniquely stressed by worries about the independent functioning of their child in the future. Further, families of children with intellectual disabilities and behavior challenges experienced a significant amount of pessimism about their child's future, which resulted in the family members giving up on seeking out therapeutic services for their child. This act of giving up may negatively impact a child's development, leaving them without services to help them. Howe (2006) found that the perseverative behaviors of children on the autism spectrum who have challenges with communication might lead to a decrease in the sensitivity and attentiveness of parents. As a result, the child with the disability may become more distressed, leading to insecure or disorganized attachment to the parent and others. Further, a study completed by Lustig and associates examining 53 mothers of children with juvenile arthritis showed a link between the severity of the child's diagnosis and the impacts on family life to be related to mother's mental health; increased symptomatology was associated with a greater psychological symptomatology in both the parents and the child (Lustig, Ireys, Sills & Walsh, 1996).

Further to this point, there is an abundance of literature that describes the differences in ways fathers and mothers react to the stress of having a child with a disability. One example of this research examines how parents uniquely experience stress as related to their child's disability, which can have a tremendous influence on a child's overall development. In a study comparing the differences in stress in parents of children with disabilities with parents of children without disabilities, Walker (2000) found that significant gender differences in mothers and fathers of children with disabilities, in terms the kinds of stress parents reported. That is, mothers reported more stress related to the day-to-day care giving for their child with a disability and parental role restrictions, whereas fathers reported more stress related to the long-term impacts on the family, such as earning a living to provide for the family, and sustaining an attachment to the child with a disability. These very distinct ways in which mothers and fathers may react to stress with having a child with a disability may have a positive effect on some relationships and a negative effect on other relationships for the parents themselves (Risdal & Singer, 2004). For those parents whose relationship endures and becomes stronger as a result of their child's disability characteristics, the overall developmental trajectory for the child could be markedly improved compared to a child whose parent's relationship suffers from the characteristics of the child's disability; however, more research is needed in this subject.

Child-school relationship. The child-school dynamic is another important relationship at the center of Bronfenbrenner's ecological framework. A child's successful adaptation to school is likely based on a number of factors, including academic, social, emotional, behavioral, and cognitive competencies (Perry & Weinstein, 1998). In their study investigating adaptive behaviors of children transitioning in the school environment, McIntyre, Blacher, and Baker (2006) recruited 67 five- to six-year olds with and without intellectual disabilities to participate, along with their parents and teachers. Parents and teachers both completed measures of the child's maladaptive and adaptive behaviors, social skills, and also a measurement of the teacher-student relationship for each child. In addition, the investigators also completed measurements with each child individually. Results showed children with intellectual disability had significantly more teacher-reported problem behavior, poorer overall student-teacher relationships, few parent- and teacher-related social skills and fewer self-regulation skills than typically developing children. These influences on a child with a disability can have quite an impact on a child's development. Schools can be a source of stress or can help parents by providing various kinds of support.

Child-primary care physician relationship. For a child with a chronic healthcare need and/or disability, the relationship between the child and his or her primary care physician can be very influential in the child's development. Primary care providers are in a unique position to promote child and family health through access to needed services and psychosocial supports (Black, 2002). Physicians who deliver primary care to children with special needs provide longitudinal supervision to determine diagnosis, develop therapies, coordinate care with family and special services, etc. They are a point of first contact for children with many different types of chronic health conditions, including those with physical, developmental, behavioral, and emotional disorders.

Communication. A large body of the research examining the child-physician relationship has focused on communication as a variable that determines the effectiveness of physicians treating children with special needs. The way primary care physicians communicate with patients has been shown to affect physiologic measurements, adherence to therapeutic regimens, and satisfaction with medical care (Tates, Elbers, Meeuwesen, & Bensing, 2002; Dulmen, 1998). Research has shown that when physicians communicate directly and empathetically with children with special needs, there is a reduction in the number of surgical complications and morbidity (Barry, Stevenson, Britten, Barber, & Bradley, 2001). Further, children are interested in clinical information and may even retain information better than adults (MacCarthy, 1974; Pantell, Stewart, Dias, Wells, & Ross, 1982). Studies have shown the health-promoting value of active child participation (DeWinter, Baerveldt, & Kooistra, 1999). In their study examining communication practices of the pediatric physicians with children and parents, Wassmer et al. (2004) analyzed recordings of 51 pediatric consultations with 12 pediatric doctors. Results found that the child's participation within the consultation was small, even though there was awareness amongst pediatricians that children should take an active part and be involved in decisions about their own healthcare. In her literature review regarding child-doctor communication practices, Coyne (2008) found that communication with doctors could be positively or negatively influenced by the child's behavior (i.e. child's protest, child's age and maturity level, etc.).

Traditional medical expertise. Despite the importance of traditional medical training for physicians, a purely scientific approach that lacks empathy in evaluating a child with special needs can sometimes prove to be a barrier in affecting movement between the child and her microsystem. For instance, research has shown that mental health issues often are neglected in a traditional medical diagnostic process, as pediatricians have difficulty identifying children with emotional and behavioral problems, assessing parental coping, and responding to psychosocial concerns raised by parents (Brown, et al., 2002; Farmer, Marien, Clark, Sherman, & Selva, 2004). In their study comparing primary care physicians' ratings of psychological adjustment of their pediatric patients living with chronic illness with parents' and children's reports, Merkens, Perrin, Perrin, & Gerrity (1989) administered a series of psychosocial adjustment measures to 63 children with either a seizure disorder or an orthopedic condition. Results showed that physician reports were only moderately correlated with child and family views regarding psychosocial adjustment, indicating the physicians may need to focus more attention on children's physical and psychological development, or listen to parents and children more. In this instance, this research suggests that a health clinic following the family-centered medical care approach would help facilitate a more accurate and more effective child-physician relationship because it would allow more effective communication patterns inasmuch as the patient and the family are the center of focus.

The Family Perspective

The relationship between a child and his family can be one of the most influential factors in a child's developmental trajectory, especially a child with a special need (Bronfenbrenner, 1979; Farnfield, 2008). As described earlier, parenting is the primary proximal process throughout the first five years of a child's life (Lustig, 2010). Therefore, this section will examine the empirical literature on the influences that impact the child-family relationship (both positive and negative) through the lens of the family.

Positive influences. Families of children with special needs experience times of great joy and also times of hardship. Many families of children and youth with special healthcare needs and/or disabilities report experiences of enjoyment and satisfaction when caring for a child with a special healthcare need and/or disability. Although many parents of children with special needs acknowledge positive effects on their lives (Hastings & Taunt, 2002; Turnbull & Turnbull, 2000), these experiences have received limited documentation in the professional literature.

A small body of research has indicated that most parents of children with special needs report a number of positive changes in their lives as a result of parenting a child with a disability, which included 1) a stimulus for personal growth, 2) a contribution to family strength, 3) improved relations with others, 4) changes in philosophical or spiritual values, 5) a pathway to learning through experience and challenges, etc. (Behr, 1988; Behr, Murphy, & Summers, 1992; Scorgie & Sobsey, 2000). Also, emerging literature on post-traumatic growth indicates that, although challenging events (e.g. illness, injury due to accident, death, etc.) tend to produce negative results initially, the positive outcomes are typically not as immediate to be realized, but are lasting and of a higher order (Palus, 1993; Scorgie & Sobsey, 2000). Further, research of survivors of even extremely challenging events has shown that for most individuals, the crisis ultimately results in positive change and personal growth (Aldwin, 1994; Davis, Watson, & Corker, & Shakespeare, 2003; Frankl, 1984; Janoff-Bulman, 1992; Moos & Schaeffer, 1986). It is important to note that some individuals do not adapt to challenging events unless given the appropriate kinds of care and/or treatment. For instance, data on recent repatriated combat veterans suggest that about one third of the veterans do not adjust to life outside of the military without intensive treatment (Sayer, et al., 2010).

Challenges. Families of children and youth with special healthcare needs and disabilities do experience the typical demands of daily life, however, family members may also encounter a number of challenges that are unique to their child's needs (Ainbinder, et al., 1998). Although having a child with a special healthcare need and/or disability does not inevitably lead to challenges, a considerable body of literature exists that documents the stresses that parents may run into (Dyson, 1997; Hastings, 2002; McKinney & Peterson, 1987; Spratt, Saylor, & Marcias, 2007).

Research has indicated that some parents possibly will experience feelings of grief, loss, and guilt. Family members that cope with the responsibilities of caring for a child or youth with special healthcare needs or disabilities may be at an increased risk to experience stress, anxiety, financial worries, and ill health, in addition to the challenges of completing everyday tasks, as compared to families with typically developing children (Diehl, Moffitt & Wade, 1991; Singhi, Goyal, Pershad, Singhi, & Walia, 1990; Singer, Irvin & Hawkins, 1988; Quine & Pahl, 1987). In addition to the pressure of ensuring quality care for their child, some parents may feel isolated, which can lead to depression and hopelessness (Hastings, 2002; Rose & McDonald, 2005; Seligman & Darling, 1989; Winch & Christopher, 1988).

Empathy as a mediator. In this paper, empathy will be presented as a key mediator in the meso- and micro-systems. Empathy was chosen over other possible mediators (e.g. self-esteem, self-efficacy, or hardiness) because empathy can be considered a core skill for developing pro-social behaviors (i.e. the actions that are involved in building close relationships, maintaining friendships, and developing strong communities) (DeWaal, 2010).

Empathy is a fundamental part of human behavior that can be an integral part of the development of a child with a special need. As Theresa Wiseman (1996) wrote in her article regarding the concept of empathy and the implications for the nursing profession, no matter if empathy is a trait or a state, empathy has four defining attributes including: 1) seeing the world as another sees it, 2) being non-judgmental, 3) understanding another's feelings, and 4) communicating the understanding.

Although the volume of the current literature on empathy is sizable, there are many definitions of empathy that may cause theoretical confusion and empirical difficulties (Duan & Hill, 1996; Draguns, 2013). For the purposes of this paper, the following definition of empathy by Decety & Jackson (2004) will be utilized: the capacity to understand and respond to the unique affective experiences of another person. Much of the current research on empathy and prosocial behavior at the microsystem layer of the ecological model of human development focuses on characteristics at the neurological level (the origins and the source of variation in prosocial tendencies), biological level (evolutionary variations), and at the interpersonal level (variations of empathy experience based on a specific context).

Neurological level. In the recent empathy literature, there has been growing interest in research on the neural mechanisms that mediate empathy (Decety, 2011; Jackson, Meltzoff, & Decety, 2005; Singer & Lamm, 2009). As a result, researchers have been using functional magnetic resonance technology (fMRI) to measure brain activity by detecting associated changes in blood flow. With the use of fMRIs, some studies have shown that observing others in pain is mediated by several brain areas that influence processing the affective and motivational aspects of pain (Jackson, Rainville, & Decety, 2006). For example, in their study examining perspective-taking and positive appraisal, Lamm, Batson, and Decety (2007) took fMRI images of 17 participants while showing the participants video clips of the facial expressions of individuals receiving painful medical treatments. Participants viewing the video clips were instructed to either imagine the feelings of the patient or to imagine oneself to be in the patient's situation. The fMRI results showed that areas of the brain known to be associated with the processing of personal pain showed significant hemodynamic responses (i.e. increased blood flow and activity) as participants watched the videos, indicating that the processes of the experience of personal pain and the experience of pain in others have common characteristics. Further, adopting the perspective of others evoked empathic concern; where as personal distress was higher when imagining oneself to be in the painful situation. That is to say, when participants watched the videos of other individuals receiving painful medical treatments, the fMRIs suggested the observer's brain reacted neurologically to the images, causing the observer to feel the other person's pain.

Biological level. Research on empathy at the biological level has been built on evolutionary theories of altruism and the inherent social nature of human beings (Andreoni & Rao; 2011; Davis, 1983; Davis, Luce, & Krauss, 1994; De Waal, 2008; Taylor, et al., 2000). Much of the evolutionary focus of the research shows strong evidence of the heritability of empathy, empathic concern, and personal distress. According to De Waal's evolutionary review of empathic behavior (2008), empathy allows one to quickly and automatically relate to the emotional states of others, which is essential for the regulation of social interactions, coordinated activity, and cooperation toward shared goals. Further, De Waal purported that the intrinsic benefit derived from the act of helping, with no reciprocation (i.e. true altruism), develops another person with shared experiences is in need (De Waal, 2008). Moreover, research also shows that evolutionary behavioral responses differ biologically between men and women (Roberts & Stayer, 1996; Taylor, 2000). According to Taylor, Klein, Lewis, Gruenewald, Gurung, & Updegraff, (2000), the fight-or-flight response may characterize the primary physiological responses to stress for both males and females, but behaviorally, females' responses are more marked by a pattern of the empathy-based behavior of "tendingand-befriending" (p. 411). These biological responses may be underpinned by the hormone oxytocin, opioids, and dopaminergic pathways (Taylor, 2006).

Interpersonal level. Research on empathy at the interpersonal level, that is empathy between two individuals within a given context, is quite extensive with a number of differing theories, many of which conflict with and challenge one another. Two very opposing empathy theories include: 1) the Empathy-Altruism Model and experiential empathy (Batson & Shaw, 1991; Batson, Batson, Griffitt, Brandt, Sprengelmeyer, & Bayly, 1989; Corcoran, 1981; Davis, 1983; Penner, Fritzsche, Craiger, & Freifeld, 1995), and 2) the Negative State Relief theory and perceived similarity (Cialdini, Brown, Lewis, Luce, & Neuberg, 1997; Stotland, 1969).

Empathy-altruism theory. The Empathy-altruism theory states that empathy is a purely altruistic action that can occur reliably, provided that it is preceded by empathic concern for another (i.e. compassion, tenderness, sympathy, etc.), and is brought on by the act of taking the perspective of another (Batson & Shaw, 1991). Also, empathy has been tied to nurturing tendencies based on the impulse to care for and protect offspring (Batson, Lishner, Cook & Sawyer, 2005). In their study investigating empathy felt for strangers, Batson, Chang, Orr, and Rowland (2002) 54 men and women were split into three groups based on how similar each participant was compared to the person being interviewed (i.e. similar, moderately similar, and dissimilar). Each group listened to an interview of a convicted heroin addict and dealer, and then was asked about recommendations for allocating funds to help drug addicts. Results of the experiment suggested the more positive attitudes evoked by empathy led to increased helping of an individual, despite the fact that the individual in need is a complete stranger. Similarly, empathy avoidance is a theory that states when one is faced with a high-cost helping scenario, individuals actively resist feeling empathy for an individual in need in order to avoid prosocial action motivated by empathic concern (Shaw, Batson, & Todd, 1994).

Negative state relief theory. On the opposite end of empathy theory research is Negative State Relief theory, which asserts that an individual's heightened empathy for a sufferer brings with it increased personal sadness in the observer and that it is the egoistic desire to relieve the sadness, rather than the selfless desire to relieve the sufferer, that motivates helping (Cialdini, et al., 1987). Further, individuals may be more empathetic to others based on perceived similarity: in other words, that we will feel sympathy and compassion for others to the degree we perceive them to be like us (Caildini, Brown, Lewis, Luce, & Neuberg, 1997; Oveis, Horber, & Keltner, 2010; Stotland, 1969). In their article examining data from three separate studies, Cialdini, Brown, Lewis, Luce, and Neuberg (1997) investigated how perceived similarity mediates empathy with over 400 participants of both female and male college-aged students. Each study examined a participant's willingness to help someone in need as compared to the amount of sadness, personal distress, empathic concern, and perceived similarity the participant felt in relation to the person in need. Results indicated that for participants with greater empathic concern and perceived similarity with the person in need, there was greater willingness to help.

Patient-professional relationship. Another aspect of the interpersonal level of empathy that has been greatly scrutinized in the literature is that of the patient-professional relationship. This line of research examines the cost of accurate empathizing with special attention given to professionals (e.g. heatlthcare providers, therapists, etc.) and volunteers (e.g. parent advocates) who routinely are a part of high-empathy inducing conditions.

Previous research has evaluated the significance of empathy within medical interactions, focusing on the importance for the provider-patient (and patient family) alliance and for the successes of the medical care (Wynn & Wynn, 2006). Much of the research in empathy within the context of the patient-professional relationship has concentrated on asymmetries and interactional dominance. Further, the research asserts a professional's need to maintain an "emotional distance" from patients in order to maintain a professional separation from the distress of the experiences the patient shares through self-other differentiation (i.e. the separation between a healthcare professionals affect and the patient's) to decrease the chances of professional burnout. Goubert, Liesbet, Craig, and Buysse (2011) stressed a misconception may exist in that individuals who consistently display highly accurate empathy for those in need could be labeled as oversensitive and may have difficulty providing effective assistance to others due to high levels of distress in both the help-seeking individual and the helping individual. In an older study investigating the maintenance of emotional separation and its relationship with empathy, Corcoran (1982) surveyed 131 graduate students of social work via two different empathy scales regarding the participants' empathic tendencies. Results revealed a curvilinear relationship of the maintenance of emotional separation and empathy; empathy is inversely related to maintaining emotional separation. Those individuals who showed more empathy to another in need had decreased ability to maintain emotional distance, whereas those individuals who maintained emotional distance from another in need displayed low levels of empathy. It has been established in the literature, however, that patients and their families who perceive, and therefore experience, their healthcare provider as empathic show more improvement in health outcomes that those who do not (Squier, 1990). An individual's experience of empathic understanding creates the conditions for increased insight into the nature of illness and for feeling cared for in a helping relationship (Hoffman, 2001). Mishler (1984) suggested that this emotional disconnect medical professionals maintain and their use of the voice of medicine seems to block empathic communication between the family members and the medical professionals because of the professionals' over emphasis of listening aimed at filtering information to make a medical diagnosis. The relationship between healthcare providers and patients and their families is vital in the development of a child with a special need. It is clear from the empathy literature discussed above that healthcare providers should incorporate empathic behaviors towards children with special needs and their families within their practice while regulating their own emotions in order to decrease levels of proximate trauma and professional burnout, as well as to provide consistent and effective care. Empathy within the framework of healthcare provider training will be discussed later in this paper.

The Mesosystem

The third level of the ecological model is the mesosystem. According to Wiseman (1996) this mesosystem moves us beyond the dyad relation. This level comprises the linkages and processes taking place between two or more settings surrounding the developing child (Bronfenbrenner, 1994). It is literally the layer that provides the interconnections between the structures of the child's Microsystems (Berk, 2000). Parent-to-parent programs and other voluntary organizations, health clinics, and other social services are a part of the mesosystem.

An example of the linkages within the mesosystem would be the interactions between parents and the primary pediatric healthcare provider, the linkages between two separate microsystems within the child's development. The connection between other larger structures, such as a church or community, can also be expected to have distal processes at work because they help the family to provide the necessary support a child needs.

The major variables that have been studied in the mesosystem level that influence the development of children with special needs that I will focus on in this section are voluntary organizations (social and other informal supports), health clinics (formal support), and the voice of medicine and the lifeworld (discourse analysis).

Voluntary organizations and social supports. Voluntary organizations can be defined as a group of individuals who enter into an agreement as volunteers to form a body or an organization to accomplish a purpose. A number of these grassroots organizations have been formed to assist individuals in need through both formal and informal forms of social support. Social support is conceptualized as a network of behaviors that may provide another person with assistance in coping with short- or long-term stressors (Pierce, Sarason, Sarason, Joseph, & Henderson, 1996). According to Cutrona & Russell (2000), social support can be provided in many forms (e.g., direct assistance, affection, encouragement, companionship, advice, etc.) and from a variety of sources (e.g. family members, friends, neighbors, religious groups, etc). A large body of literature has shown the benefits of social support to families of children with special needs (Blacher, Neece, Paczkowski, 2005; Boyd, 2002; Dyson, 1997; Floyd & Gallagher, 1997; Hastings, Allen, McDermott, & Still, 2002; Horton & Wallander, 2001; Thoits, 1986; White & Hastings, 2004).

A number of voluntary organizations exist currently to help provide social support (including emotional and informational support) for families of children with special needs. An example of such a voluntary organization is parent-to-parent support. (Ainbinder, et al., 1998; Kerr & McIntosh, 2000; Santelli, Turnbull, Marquis, & Lerner, 2000). In a study examining the effects of social support on 80 mothers of children with disabilities, Weiss (2002) found that social support: predicted the mother's ability to adapt to the child's disability; led to increased parenting efficacy; and reduced symptoms of depression. Further, voluntary organizations not only can provide support directly to the family members, but they also can help facilitate collaboration and connections with professional systems of support, such as with medical professionals or school administrators (Dennis, 2003; Frazier, Abdul-Adil, Atkins, Gathright, & Jackson, 2007; Konrad, 2007; Leake, Longworth-Reed, Williams, & Potter, 2012; Munson, Hussey, Stormann, & King, 2009; Winch & Cristoph, 1988).

Health clinics and formal supports. Health clinics and other sources of formal support for family members of a child with special healthcare needs and/or disabilities may have a significant influence on a child's development. Much of the literature examining medical clinics within the context of supporting families of children with disabilities concentrates on: levels of family-provider communication and collaboration (Ahrens, Yancey, & Kollef, 2003; Andreoni & Rao, 2011; Bhasale, 1998; Barry, Stevenson, Brittten, Barber, & Bradley, 2001; Denboba, McPherson, Kenney, Strickland, & Newacheck, 2006; Gallant, Beaulieu, & Carnevale, 2002; Brunett, et al., 2001; Nolan, Orlando, & Liptak, 2007); family's access to specialty care through care coordination (Anderson, McIntyre, Rotto, & Robertson, 2002; Cooley & Sagerman, 2011; Orchard, Curran, & Kabene, 2009); number of school days the child has missed, as well as number of days the child has spent in the hospital and medical costs for the family (Ahrens, Yancy, & Kollef, 2003); and the impacts of family-centered care (Evans, Dollard, Kuppinger, Mood, Armstrong & Huz, 1994; King, Teplicky, King, & Rosenbaum, 2004; MacKean, Thurston, & Scott, 2005; Pettoello-

Matovani, Campanozzi, Maiuri, & Giardino, 2009). In this section I will discuss each of these areas described above.

In their 2006 study, Denboba, McPherson, Kenny, Strickland, and Newacheck analyzed a nationally representative survey of families of children with special healthcare needs in which 38,866 telephone surveys were completed. Bivariate and multivariate statistical methods were utilized to assess family-provider partnerships within the context of age, type and severity of disability, gender, socioeconomic status, amounts of insurance coverage, and overall quality of care. Results indicated that families who felt like a partner with healthcare providers had better access to specialty care, more satisfaction with care, and children had fewer missed school days, as compared to the families who did not feel like a partner with healthcare providers. Overall, this study illustrates that over 85 percent of families of children with special needs felt like a partner with healthcare providers in the care of their children. However, 14 percent of families, approximately one million nationwide, lacked a sense of partnership. Poverty, minority or racial status, absence of health insurance, and greater severity of functional ability of the child placed families of children with special needs at an elevated risk of being without a sense of professional partnership.

Bhasale (1998) examined incident reports from 219 general practitioners from over 500 diagnostic incidents with families of children with special healthcare needs and/or disabilities in order to identify how diagnostic incidents occur. Results demonstrated that healthcare professional errors in the diagnostic process occur through errors in judgment and systems of information transfer (diagnostic tests, care coordination with specialty care teams, medical records failures), and due to poor communication between patients' families and the healthcare professional. These diagnostic errors can result in misdiagnoses, increase in hospital stays and missed school days for the child, and a major increase of medical care costs.

Evans, Dollard, Kuppinger, Wood, Armstrong and Huz evaluated the effectiveness of care from outpatient family-based intervention programs for families of children with serious emotional disturbance as compared with in-patient treatment. The family-based intervention consisted of a case manager and a parent advocate (to facilitate the family's communication and collaboration with healthcare providers), respite care, parent support groups, and behavior management skills training. Thirty-nine families of children between the ages of five and 12 years were randomly assigned to the intervention group (*n* =15) and non-intervention group in the inpatient program (*n* = 24). Results indicated that the family-based interventions results generalized better once the study was complete for families in caring for their child's needs outside of the clinical setting as compared to those participants who took part in the clinic-based setting intervention. Further, for families who received the intervention, the child was able to stay at home, whereas those children who received treatment as an inpatient had to be away from home for an average of 13.2 months.

The voice of medicine and the lifeworld. Research in the field of discourse analysis is beginning to emerge in the field of medicine and within other contexts (Hepburn & Potter, 2007; Heritage & Lindstrom, 1998; Brunett, et al., 2001; Platt & Keller, 1994; Pudlinski, 2005). The technical- and jargon-laden discourse found in professional settings and the naturalistic discourse found in non-professional settings are drastically different and therefore have different influences on the development of an individual, especially the development of a child with a disability (Barry, Stevenson, Britten, Barber, & Bradley, 2001). The voice of medicine reflects the common discourse in doctor-patient encounters, engages a technical interest and expresses a “scientific attitude.” That is to say, the meaning of events is provided through abstract rules that serve to decontextualize events, to remove them from particular personal and social contexts (Mishler, 1984, p.104). The voice of medicine is often used within the context of the medical world as a form of communication with lower levels of empathy between medical professionals and patients or patient’s families, in addition to other parent/professional contexts including Individualized Education Meetings (IEP) in schools. In contrast, the voice of the lifeworld refers to an individual’s contextually grounded experience of events and problems in his or her life (Barry, Stevenson, Britten, Barber, & Bradley, 2001). More explicitly, lifeworld discourse is the use of a more natural attitude with higher levels of empathy to describe everyday life. The voice of the lifeworld is often used in non-professional settings between family members and friends.

Barry, et al. (2001) examined Mishler’s premise that the discourse of medicine produces poorer results when compared to the discourse of the lifeworld (i.e. a less technical, more natural way of expressing details of everyday life). The investigators interviewed 20 healthcare providers about their choice of discourse for patients and the family members. Thirty-five provider-patient cases from diagnosis to follow-up were studied in detail. Results showed that the quality of results of each case (i.e. diagnosis process; present levels of functioning for the child; ability of the provider to communicate with the child or family members; quality of healthcare treatments; families’ overall compliance with the provider’s recommendations; and health outcomes for the child) was dependent upon the providers’ choice of discourse utilized with the family. That is, the voice of medicine cases resulted in the poorest outcomes, especially when the families’ use of the lifeworld (i.e. more casual, non-technical use of discourse) was blocked or ignored by the physician, whereas the voice of the lifeworld cases resulted in the best outcomes for families.

Group-related empathy, empathy training, and volunteering. Another level of empathy research exists within the mesosystem level of Bronfenbrenner's ecological model of human development. It is the research of group-related empathy, empathy training, and the impetus to volunteer.

Group-related empathy. According to Stephan & Finlay (1999), empathy can play a significant role in improving intergroup relations. Bridgeman (1981) found that when children work interdependently with children from other groups, they learn to take the role of the other students and learn to view the world from their perspectives due in part to empathy. Batson and Shaw (1991) has shown that not only can inducing empathy for a member of a stigmatized group improve attitudes towards the group as a whole, but it also can increase the overall altruistic motivation within those who experience the empathic emotion.

Empathy training. Empathy research has concentrated on the training empathy for volunteers and professionals working with others in need (Monroe, 2006; Price & Archibold; 1997; Payne, Weiss, & Kapp, 1972). According to Platt and Keller (1994) empathic communication is a learnable skill that must be provided to individuals who are in positions of helping others. Spiro (2009) also emphasized that empathy is a foundation of patient care for medical providers and should frame the skills of the profession. In their study examining the effects of an empathy-training program, Schonert-Reichl, Smith, Zaidman-Zait, & Hertzman (2012) recruited 585 fourth- to seventh-grade children from 28 classrooms to participate. The training program focused on decreasing children's aggression and facilitating the development of their social-emotional understanding and prosocial behaviors.

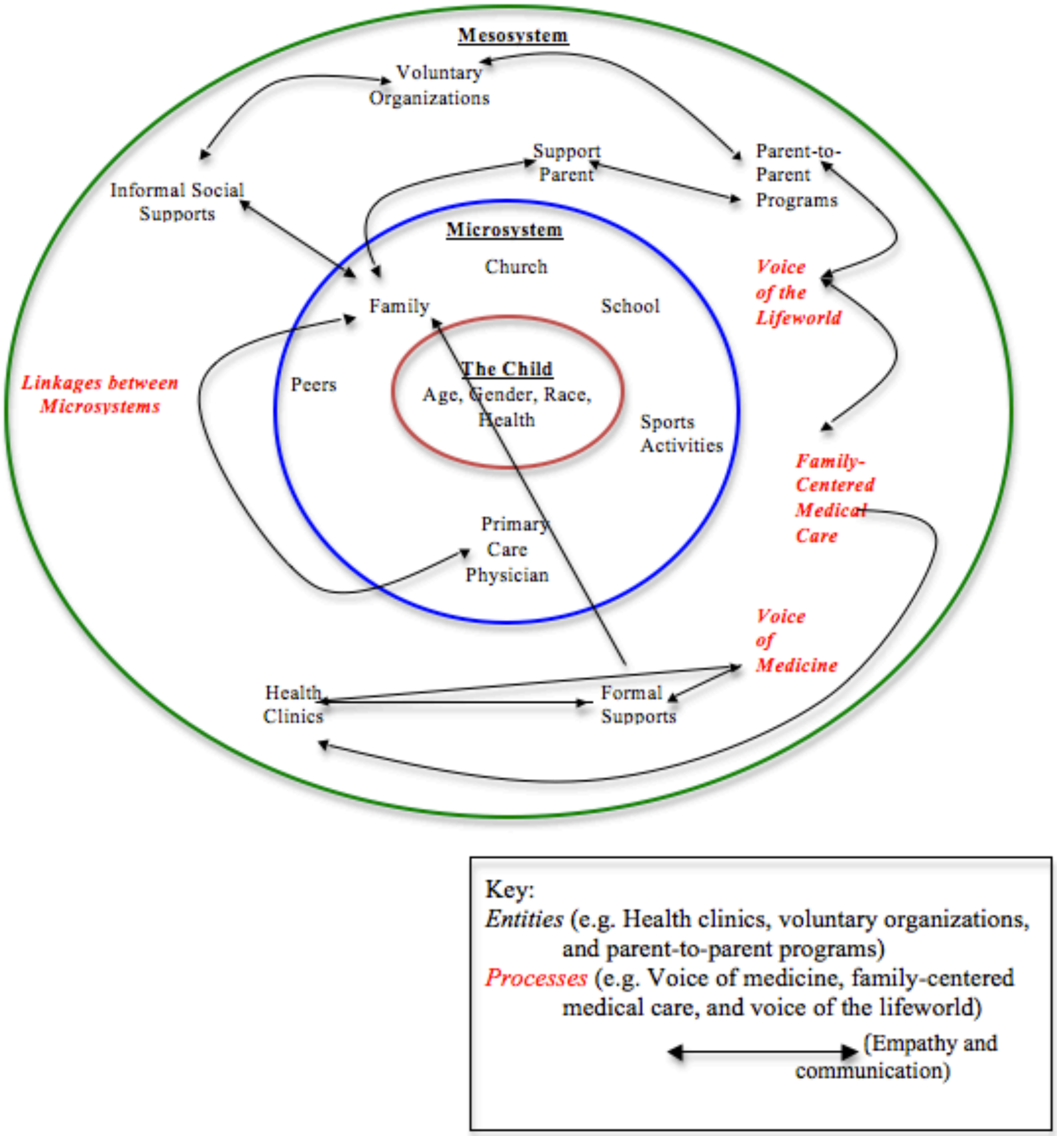
Outcomes from the study showed significant increases in the participants' prosocial behaviors towards others.

Volunteering. A small body of research has examined empathy and the act of volunteering. In their 1999 study, Davis, Mitchell, Hall, Lothert, Snapp, and Myer showed that individuals who have high level of empathic concern and low personal distress are most likely to volunteer in direct service to those in need and, subsequently, to find the work satisfying. In her 1991 study, Unger examined the existence of altruistic motive to volunteer by analyzing data from 326 telephone-survey respondents. Participants responded to questions in regard to amount of time spent working and not working, types of volunteer activities, demographic information, and perceived community need (i.e. a high homeless population, underserved and unrepresented children in schools, children going hungry, etc.). Results indicated that the evidence for altruism as a motive for volunteerism was supported in that perceived community need was the strongest predictor of volunteer activity.

The Microsystem–Mesosystem Relationship

As described above, mesosystems affect the child directly. That is, the child is actively able to engage and socialize with others in the mesosystem (see Figure 5 below). Mesosystems can be thought of as opportunities to build a bridge between two different settings, thereby providing consistency and familiarity in the child's life. Both positive and negative interactions, or linkages, between microsystems can affect the child's development (Bronfenbrenner, 1988). Within this section I will focus on the parent-health clinics relationship, and how voluntary organizations and social supports affect the interactions between these two microsystems.

Figure 5. The mesosystem: An example of the units of analysis and the directions of influence within the third level of an ecological model.



(Wood, 2014)

Parent-health clinic relationship. The complex relationship between parents of children with special needs and health clinics is an important component of the micro-mesosystem connection of a child's development. It stands to reason, and much of the research from the parent-health clinic relationship agrees, the family's relationship quality with health clinics impacts the child's overall health outcomes (Anderson, McIntyre, Rotto, & Robertson, 2002; Denboba, McPherson, Kenney, Strickland, & Newacheck, 2006; Orchard, Curran, & Kabene, 2009). That is, families rely on health clinics and the physicians within to provide effective care (including diagnosis, development of treatments, coordination of care with specialty service providers, etc.) and health clinics and physicians rely on families to follow through on health treatments, and to provide clients that produce revenue. Clinics follow a very formal infrastructure, with a strict set of guidelines and protocols as a framework to provide care. Families, on the other hand, come into the clinics in a more naturalistic, informal manner with only their life experiences and questions regarding their child's needs. Communication and collaboration are two moderators that affect the relationship between the parents and the primary care physician.

Communication and collaboration. Data from this section of the literature suggest that medical providers and families often have challenges communicating and collaborating effectively, leading to poor quality healthcare and the families' inability to comply with medical guidelines (Bhasale, 1998). In this case, direct processes of empathy might characterize doctor-patient face-to-face interactions (Levinson, Lesser, & Epstein, 2010; Suchman, Markakis, Beckman, & Frankel, 1997). That is, medical providers who lack empathic communication with families may lead to medical decisions lacking in quality. One reason for this lack of communication and inability to coordinate care may be the medical providers' use of the technically laden voice of medicine, as well as a lack of demonstrated empathy (Barry, Stevenson, Britten, Barber, & Bradley, 2001; Bhasale, 1998). Furthermore, the organizational entity that houses medical professionals and medical training programs might either foster or suppress empathetic communication through policies, practices, and culture (Mauksch, Dugdale, Dodson, & Epstein, 2008;. Edelhäuser, et al., 2010).

Voluntary organizations and social supports. One vital entity that exists within the mesosystem is that of voluntary organizations and social supports that can also behave as a variable to help moderate movement between a child's microsystem and mesosystem. Voluntary organizations and other forms of social support not only can help families adapt and thrive in the face of the challenges of raising a child with a disability (i.e. the child-microsystem relationship), but they can also help improve communication and collaboration between parents and health clinics (i.e. the microsystem-mesosystem relationship). That is to say, there can be organizational entities that have a major function of facilitating micro-social interactions (e.g. Individualized Education Plan meeting facilitators or advocates) or in helping families gain access to other mesosystem entities (e.g. case managers at federally-funded regional centers or parent-to-parent PCs who can assist families with navigating complex insurance companies) (Algood, Harris, & Hong, 2013; Bricourt, Porterfield, Tracey, & Howard, 2004). These processes might include providing information, giving encouragement, serving as an advocate, or modeling a skill.

Availability and helpfulness. Voluntary organizations are often the first resource that parents in distress turn to for social support (Thoits, 1986). Thoits (1986) describes social support as the functions performed for a distressed individual by significant others such as family members and friends (informal support) or support groups and mental health professionals (formal support) that will help the individual cope when handling stressors. Thoit also showed that peers could assist an individual in coping with stress by helping them manage or change the situation that is causing them stress, or by helping to reduce their negative feelings from stress (1986). Voluntary organizations and other forms of formal social support provide informational and emotional support, and remind the parent that they are not alone in their experiences (Ainbinder, at al., 1998). The extent that voluntary organizations and social supports are made available to families in the microsystem can largely determine how well parents cope and adapt while caring for their child with special needs. Much of the current literature focuses on identifying how resources available to parents of children with disabilities can affect the psychological outcomes of the family members (Hastings & Taunt, 2002). One important potential resource variable is the availability and/or helpfulness of formal social supports from voluntary organizations and other forms of social support (Beresford, 1994). For example, some parents may experience stress if they perceive the formal social support resources available to them (e.g. volunteer organizations, early intervention providers, or social service managers) are inadequate to help the family members manage the challenges of caring for a child with a disability (White & Hastings, 2004).

In his literature review, Boyd (2002) investigated the relationship between social supports and stress in mothers of children with Autism and found low levels of social support were the most powerful predictor of depression and anxiety in mothers. Results also showed that mothers who had the least reliable supports displayed more negativity towards their child and pessimism regarding their child’s independence in the future. These pessimistic feelings toward the child may have a negative influence on the child’s development. The direction of causality between depression and lack of social support is not established in this study.

When the support from voluntary organizations and other forms of social support (such as parent-to-parent programs) is effective and helpful, families have shown a decrease in stress (Dyson, 1997; Floyd & Gallagher, 1997; Horton & Wallander, 2001; Kerr & McIntosh, 2000; McCabe, 2008; Solomon, Pistrang, & Barker, 2001; Thoits, 1986; Weiss, 2002) and in increase in empowerment (Gibson, 1995; Koren, DeChillo, & Friesen, 1992). This decrease in stress and increase in familial empowerment (facilitated by an effective interaction between the mesosystem and the microsystem) can then enable families to be better informed and more proactive in their care of their child, as well as become more involved and empowered partner with health clinics. The research cited above is an example of how voluntary organizations and other social supports facilitate a more positive relationship between the child and the family. However, social supports can also facilitate a more positive relationship between family members and health clinics.

Support: a connection with parents and health clinics. When voluntary organizations, such as parent-to-parent programs, effectively provide informational and emotional support as the goals of such programs intend, families and health clinics both are affected. Families learn through the experiences of others how to successfully navigate health clinics and the health systems in general (e.g., what kinds of questions to ask primary care physicians, where to find specialty care, etc.) and empower families to collaborate equally with physicians in health clinics. On the other hand, voluntary organizations can also affect health clinics by providing training in how to empathetically collaborate with families, resulting in a better understanding of families’ needs in order to provide care that is more family centered (i.e., putting the needs and wants of the families first). Further, voluntary organizations may be able to mediate the relationship between health clinics and families by providing an additional source of information and support to families that the health clinics may not typically be able to offer families (Wood & Singer, 2014). As a result of the additional support provided by voluntary organizations, research has shown that improved communication and collaboration between health clinics and family members can lead to improved healthcare outcomes for the child and a decrease in medical costs (Ahrens, Yancey, & Kollef, 2003; Gallant, Beaulieu, & Carnevale, 2002). For example, in their review of the literature regarding the effectiveness of family-centered care within health clinics, Turchi, Gatto, & Antonelli (2007) found that achieving family-centered care is linked with: 1) increases in family satisfaction and linkages to specialists; 2) decrease in school absences and other unmet needs for the child; 3) a providing care that is linked with the medical home concept of care as designed by the American Academy of Pediatrics (AAP); 4) better coordination of care with specialists; and 5) a decrease in medical care costs for health clinics.

Family Access to Supports

As described above, influences within the mesosystem, the third level of Bronfenbrenner's ecological model, can have a strong impact on the family of a child with a disability. Challenges within the parent-healthcare system relationship and a lack of social supports are entities from the mesosystem level that can influence families, whereas the voice of medicine can be characterized as an active process that creates links to or blocks entities from accessing one another.

Parent-healthcare system relationship. Research has shown that families consistently stumble on unforeseen barriers within the healthcare system in an effort to access information, services and supports needed to be engaged and empowered partners when working with healthcare providers (Wagner, et al., 2001). Although meeting the complex and specialized needs of a child with disabilities requires collaboration between parents and professionals (Watson, Townsley, & Abbott, 2002), parents rarely experience an equal relationship with professionals.

Summers, Behr, Turnbull, Singer, & Irvin (1989) described how practitioners seldom receive instruction on how to work with families who have children with disabilities (especially those with positive adaptation) and instead are instructed to take over the care decisions in order to “fix” the problems associated with having a child with a special need. Moreover, parents may be lacking the knowledge, expertise or power to influence decisions, participate in interventions, or negotiate the services affecting the child when working with professionals (Brett, 2002; Case, 2000; Dale, 1996).

Caregivers have reported the feeling of a lack of understanding and empathy from their child’s healthcare providers in regards to the families’ individual needs and wants (Case, 2000; Dale, 1996), and even their cultural beliefs (Harry, 2008). In fact, some caregivers report medical professionals often exclude family members completely in the healthcare decision-making process for their child (Case, 2000).

In his survey and interview study with families throughout the United Kingdom, Case (2000) examined the efficacy of healthcare provided from the perspective of 114 parents of children with developmental disabilities. Data revealed that: 1) professionals continue to control the parent-professional relationship, assuming the role of expert, rather than collaborating with parents; and 2) parental needs were prescribed specifically by professionals, thus marginalizing and disempowering the parent (Case, 2000). For example, parents reported doctors rarely showed concerns for the parent’s feelings, provided mostly negative feedback, and an overall lack of concern or consideration for the parents (Case, 2000).

Voice of medicine. In addition to the challenges for families of children with special healthcare needs and/or disabilities described above, a further barrier can impede access to collaboration with healthcare providers; that is, the provider's use of the voice of medicine. Bureaucratic and professionally staffed organizations seem to readily give rise to formal kinds of discourse such as the voice of medicine (Barry, et al., 2001; Freidson, 1970).

The current literature has shown that healthcare providers often use a technical way of speaking when discussing a child's diagnosis and treatment plans with family members. According to Mishler (1984), the voice of medicine reflects medical professionals' technical interest and is often expressed with a scientific attitude, which can leave families feeling uncomfortable and isolated (Barry, Stevenson, Britten, Barber, & Bradley, 2001). A healthcare provider's incapacity to communicate more naturally and his/her inability to collaborate with families of children with disabilities can lead to: 1) misdiagnosis due to missed symptoms and an inability to elicit information from the child or family members; 2) poor quality healthcare treatments; 3) lack of compliance of the provider's recommendations; 4) further health complications for the child; and 5) greater stress on the family itself (Bhasale, 1998).

According to Barry, Stevenson, Britten, Barber, & Bradley (2001), the use of the voice of medicine often isolates families and leaves them on their own to learn about their child's diagnosis, and discover without guidance what the diagnosis may mean for their child, as well as for their family as a whole (Hummelinck & Pollock, 2005). Parents must learn the language of the medical, legal, financial, and special education worlds, and find their way in a service system that may or may not provide appropriate support (Avila, 2009).

These challenges may be magnified for families who are underserved and underrepresented, including families who are living in poverty, those from various cultural and linguistic groups and families living in extremely rural areas of the country (Harry, 2008; Markey, Markey, Quant, Santelli, & Turnbull, 2002). Further, healthcare professionals may also create feelings of meaninglessness in parents by withholding the full extent of medical prognoses from parents, which may cause more stress for parents than receiving detailed and accurate information, regardless of the severity of the prognoses (Case, 2000; Dale, 1996; Mack, et al., 2007).

Few social supports. Due to the challenges described above that some families of children with special needs may face, parents often report feelings of isolation and loneliness, due to few social and emotional supports being available (Santelli, 2002; Seligman & Darling, 1989). Empirical literature has shown that social support (both informal and formal) can help mediate the effects of stress and other negative impacts on families of children with disabilities (Boyce, Behl, Morensen, & Akers, 1991; Byrne and Cunningham, 1985). In a comparison study assessing the effects of social support and hardiness on the level of stress in mothers, Weiss (2002) examined 80 mothers of children with varying types of disabilities, and 40 mothers of children without disabilities. Results indicated that mothers who reported having social support had fewer depressive symptoms related to stress or depression.

Support from professionals also can buffer the effects of stress. Honig and Winger (1997) investigated the effects of professional support on stress in 65 families of children with developmental disabilities and found that professional services made a measureable difference in decreasing levels of parental perceptions of stress. White and Hastings reported findings of a positive relationship between the perceived availability of social support and measures of parental wellbeing (2004). That is, just knowing that support was available to family members of children with disabilities, the wellbeing of the parent increased (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Summers, et al., 2007).

Despite the strong empirical evidence showing the ameliorating effects of social support, current literature shows that, when asked about supports in their healthcare system and within their communities, parents of children and youth with disabilities identified several unmet needs, including information and support for parents, and support navigating the complex systems and services through formal types of support. (Farmer, Marien, Clark, Sherman, & Selva, 2004).

The Exosystem

Moving even further out in Bronfenbrenner's ecological framework of human development, the exosystem sits at the fourth level. This is the system of institutions that the child does not directly interact with, but which has a profound influence on the child's microsystem and the child itself via the linkages from the mesosystem. That is to say, the structures in this level impact the child's development by interacting with some structure in his or her microsystem, without direct contact with the child (Berk, 2000). Contrasting with the mesosystem and microsystem, the exosystem influences the child indirectly as it filters down through other individuals that have an influence on the child's life. Exosystems that may indirectly influence a child through their microsystems include: the community parent-teacher organization, the child's broader community outside the neighborhood, the school district, health insurance, parents' workplace, local politics and industry, mass media, technologically-based social networks, etc. For example, a parent's workplace schedule (e.g., shift work) can influence the proximal processes that occur and, consequently, the development of the child.

Research in the exosystem arena has focused on population studies, which have established associations between measures of social relationships and mortality, psychiatric and physical morbidity, and adjustments to and recovery from chronic diseases (Dennis, 2003). Furthermore, research also has shown that interventions designed to alter the social environment and the individual's transactions within it have been successful in facilitating psychological adjustment, aiding recovery from traumatic experiences, and even extending life for individuals with serious chronic disease (Cohen, 2004). The major variables that have been studied in the exosystem level that influence the development of children with special needs that I will focus on in this section are medical institutions and policies, including the medical home model of care, health insurance companies, large health institutions, and the American Academy of Pediatrics.

Medical institutions and policies. Medical institutions and policies may have a remarkable impact (both positive and negative) on the overall developmental trajectory of a child with a special healthcare need and/or disability. Even though the child rarely, if ever, has direct contact with these components of the exosystem level, medical institutions, and the policies developed from these institutions, can directly affect other influential entities in the child’s life. For example, much of the current research in medical care within the context of the exosystem level has suggested that models of enhanced primary care can lead to health care systems with better performance (Sia, Tonniges, Osterhus, & Taba, 2004). Research has shown that interventions within medical systems of care that employ quality improvement processes, practice systems change, and provider education effectively improve care for children with special needs (Rankin, Cooper, Sanabria, Binns & Onufer, 2009). The American Academy of Pediatrics (AAP), a professional association of over 62,000 pediatricians, is a medical institution that has published hundreds of policy statements ranging from advocacy issues to practice recommendations. In 1967, the AAP introduced the concept of the Medical Home Model of care (Carrier, Gourevitch, & Shah, 2009). Many commentators have adapted the model of the patient-centered medical home as policy shorthand to address the reinvention of primary care in the United States (Landon, Gill, Antonelli, & Rich, 2010). It is an approach to providing comprehensive primary care for children, youth and adults (Cooley, 2004; McAllister, Presler, & Cooley, 2007). The provision of medical homes may allow better access to healthcare, increase satisfaction with care, and improve quality of healthcare (Cooley & McAllister, 2004; Turchi, Gatto, & Antonelli, 2007). The development and implementation of the medical home concept has received support from the Maternal Child Health Bureau, the AAP, the Pediatric Societies, and national and state family organizations (Sia, Tonniges, Osterhus, & Taba, 2004).

In their extensive project to develop a scale to measure the medical home, Cooley, McAllister, Sherrieb, & Clark (2003) used data from a pilot survey study and interview data from 16 New England primary care pediatric practices and 27 other pediatric practices throughout the United States. The pediatric practices varied in sizes ranging from 1,000 patients to 45,000 patients. The survey and interviews measured six domains within the pediatric systems including organizational capacity, chronic condition management, care coordination, community outreach, data management, and quality improvement. On average, practices reported estimates of 50 percent of patients with private insurance and 34 percent with public insurance. Some 32.6 percent of the practices indicated that they had a designated staff person to coordinate care for children with special needs and their families. Only 4.7 percent of the practices reported no knowledge about the medical home concept.

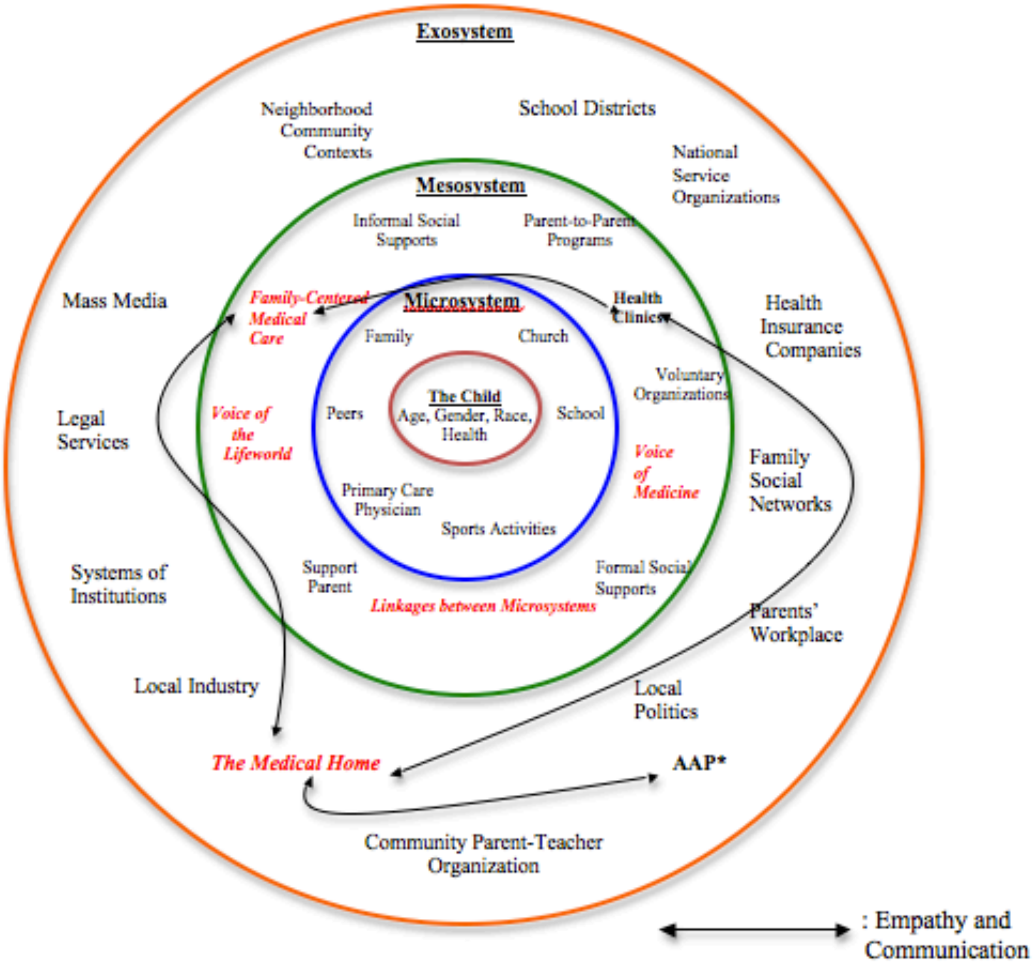
In a study investigating implementation and costs of medical home models of care, Antonelli & Antonelli (2004) examined 774 medical encounters with care coordination at a large medical center, serving children with special healthcare needs in the Northeast of the United States. The researchers focused on the complexity of care, type of service required, outcome of the service, and the amount of time and money spent to complete the activities. Results showed that care coordination through a medical home approach cost between the 25th and 75th percentile on the basis of a national survey of medical practices. That is, the cost of implementing the medical home approach within clinics was appreciable but not prohibitive.

The Mesosystem–Exosystem Relationship

As described in detail above, the exosystem contains the settings or events that the child does not actively participate in but which can have a profound effect on a child's development. Unlike the mesosystem and microsystem, the exosystem influences the child indirectly as it ‘trickles down’ through other individuals that have an influence on the child’s life. Exosystems influence the wellbeing of those who come into contact with the developing child, and may also exert policies or decisions that impact the child or the child’s family (Lustig, 2010). The child will feel the positive or negative force involved within the interaction with his or her own system without direct contact (see Figure 6 below).

At this level of Bronfenbrenner’s ecological theory of human development, the relationships between entities within the meso- and exosystem become even more strikingly complex. The numerous relationships that exist between these two concentric circles within the ecological framework have myriad influences upon one other. In order to discuss the complexities at this level of a child's development, I will focus on the relationship of policy in the exosystem and how it affects entities within the mesosystem, and vice versa. That is, I will focus on the relationship between the American Academy of Pediatrics (AAP) and health clinics. Further I will examine how family-centered care is a variable that can affect the relationship between health clinics and the AAP.

Figure 6. The exosystem: An example of the units of analysis and the directions of influence within the fourth level of an ecological model.



(Wood, 2014)

The health clinic-AAP relationship. The relationship between health clinics and the American Academy of Pediatrics (AAP) is an important meso- and exosystem connection affecting a child's development. Health clinics rely on social policies and values formulated and promulgated through major research, professional societies, and policy makers such as the AAP within the exosystem to set clear standards in order to operate efficiently and, more importantly, effectively. Conversely, elements within the exosystem, such as the AAP, rely on entities within the mesosystem, such as health clinics, within which to incorporate and examine the efficacy of policies and the standards that have been set. As illustrated in figure 5 above, the AAP and the medical home model of care are two distinct entities that exist in a child's exosystem. The AAP is a major professional organization whose goal is to provide policies and guidelines to pediatric health professionals. In 1967, the term "medical home" appeared in a book titled *Standards of Child Healthcare* written by AAP council on pediatrics. The AAP produced this book in reaction to the problems facing families of children and youth with special healthcare needs and disabilities at the time: Children with special needs receive inadequate care from many different practitioners who work in disparate locations independent of each other causing duplication and gaps in services that occur as a result of a lack of communication and coordination (Sia, Tonniges, Osterhus, & Taba, 2004).

The AAP initially introduced the medical home concept to serve as a central repository for children's medical records (Sia, et al., 2004; Turchi, Gatto, & Antonelli, 2007). Over the past 60 years, the standards and policies that make up the medical home concept have evolved and been modified into a description of a process of community-based primary care. The medical home model for care today states that children and youth with special needs, and their families, should be at the center of care. Health clinics must provide care occurring in an environment of trust and mutual responsibility between the family, child, and the primary care physician (Turchi, et al., 2007).

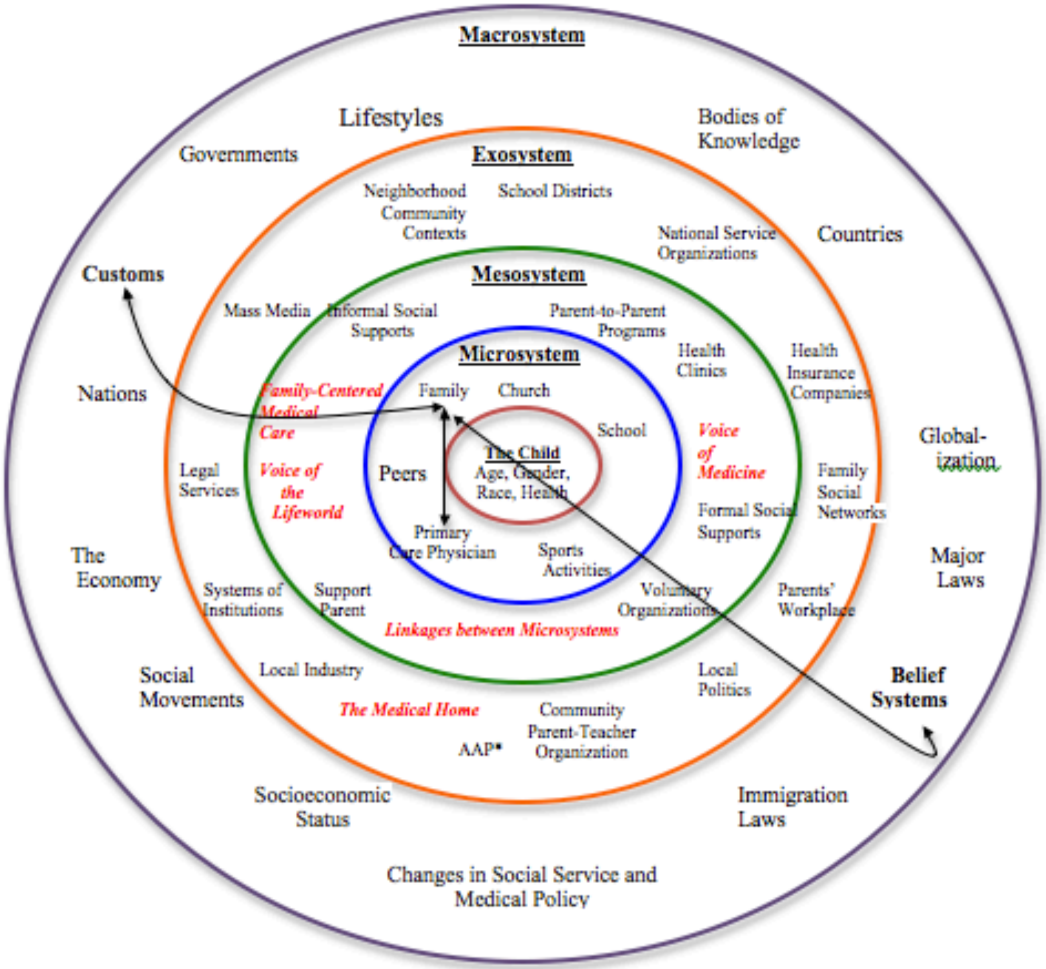
Family-centered care. Family-centered care exists within the mesosystem level of a child's development and can be a variable that affects the relationship between health-clinics within the mesosystem and the policies created by the AAP within the exosystem. Family-centered care is not so much an entity but rather an approach to medical care. As the title of this approach implies, it puts the needs of the family of an individual with special needs at the center of care and requires that healthcare professionals partner with families as allies to create the most effective treatment plans possible (Eckle & MacLean, 2001). Studies within this line of research have shown that health clinics that have incorporated a family-centered care approach to caring for children with disabilities are better able to provide a medical home as directed by the AAP (Nolan, Orland & Liptak, 2007; Pettoello-Mantovani, Campanozzi, Maiuri, & Giardino, 2009). Further, the care provided is more cost-effective, coordinated, and, especially, more successful for families and the child (Cooley, 2004; Palfrey, et al., 2004; Sia, et al., 2002). Additionally, research has shown that through the use of a family-centered care approach, healthcare professionals can learn to empathetically communicate and collaborate with families, enabling the development of effective partnerships with the families by providing a medical home (Denboba, McPherson, Kenney, Strickland, & Newacheck, 2006).

The Macrosystem

The fifth level of Bronfenbrenner's model of human development is the macrosystem. This system involves the culture and subculture of where the child lives. More specifically, it is the overarching pattern of micro-, meso-, and exosystems characteristics within the belief systems, bodies of knowledge, material resources, customs, lifestyles, opportunity structures, the economy, changes in social service and medical policy, and life course options embedded in each of these broader systems (Bronfenbrenner, 1994). The exosystem also includes societal factors that either create a level of acceptance or intolerance for violence. Also included are factors that can create and sustain gaps between different segments of society. Other examples of complex macrosystems include socioeconomic status, immigration laws, poverty, and ethnicity. Since an individual's income level can impact where one lives, area-level socioeconomic status can be equally important as individual level socioeconomic status in explaining a child's development. Evidence to date suggests that socially and economically disadvantaged areas are more likely to have proportionately large numbers of children who are at risk of developmental delays and disabilities (Evans, 2004; Krishnan, Cozier, Rosenberg, & Palmer, 2010).

Cultural values, health, and public policy and laws are all a part of the macrosystem. The effects of larger principles defined by the macrosystem have a cascading influence throughout the interactions of all other layers (see Figure 7 below). The macrosystem is an extraordinarily complex level within a child's development. Therefore this review will provide an example of how the macrosystem can affect entities within the microsystem. Namely, how the context of cultural norms and belief systems can influence the parent-physician relationship.

Figure 7. The macrosystem: The fifth level of Brofenbrenner's ecological model



(Wood, 2014)

The context of culture, which is defined and shaped by the macrosystem, may strongly influence a child as members of cultural groups may share the same religious beliefs, customs, cultural identity, heritage, and values. These cultural variables all strongly influence the child through their microsystems (Danesco, 1997). The political, cultural, or religious beliefs individuals adhere to can be disruptive or comforting (Lustig, 2010). The macrosystem evolves over time, as each successive generation may modify the macrosystem, leading to their development of their own distinctive macrosystem (Kail & Cavanaugh, 2010). For example, in a qualitative study examining cultural beliefs and coping strategies related to childhood cancer, Banerjee and associates (2011) interviewed 25 South Asian families of children with cancer. Results showed that families live with major culturally bound beliefs including childhood cancer being incurable, rare, unspeakable, and understood through religion. Further, for many people of South Asian origin, developing a disease such as cancer was viewed as part of one's destiny and God's will. These cultural beliefs may strongly influence South Asian parent's attitudes in decision making for disease management with their child (e.g., perceptions of the diagnosis, symptoms, interventions, and approaches to healthcare practices for the child), which may lead to challenges with the healthcare provider. To put it simply, these cultural influences from the macrosystem that have impacted the beliefs and customs of family members can have an effect on the parent-healthcare provider relationship, leading to changes in the medical prognosis for the child, which may have significant impacts (both positive and negative) on the child's overall development (Coll & Patcher, 2002).

Crossing Cultural Norms

Influence from the second-largest ring of Bronfenbrenner's ecological framework, the macrosystem, has a significant impact on society's understanding and, often, misconceptions of what having a child with a special need might be like for a family. Cultural norms and belief systems that are established at the macrosystem level and upheld at the exosystem level can have a serious impact on a family and affect all levels of a child's development. In fact, research has shown that many parents of children with special needs report encountering psychological, social, and political consequences such as isolation and social marginalization, stigmatization, and disempowerment (Byrne, Cunningham, & Sloper, 1988; Pahl & Quine, 1987).

Despite the fact that disability is not inevitably stigmatizing, research reveals that societal misconceptions exist based on an historical and/or a cultural base of exclusion. That is, individuals within our society who are considered to be outside the norm are often misunderstood and excluded (Bagenstos, 2000). Summers, Behr, Turnbull, Singer, & Irvin (1989) described how society as a whole tends to view families who have a member with a special need with pity because of the mistaken belief that having a child with a disability is "an unutterable tragedy from which the family may never recover" (p. 27).

The relatively small body of literature dedicated to the importance of examining cross-cultural perspectives in disability research shows that stigma levels vary within different types of ethnic communities based on cultural beliefs and norms. In a survey study of Chinese, Italian, German, Greek, Arabic, and Anglo-Australian communities in Australia, attitudes of community members towards individuals with a wide variety of disabilities was assessed via 665 local community health practitioners (Westbrook, Legge, and Pennay, 1993). Results indicated that different attitudes toward individuals with a wide range of disabilities existed across different cultures throughout the world. Data also revealed that the Anglo members of the community expressed the greatest level of acceptance of individuals with disabilities, while members from the Asian community expressed the least amount of acceptance and the greatest amount of pessimism.

As described above, parents find that they often are confronted with a society that sees only the negative characteristics of having a child with a disability, which can further isolate parents from the "typical" world around them. According to Ainbinder, et al. (1998), one stable and pervasive stress that seems to confront families of children with special needs is a society that traditionally fails to understand and accept their children due to a lack of empathy and understanding. Meeting the personal, medical, educational, and social needs of a child with a disability or chronic illness within the context of public attitudes that habitually are negative based on common erroneous beliefs of disability and stigma, and within a non-collaborative and often inaccessible service delivery system, can be emotionally exhausting and financially draining for parents (Green, et al., 2005).

The Chronosystem

Finally, the sixth and final level of Bronfenbrenner's ecological model of human development is the chronosystem. The chronosystem includes the dimension of time not only as it relates to the child's chronological age, but also as it relates to a child's environment (Bronfenbrenner, 1989). The chronosystem encompasses the patterning of environmental events (e.g., hurricanes, tornadoes, earthquakes, etc.), transition throughout the lifecourse (e.g., changes in family structure, death, diagnosis of an illness or disability, etc.), or sociohistorical circumstances (e.g., legality of gay marriage, the great depression, civil war, Brown vs. the Board of Education, etc.) An event has varying degrees of impact on development, and the impact on the family of a child with a special need often decreases as time progresses. Events, such as a parent's debilitating illness, divorce, or change of residence can have a more profound impact on a younger child as opposed to an older child.

Providing Support: Two Concepts for Families

Parent-to-parent programs and the medical home model of healthcare delivery are separate organizational contexts with distinct ways of functioning that have been created to support children living with special needs and their family members. These two organizational contexts focus on empathic behavior and communication in order to function. Parent-to-parent programs are based on nonprofessional standards with dependence upon volunteers to serve families of children with special needs, whereas the medical home model programs are highly professionalized and rely on formally structured bureaucratic frameworks in order to operate successfully.

These two forms of support, although very different, may have an even greater positive impact on the development of a child with a disability and their family when combined together, as compared to the positive impact of a single program. Parent-to-parent support programs will be discussed first, the medical home concept will be discussed second, and finally the advantages and challenges of combining these two programs to provide support for families of children with special needs will be illustrated.

Parent-to-Parent

Peer support. A growing body of literature indicates that, for some parents, peer support can be helpful in adapting to the challenges of family care giving (Ainbinder, et al., 1998; Corcoran, 1981; Ireys, Chernoff, DeVet, & Kim, 2001). According to Mead, Hilton, and Curtis (2001), peer support is defined as a system of the giving and receiving of help founded on key principles of respect, shared responsibility, and a mutual agreement of what is helpful.

Some parents report that connecting with other parents of children with similar conditions is invaluable, especially when the other parents were able to provide needed information and support, particularly advice and information about navigating the health and insurance systems (Farmer, et al., 2004). Mead, Hilton, & Curtis (2001) illustrated that peer support providers attempt to think creatively and not judgmentally about the way individuals experience and make meaning of their lives, in contrast to diagnosing and labeling the actions and feelings of help-seeking parents. The primary types of support provided by peers are: emotional support (i.e. offers esteem, attachment, and reassurance); instrumental support (i.e. offers material goods and services); and informational support (i.e. offers advice, guidance, and feedback) (Solomon, 2004). Peer support can be provided in a variety of contexts, including: support groups moderated by professionals (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003); on crisis warm lines (Pudlinski, 2005); or communicating via text message or other social media on a portable electronic device (Wood & Singer, 2014).

The program. Parent to Parent is a program that intentionally links families of children or youth with special needs with an experienced volunteer support parent who has received specialized training (Parent to Parent USA, 2014). That is, family members of children and youth with special healthcare needs and disabilities who are newly referred to a parent-to-parent program by healthcare providers or other professionals are deliberately connected with trained and experienced veteran parents who provide one-to-one emotional, instrumental and informational support. Trained veteran parents share what they have learned from their experiences of both the joy and the challenges when parenting a child with special needs. These support parents may be able to provide a more encouraging life picture to help-seeking parents who may be struggling (Ainbinder, et al., 1998). Gable, Reis, Impett, and Ahser (2004) examined the impacts of communicating a personal positive event with another and found that sharing between two individuals can increase the teller's positive affect and well being, especially if the telling was received enthusiastically.

Parent-to-parent programs are committed to listening and learning from families, and developing an array of services and supports in response to the needs families identify. In general, parent-to-parent programs are: 1) parent-directed; 2) all inclusive, serving families of children and adults of all ages; 3) cross-disability; and 4) able to create matches that evolve based upon the needs and preferences of the help-seeking parents.

Training. As mentioned above, parent-to-parent programs provide emotional and informational support to parents of children with special healthcare needs and disabilities through trained peer supports (Santelli, Turnbull, Marquis, & Lerner, 2000). Previous research indicates that parent-led organizations providing structured training and follow-up are successful in preparing experienced parents as volunteer mentors (Singer et al., 1999). In parent-to-parent programs, peer support parents are trained via the current best-practice techniques established from empirical research. Program orientation typically includes: empathy training (such as active listening and communication skills); cultural diversity training; leadership skills training; and professional collaboration skills.

Empathy. Parent-to-parent programs differ from other types of formal support in that parent-to-parent support has the capability of providing meaningful, experiential empathy based on perceived similarity (Corcoran, 1981; Miessner, 1996). Perceived similarity, a term often used in social psychology, is the compassion an individual can feel for another person related to the similarities shared and identified between each individual. Stotland's early research on perceived similarity in 1969 proposed that increased perceived similarity between an individual and another in need will increase empathy and may enhance the likelihood of help being offered to the help-seeking individual. In addition, in their work examining the empathy-altruism model, Cialdini, et al. (1997), found that in situations of high empathy, empathic concern led to an increase in helping related to perceived oneness. In two studies examining the relationship between adversity and prosocial behavior, Vollhardt and Staub (2011) surveyed over 300 university students regarding their volunteer behavior and past traumatic life events. Results showed that those students who had suffered from traumatic life events were more likely to volunteer to help others in need compared to those who had not suffered from traumatic life events.

Based on the research described above, data show that families who have experienced hardship or stressful life events in regards to their child's special need may be more likely to volunteer to support others in similar situations with a child with a special need based on their past experiences. Parent-to-parent programs can provide a help-seeking family with a way to connect with a veteran family that is empathetic to the experiences, feelings, and questions of the help-seeking family based on the common experiences the two families share (Wood & Singer, 2014).

The theory of "oneness" (i.e. the amount of perceived self-overlap to others) described above as an indicator of empathy discussed by Caildini, et al. (1997) is closely related to the evidence-based practice of parent-to-parent programs throughout the United States. Research on the efficacy of peer-support programs has shown that parent-to-parent support can be successful and families tend to consider their linked parent a reliable ally when there is "perceived sameness," there are comparable situations for learning relevant skills and gathering useful information, the support is easily accessible, and there is mutuality of support (Ainbinder, at al., 1998). This research demonstrates that perceived sameness of lived experiences is a fundamental reason why parents trust other parents (Ainbinder et al, 1998). In a study examining the impacts of adding a parent-to-parent program to medical clinics in Minnesota in which 15 participants taking part in the program were interviewed including families of children with disabilities and healthcare professionals, Wood & Singer

(2014) found that families often felt that the information coming from another parent with shared experiences can be more trustworthy compared to the information received from a healthcare professional.

Voice of the lifeworld. In addition, parents provide support to help-seeking parents through the voice of the lifeworld; the use of narrative and story sharing. Mishler (1984) described the voice of the lifeworld as the way an individual reports and describes the world of everyday life that is expressed from the perspective of a natural attitude. This ability to communicate in a more natural manner can help families feel comfortable, allowing more space for casual discussion and story sharing regarding their child's disability, which can lead to a decrease in feelings of isolation (Wood & Singer, 2014; Barry, Stevenson, Britten, Barber, & Bradley, 2001). According to Barry, et al. (2001), the increased use of the voice of the lifeworld for practitioners with families of children with special needs makes for better outcomes and more humane treatment of patients as unique human beings.

Similar cultures. Parents from the same ethnic and linguistic groups facing similar challenges are likely to have information and emotional support that is highly salient to help-seeking parents (Banerjee, 2011; McCabe, 2008). In her study examining the impacts of parent-to-parent support in China, McCabe (2008) interviewed 43 parents of children with autism who took part in a three-month intervention program at two separate locations. McCabe showed that: 1) parents enjoyed conversing with other parents of children with disabilities that was free of judgment; 2) the act of learning from other parents also provided moral support; and 3) parents had the opportunity to engage with other parents in a more equal relationship.

Linking trained peer supports with families of children and youth with special healthcare needs and disabilities through a parent-to-parent program can potentially provide caregivers with emotional and social supports that may lead to decreases in the levels of stress, anxiety, and feelings of isolation (Ireys et al., 2001). Further, these links may lead to an increase in engagement, empowerment (Ainbinder, et al., 1998), and access to community resources and better healthcare (Bhasale, 1998). Moreover, parents who have participated in parent-to-parent programs have shown increased confidence in parenting children with special needs (Singer et al., 1999).

Reciprocity of support. Interestingly, individuals who provide social support through volunteering often experience less depression, heightened self-esteem and self-efficacy as well as improved health behaviors and health outcomes. In their study examining the impacts of volunteering to help others, Klein and McCabe (2007) interviewed 14 mothers working in the field of early intervention after having children with disabilities. The study investigates mothers' experiences with, reactions to, and views of their employment situation and its relationship to adaptation and coping. Results indicated that individuals who volunteered felt better about themselves, were more confident, and were more positive about their experiences when they were involved in helping other parents of children with disabilities. Furthermore, data has shown that parent-to-parent peer support programs can provide opportunities for parents to build on their strengths by offering training for emerging leaders in policy, healthcare financing, advocacy and other areas of leadership development. (Ainbinder et al., 1998).

The Medical Home

The medical home is not a building, house, hospital, nor is it a home healthcare service. Rather, it is an approach to providing comprehensive primary medical care. The medical home is a concept of care that was first introduced by the American Academy of Pediatrics (AAP) in 1967. According to the literature regarding the medical home model of healthcare delivery, there is not one clear definition of what the medical home concept is and there are currently few guidelines for providers to follow in order to implement the model within their health practices. The lack of definitions and guidelines has likely caused the delay of model implementation within healthcare systems throughout the United States (Landon, Gill, Antonelli, & Rich, 2010).

In its initial version, the AAP defined the medical home as the center of a child's medical records. At the time, the care of children with special health care needs was the primary focus of the medical home concept. Over time, however, the definition of the medical home evolved to reflect changing needs and perspectives in the healthcare system. Today, the medical home is an approach to achieving family-centered healthcare that provides comprehensive primary medical care through the facilitation of partnerships between patients, physicians, and families.

Family-centered care. For the purposes of this paper, family-centered care will be defined as placing the needs of children, in the context of their families and community, at the center of medical care. In essence, this approach directly follows Bronfenbrenner’s ecological model of human development (1994) by placing the child at the center of the model and the family within the next concentric circle; the microsystem level. Family-centered care has developed as a result of the increased awareness of the importance of meeting the psychosocial and developmental needs of children and of the role of families in promoting the health and wellbeing of their children (Sia, Tonniges, Osterhus, & Taba, 2004). Family-oriented care aims at extending the responsibilities of the pediatrician to include screening, assessment, and referral of family members for physical, emotional, social problems or health risk behaviors that can adversely affect the health and emotional or social well-being of the child patient (Pettoello-Mantovani, Campanozzi, Maiuri, & Giardino, 2009).

In collaboration with the family, the medical team designs an individualized and dynamic model of care in collaboration with the child and family that will best meet these needs based on each individual family's wishes, strengths, and needs. (Allen & Petr, 1996; Eckle & MacLean, 2001). It is important to note here that family-centered care is not the training of parents to assume more responsibility for their child. It is, rather, a collaborative relationship where the respective roles of parents and professionals are jointly determined rather than dictated by the healthcare professionals (MacKean, Thurston, & Scott, 2005).

In their literature review, Turchi, Gatto, and Antonelli (2007) found that achieving family-centered care is associated with: 1) families' increased linkages and satisfaction with specialists; 2) families gaining better access to information regarding care; 3) decreased number of school absences for the child with a special need; and 4) decreased medical costs

Definition of medical home. Over the past fifteen years, the AAP has been at the forefront of numerous initiatives to promote the adoption and spread of patient- and family-centered care in a medical home approach (Hagan, Shaw & Duncan, 2008). One major issue that has emerged through the research into the implementation of the medical home within medical clinics throughout the United States is the lack of a clear and agreed upon definition for a medical home. Within this study, I will use the following definition as described by

Pettoello-Mantovani, Campanozzi, Maiuri, and Giardino (2009): A medical home is an approach to medical care in which the primary pediatric care team works in partnership with a child and a child's family to assure that all medical and non-medical needs of the patient are met.

The dimensions of a medical home include accessibility, continuity, coordination, comprehensiveness, communication, and compassion, and cultural competence of medical care providers (Kahn, 2004). That is, medical care must be accessible and available. Care must be continuous, including the requirement that more than 50 percent of a patient's medical home visits are with the same provider/physician team. The standards also require documentation of all consultations, referrals, and appointments in the clinical record, and proactively planned transitions of care. Care must also be coordinated and integrated between complex health care systems, for example across specialists, hospitals, home health agencies, and nursing homes, and also include the patient's family and community-based services. Comprehensiveness of care refers to the preventive and wellness care, acute injury and illness care, chronic illness management, and end-of-life care. Standards for the provision of appropriate patient education, self-management, and community resources also are addressed. Communication and compassion refers to the understanding and collaboration between the patient, family members, and the provider and physician-directed health care team. Finally, cultural competence refers to the capability to respect the beliefs, language, interpersonal styles, and behaviors of individuals and families receiving services, as well as staff who are providing such services (American Academy of Pediatrics, 2014).

According to Frazier, Abdul-Adil, Atkins, Gathright, and Jackson (2007), involving family members in the design and delivery of services for children and youth with special healthcare needs and disabilities could provide perspective that reflects the daily experiences of families and that offers clinicians a window into their cultural world. According to Barry, et al. (2001), physicians may have to change their notions of success from purely technical considerations to include family members of children with disabilities feeling understood, listened to, and treated like whole and unique human beings. If doctors could be sensitized to the importance of dealing with the concerns of daily life for families of children with disabilities it might be possible to obtain better care for patients.

Improved communication and lower costs. In a study from 2004, Spann estimated that if the recommendations for implementation of the medical home model, health care costs would likely decrease by 5.6 percent, resulting in national savings of 67 billion dollars per year, with an improvement in the quality of the health care provided. In a review of the literature, Starfield and Shi (2004) determined that medical homes are associated with better health outcomes, with lower overall costs of care and with reductions in disparities in health.

In a randomized control trial study, Ahrens, Yancey and Kollef (2003) examined the impacts of adding a communication medical team to traditional intensive care unit (ICU) medical teams. These communication teams included physician and nurse practitioners working as case-managers to help facilitate communication between the traditional care team and family members. One hundred fifty-one families of patients with extreme health needs participated in the study and 43 of the families received the added support of the communication team. Results showed that the patients that received support from the communication team had shorter hospital stays and lower medical bills for services rendered compared to the patients who only received care from the traditional ICU medical teams.

In an evaluation study of the implementation of medical homes in medical practices, Rankin, Cooper, Sanabria, Binns & Onufer (2009) surveyed over 360 families of children and youth with special healthcare needs from six separate pediatric primary care practices. All six pediatric practices implemented the pilot phase of a practice-directed medical home quality improvement project by developing case-management teams for families. Results from this study showed that achieving a medical home in primary care practices is feasible (both structurally and economically) and can lead to higher levels of practice coordination. Families reported better care coordination and fewer missed days of school and hospitalization for their child post intervention.

Considering the research of the need by and types of support for families of children with special healthcare and/or disabilities reviewed in the previous section of this chapter, this study will examine the impacts of adding a parent-to-parent program to comprehensive medical care in order to help achieve a medical home for families.

CHAPTER III: RESEARCH METHODOLOGY

Research Design

An essential component of a study of examining the impacts of a volunteer program such as Parent to Parent or any human service is its impacts on the recipients, as they perceive them to be. The design for this research project is a qualitative methods, multiple perspectives study (Creswell, 2012)**.** This research project presents data from qualitative interviews with key stakeholders who were taking part in a parent-to-parent program as part of comprehensive medical care. Maxwell (1992) argued that the goal of understanding a phenomenon from the point of view of the participants and its particular social and institutional context is particularly salient when data are collected qualitatively. Therefore, qualitative interviews were utilized for this portion of the study, to preserve the point of view of the participants. Several reasons for selecting this approach to the research include 1) the dynamic nature of the interview process, which engages respondents more actively than is possible in more structured quantitative methods, 2) the opportunity to ask follow up questions, enabling the researcher to reach beyond initial responses and rationales, 3) and the opportunity to hear, record, and interpret voice intonation and pauses as part of the respondent’s feedback, which can be invaluable during interviews and data analysis.

Modified grounded theory. The qualitative interviews for this study were conducted via semi-structured interview protocols described in detail below. The qualitative responses from the 24 interview participants were coded using a modified Grounded Theory approach (Charmaz, 2004; Glaser & Strauss, 1967). Grounded theory method is a systematic generation of theory from data that contains both inductive and deductive thinking. This qualitative research method begins with data collection and transitions into the development of theory grounded in data. This method is often used in research studies for which no a priori hypotheses exist. The main goal in Grounded Theory research is to generate a theory related to the complex behaviors involved in the phenomena under investigation (Glaser & Strauss, 1967). Grounded Theory methods have earned their place as a standard social research method and have influenced researchers from varied disciplines and professions (Charmaz, 2004). According to Marshall and Rossman, the Grounded Theory approach to research is primarily descriptive and relies on other individuals' words, focuses on everyday life experiences, values participants' perspectives, and inquires as an interactive process between researcher and respondents (2014). A Grounded Theory study does not seek representativeness to achieve statistical generalizability but instead aims to explain and sometimes predict phenomena based on empirical data. In her presentation of Modified Grounded Theory, Charmaz (2004) provided guidelines for data collection and analysis consisting of coding, comparisons between data, memo writing, and theoretical sampling. Grounded Theory is an appropriate choice when exploring a new psychosocial construct, and can be utilized with interview data, among other sources of data.

There are several steps involved in the conducting of Grounded Theory research. Open-ended data were gathered, in the case of this study, via a semi-structured interview protocol, which was guided by interest in a particular phenomenon or question (Glaser & Strauss, 1967). The Grounded Theory Approach as modified by Charmaz (Charmaz, 2006) also aims to guard against researcher bias by careful adherence to systematic data collection and analysis procedures in a specified sequence. This process allows a researcher to capture all information related to the topic of study that may prove to be relevant as soon as it is discovered, and hypotheses are revised constantly throughout the research process until they hold true for all the gathered evidence (Corbin & Strauss, 1990).

According to current literature, a number of benefits exist in using a modified Grounded Theory Approach to research. One of these benefits is that of ecological validity. That is, the theories derived via this type of research may accurately represent real-world settings because they adhere closely to the data from which they are established; and these data are collected in such a way as to provide a rich description of these settings. Another benefit to qualitative research is that grounded theories are not tied to any preexisting theory, and therefore often are novel and have the potential for innovative discoveries in social science and other areas. Lastly, grounded theories aim to provide practical and simple explanations about complex phenomena by converting them into abstract constructs and hypothesizing their relationships (Miles & Huberman, 1994).

The Grounded Theory Approach and qualitative research in general have a number of limitations that many researchers criticize. One of these limitations involves subjectivity. That is, the inherently subjective nature of the information that can be gleaned from qualitative methods, such as interviews and case studies, can sometimes lead to misrepresentation and observer bias based on the researcher’s own interpretation (Thomas & James, 2006; Layder, 1993). There are several ways that qualitative researchers attempt to address this critique depending on their epistemological and procedural approaches. In their study examining qualitative design methods, Baxter and Eyles (1996) reviewed 49 qualitative studies in order to develop a framework for valid qualitative research. They found four important components of qualitative research that must be addressed for the research study to be valid. These four components include: 1) credibility – the degree to which a description of human experience is such that those having the experience would recognize it immediately and those outside the experience can understand it (Lincoln & Gruba, 1985); 2) transferability – the degree to which findings fit within contexts outside of the study (Baxter & Eyles, 1996); 3) dependability – the degree to which idiosyncrasies and variability in interpretation can be minimized (Lincoln & Gruba, 1985); and 4) confirmability – the extent to which biases of the researcher influence interpretations and the degree to which these biases can be minimized (Baxter & Eyles, 1996). The following methods were developed to ensure the four components of valid qualitative research were attained in this research study as a way to attempt to overcome the individual bias of the researcher: a) purposive sampling to obtain a range of opinion including sampling for diversity in socio-economic status and culture and linguistics; b) multiple perspectives– sampling of individuals in different roles in the project including medical professionals, coordinators, volunteers, etc.; c) writing reflection notes during data collection and analysis to make my opinions open and clear; d) obtaining inter-observer reliability for key stages of coding transcripts; e) making transcripts and other data available for public scrutiny; f) completing member checks; and g) reviewing of findings by an outside expert. Purposive sampling, inter-observer reliability, member checks, and multiple perspectives will be explained in further detail in the procedure section below.

Purposive Sampling

Some researchers have concerns related to how many participants to recruit in qualitative studies in order for the research to be deemed credible or reliable. Namely, how many participants need to be included in data collection when utilizing purposive sampling (*i.e.*, participants are selected because of their relationship to the phenomenon of study) before data saturation is reached. According to Glaser and Strauss (1967), data saturation refers to the point in data collection when a conceptual category is not developed further by continued data collection. Guest, Bunce, and Johnson (2006) researched the concept of data saturation by examining the data from interviews with more than 60 female participants in Western Africa. The authors found that saturation was achieved within the first twelve interviews and that the basic themes emerged within six interviews (Guest, Bunce, & Johnson, 2006). In his meta-analysis regarding sample size and saturation, Mason examined over 500 qualitative interview studies and found that the average number of participants in the studies was between 20 and 30 (2010). According to Charmaz, a research study sample size should be determined in relation to the nature of the research project itself, with studies of phenomena in smaller, more specific settings requiring fewer participants than those which intend to have greater transferability (Charmaz, 2006). Therefore a sample size of 24 represents a sufficient amount of data collection upon which to build overarching themes and theories.

Recruitment. Twenty-four individuals were interviewed. Participants were recruited in order to sample key stakeholders in all of the major roles they play in the parent-to-parent service model linked to the medical clinics and medical professionals. The largest subgroup interviewed were parents who have both provided and received peer support. Key stakeholders in an experimental program run by an organization called Family Voices assisted in recruiting all of the 24 participants for the qualitative portion of this research study. In order to obtain multiple perspectives, people at all levels of the combined clinic and peer support program have been interviewed. Program coordinators (PCs) contacted individuals involved in the program to invite those interested and willing to participate in the study. A university's Institutional Review Board approved the research plan for this research project in advance of data collection for this study. Participants were sent a mailing that included an introductory letter and a consent form soliciting permission to record the interviews. Participants were informed that interviews would be conducted over the phone by the coordinator of the qualitative study, an individual trained in disabilities research. The letter explained that the responses to interview questions would be confidential and any identifying information would not be revealed to their local parent-to-parent program. Interested participants signed the consent form (See Appendix A through D) and mailed it back to the researcher in charge of the investigation. All 24 participants returned signed consent letters, which were kept in a locked cabinet. After receiving the signed consent form, the researcher called the participants and set an interview time at the individuals' convenience.

Participants. The 24 participants interviewed for this study fell into four separate categories. A participant was considered a healthcare provider (HP) if the individual was a physician, nurse, mental health therapist, health insurance representative, social worker, school psychologist, teacher, etc. and referred clients to the parent-to-parent program. A participant was considered a program coordinator (PC) and parent support navigator (PSN) if the individual was working directly with the parent-to-parent program, recruited and trained parent and healthcare providers, matched families together, and worked on the overall day-to-day details of the project. A participant was considered a parent support volunteer (PSV) if the individual was trained in parent-to-parent protocols and provided peer support to help-seeking families. Finally, a participant was considered a referred parent (RP) if the individual had been referred to the parent-to-parent program through a healthcare provider, was connected with a PC, and was matched with a PSV to receive social and informational support.

Demographic information is presented in Table 1 below. In total, 13 percent of the interview participants were HPs, 25 percent were PCs or PSNs, 25 percent were parent support volunteers and 38 percent were referred parents. 23 of the interview participants were female and one was male. The sample was made up of 67 percent (*n* = 16) Caucasian and 33 percent (*n* = 8) culturally and linguistically diverse participants (including African-American, Hmong, and Spanish-speaking families, as well as family members who had recently immigrated from Africa, and families from Native American populations). Twenty-one percent of participants (*n* = 5) spoke English as a second language. In addition, 38 percent of participants (*n* = 9) were employed full time, 42 percent of participants (*n* = 10) were employed part time, 16 percent of participants (*n* = 4) did not work, and one participant was retired. About 50 percent of the participants (*n* = 12) would be considered low-income earners. Participants fell in one of four age categories: About 17 percent of participants were 20 to 29 years old (*n* = 4); about 33 percent were 30 to 39 years old (*n* = 8); about 33 percent were 40 to 49 years old *(n* = 8), 2 participants were 50 to 59; and 2 participants were over 60. Excluding the three healthcare providers, all the other 21 participants were parents of children and youth with special needs. As shown in Table 1 below, 50 percent of parents who were interviewed for this study had children who were female and 50 percent had children who were male. 21 percent of participants (*n* = 5) had more than one child with a disability in his or her family. About 19 percent of participants who were considered a part of the majority white culture (*n* = 3) had adopted children who were considered culturally and linguistically diverse. Ages of the children ranged in age from two-years old to over eighteen-years old with a wide variety of medical diagnoses and special healthcare needs.

This purposive sampling was designed to recruit individuals most capable of providing data relevant to the research questions.

Table 1

Demographic information of parents interviewed

	N = 24	**%**
Role		
Healthcare Provider	3	13
Program Coordinator/Navigator	6	25
Volunteer Support Parent	6	25
Referred Parent	9	38
Sex		
Male	1	4
Female	23	96
Employment Status		
Employed Full Time	9	38
Employed Part Time	10	42
Not Employed	4	16
Retired	1	4
SES		
Low-Income Earner	12	50
Middle-Income Earner	8	33
High-Income Earner	4	16
Age		
20-29 Years	4	17
30-39 Years	8	33
40-49 Years	8	33
50-59 Years	2	8
60+ Years	2	8
Race		
White Majority	16	66
CLD	8	33
Child		
With a Disability	21	88
Without a Disability	3	12
Other Children		
With a Disability	5	21
Without a Disability	19	79
First Language		
English	19	79
Other Language	5	21
Number of Child's Diagnoses		
One	2	8
More than one	21	92

Note. N= Number of Participants. %= Percentage of Participants

It is important to note here that the definition of a parent for families from the parent-to-parent program may go beyond the traditional understanding of what makes up a family. For the purposes of this study, the definition of family included biological parents, stepparents, grandparents, siblings, uncles and aunts, cousins and other family members, adoptive parents, foster parents, legal guardians, and any other individual who was the main caregiver for an individual with special healthcare needs and/or disabilities. All respondents who were service recipients in this study were the primary caregivers for the children with disabilities.

Settings

All phases of this qualitative study were conducted by telephone by the lead investigator with the assistance of two research assistants (primarily during the transcription and coding phase of the study) in the state of California to participants throughout the states of Minnesota and Wisconsin. One interview participant who had been matched with a family in Minnesota resided in a city in Southern California. The interviews were conducted at the interviewee's requested date and time. The interview participants resided in various locations throughout the two states, from large urban areas of 100,000 residents or more, to small rural areas of fewer than 5,000 residents.

Materials

A computer and digital recorders were used to complete the interviews for the qualitative portion for this study. All interviews were conducted via Skype © and were recorded on two separate digital recording devices. The interviewers followed open-ended interview protocols that were developed by the lead investigator. Details of these interview protocols are described in the procedures section below.

Interview Procedures

The primary researcher of this study conducted 23 of the 24 original interviews and one research assistant conducted the remaining interview. The method of using predominantly one interviewer was chosen for this study as it allowed for consistency in interviewing participants spread out geographically throughout the Midwestern states in which this parent-to-parent program took place. Furthermore, the primary researcher of this study is also a mother of four children whose eldest child experienced significant health challenges at birth that nearly resulted in death, all while living abroad in an East Asian country. These medical challenges ultimately led to developmental delays and required the lead investigator and her husband to seek out supports for their child in the medical industry, in their local community, and to navigate a complex health insurance system within a culture and language that were different from their own. These parental experiences helped provide the lead investigator with a unique perspective when examining the complex demands of caring for child with a special need and the challenges families may face when navigating a complicated healthcare system within the framework of a language and a culture that is not familiar. The lead investigator revealed her personal background to each of the 23 participants with whom she conducted the interviews in order to help gain trust and build rapport with the families and healthcare providers, thereby assisting the lead investigator in eliciting more detailed information from participants.

All 24 interviews were completed on Skype ©. Although, interviews conducted by telephone may reduce the volume of information received by the investigator due to the loss of many non-verbal cues (Kvale, 1996), research has indicated that participants disclose as much personal information and express the same views via different interview media (Miller

& Fox, 1997). Interviews were semi-structured, using a standardized interview guide. One interview guide was developed by the lead researcher with the guidance of program developers to ensure appropriate data collection for purposes of evaluating the program. Four variations of the main interview guide were produced with modified language to fit the role for each category of interviewee. The four sets of questions are presented below in Appendix E through H. The interview protocol was reviewed and edited by the primary investigator in conjunction with an experienced researcher.

All four interview guides began with open-ended questions regarding experiences with the program such as, "When I talk about the parent-to-parent program what does that mean to you?" and, "How would you describe your parent-to-parent experience?" The interviewer used more specific probes if the interviewee had difficulty initiating a description of their experience including how they learned about the parent-to-parent program, what motivated them to become connected with the program, how the support from the program affected their day-to-day life, if and how parent-to-parent support was unique compared to other types of available resources, if the program achieved their expectations, etc. Questions from the interview protocol aimed to elicit information regarding the effectiveness of the parent-to-parent program included, "What is it that transpires when parents talk to each other?"; "What is it about the parent-to-parent program that one may or may not be able to get from other sources of support?"; and "What characteristics do you see, if any, that indicate that the parent-to-parent program is helping the families receiving support?" Questions from the interview protocol aimed to elicit information regarding experiences collaborating with medical professionals and medical clinics included, "Can you tell me what you gained from the parent-to-parent program, if anything, as it pertains to collaborating with your child’s medical provider and accessing/navigating the medical care system?” and “Do you feel that being connected with another veteran parent through the parent-to-parent program has changed your relationship with your medical provider in any way?” Further, families were asked about their experiences with the parent-to-parent program in relation to cultural and linguistic diversity. These questions delved more into the experiences and perspectives from the culturally and linguistically diverse populations. This area of questioning included probes such as the following: “Do you feel it is important to provide support/receive support to/from families of similar backgrounds and/or identities? Why or why not?”; “Do you notice a difference when you speak to someone from your own cultural background or identity as compared to someone from a different cultural background or identity? Why or why not?”; “Do you notice a difference in the type or quality of support you receive when you talk with a family from your own cultural background compared to when you talk with a family who is not from your own cultural background? Why or why not?”; and “Do you feel the support you receive from medical professionals is different than the support you receive from families of different cultural backgrounds? Why or why not?”

Medical providers were asked similar questions in regards to their experiences with the parent-to-parent programs. Questions later in the interview addressed specifically what was not helpful about the experience, areas for improvement within the program, and whether they would refer the program to other families. Throughout the interviews, topics of personal significance (i.e. experiences of communicating with parent support volunteers while child was in surgery or intensive care; talking with a parent who has a child with a similar diagnosis that is extremely rare; family stress and marital discourse, etc.) were explored (as initiated by the interviewee), in addition to the questions on the standardized interview guide. This approach resulted in a data set balanced with both standardized areas of inquiry and personalized feedback. Interviewees were not given a copy of the protocol guide prior to the interview, unless requested, but were briefed beforehand via email or telephone regarding the basic areas of interest and type of information to be targeted in the investigation.

Interviews lasted from 25 to 75 minutes. Generally speaking, the shorter interviews tended to occur with medical provider interviews as these particular interviewees had very tight schedules because of their responsibilities in their professional practices and only were able to speak for an abbreviated amount of time. Despite the shortness of the interviews, the healthcare providers gave in-depth and invaluable data regarding their experiences with the parent-to-parent program.

Data analysis

All 24 qualitative interviews were recorded and fully transcribed. Names of the interview participants were removed to ensure confidentiality of participants and any persons and places mentioned during the course of the interviews.

As described earlier in this study, transcribed interviews were coded by the lead investigator and one undergraduate research assistant using an interactive process in which the themes were identified as they emerged from the reading of the transcripts according to Charmaz’s Grounded Theory Procedures (2002). Transcripts from the interviews were initially entered into Dedoose, an encrypted qualitative and mixed methods software program (Dedoose, 2015). Using Charmaz’s Grounded Theory Approach (2002), the lead investigator and research assistant independently identified codes that emerged from the data through three levels of coding and not from preconceived hypotheses. The lead investigator coded

100 percent of the twenty-four interviews, while the research assistant coded 33 percent of the twenty-four interviews independently from one another utilizing the procedures described below. Once the lead investigator and the research assistant completed the four-step process of the Grounded Theory Approach, the lead investigator and the research assistant completed the steps to check reliability described in a further subsection below.

The Grounded Theory Approach (Charmaz, 2006) utilizes a four-step process as a means to analyze data, which includes 1) coding data to facilitate the emergence of some basic categories via line-by-line and focused coding, 2) grouping concepts together, 3) generating categories based on the concepts, and 4) developing theories. (Glaser & Strauss, 1967). Coding is the first step of data analysis, as it helps move away from particular statements made by individuals to more abstract interpretations of the interview data (Charmaz, 2006).

In this study, the lead investigator and the research assistant coded the data independently from one another. The two coders utilized a line-by-line process whereby each line of written data was named. Line-by-line coding, which is also known as open coding, provided a good starting point to identify initial phenomena and produce a list of concepts of importance to the interviewee. That is, this preliminary stage of the coding process identified anchors that allowed the key points of the data to be gathered together. Conceptual labels were then attached to almost every line in the interview transcript to capture what had been said. These labels were assigned to participants' words and statements to develop concepts, constituting the beginning of the analytic process. The detailed and meticulous process of line-by-line coding helped to open up the text and interpret the transcript in new and unfamiliar ways, which also helped test the lead researcher's assumptions.

Additionally, the lead investigator and the research assistant independently completed memo writing at this stage of analysis. According to Glaser (1978) memo writing is an important step at the stage of analysis in addition to the line-by-line coding practice. Memos were theoretical notes made by the researcher about the data and the conceptual connections between categories. The process ran parallel with coding and analysis process to capture the researcher's emergent ideation of substantive and theoretical codes and categories.

The next level of the coding process, known as focused coding, is more abstract than line-by-line coding. Charmaz (2006) reasoned that focused coding can be then utilized to synthesize and explain larger segments of information followed by a third phase of thematic coding. In this study, focused codes were applied to several lines or paragraphs in the interview transcripts and required the lead researcher and the research assistant to choose the most telling codes to represent the interviewee's voice. Focused codes were often larger constructs that summarized a set of related smaller finer grained codes. These focused codes were then tested on further interview transcripts to verify the adequacy of the initial concepts developed.

The following level of the coding process after open coding was axial coding, in which categories and subcategories were connected along the lines of their properties and dimensions (Strauss & Corbin, 1998). Charmaz (2006) recommends approaching data in this step of the coding process less formally than Straus and Corbin by reflecting on the categories and sub-categories, and to establish connecting links between them to make sense of the interview data. That is the process by which concepts of process groups' codes of similar content together are created, which leads to developing categories (i.e. integrating broad groups of similar concepts). After coding several interview transcripts, the lead two coders in this study separately identified many issues that were of importance to the respondents. These issues were also known as phenomena and were assigned a conceptual label to become a code, also known as a concept by Strauss and Corbin (1998). These issues were more molar concepts, less fine grained, more inclusive, and capable of describing larger units of text and collating concepts across participants. A few of the themes identified at this point in the coding process include:

1. Anxiety and stress
2. Communicating with healthcare providers
3. Navigating insurance
4. Lack of information and empathy from professionals
5. Other parents understand
6. No judgment
7. Sense of belonging

The final stage of coding involved reviewing emerging themes from the data and then grouping codes into prominent themes. That is, the categories from the transcripts that detail the subject were synthesized together within overarching themes. By identifying the relationships between and amongst the themes and codes, the theme was developed and constructs were defined (Charmaz, 2006). A theme represented a level of patterned response or meaning from the data that was related to the research questions at hand. Themes differed from codes in that themes were phrases or sentences that identified what the data mean. Themes described an outcome of coding for analytic reflection. Themes consisted of ideas and descriptions within a culture that could be used to explain causal events, statements, and morals derived from the participants' stories. Thematic analysis allowed for categories or themes to emerge from the data including: repeating ideas; indigenous terms, metaphors and analogies; shifts in topic; and similarities and differences of participants' linguistic expression. It was important at this point to address not only what was present in the data, but also what was missing from the data (Saldaña, 2009). At the final phase of analysis, identification of the themes' essences related to how each specific theme affected the entire picture of the data. Analysis at this final stage was characterized by identifying which aspects of the data were being captured, what was interesting about the themes, and why the themes were interesting. The following themes ultimately guided my analysis:

1. Trust and empathy
2. Resources and accessibility
3. Awareness and understanding
4. Cultural competence
5. Partnerships and mutual respect
6. Empowerment and advocacy

Once the data were coded using these six themes above, the lead investigator organized the data under these categories using the Dedoose © qualitative data program to visually represent quotes from the interviews. Please see table 2 below representing the thematic analysis completed in this final stage of the coding process.

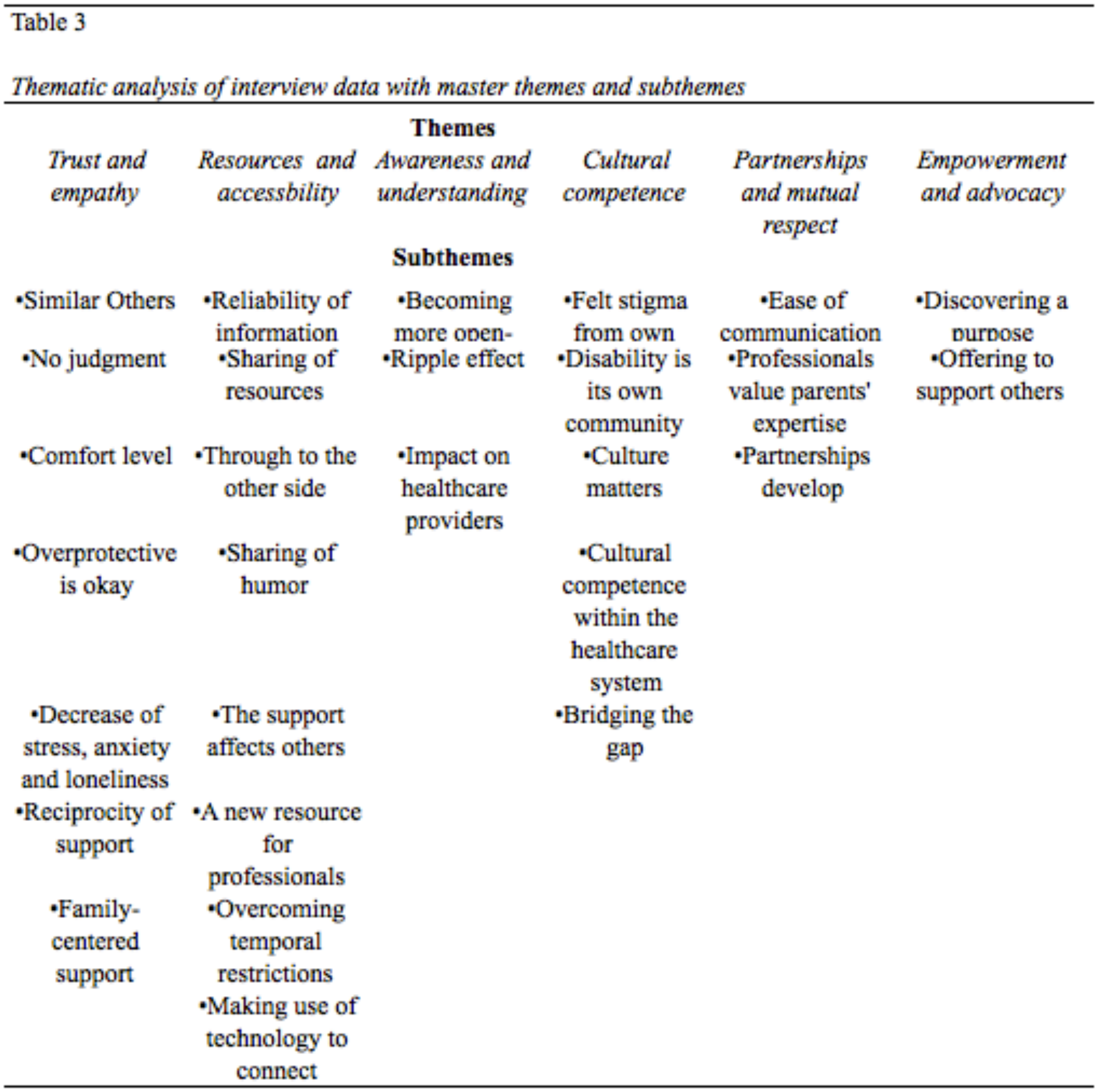


Table 3

Thematic analysis of interview data with master themes and subthemes

		Themes			
Trust and empathy	*Resources and accessbility*	*Awareness and understanding*	*Cultural competence*	*Partnerships and mutual respect*	*Empowerment and advocacy*
		Subthemes			
•Similar Others	•Reliability of information	•Becoming more open-	•Felt stigma from own	•Ease of communication	•Discovering a purpose
•No judgment	•Sharing of resources	•Ripple effect	•Disability is its own community	•Professionals value parents' expertise	•Offering to support others
•Comfort level	•Through to the other side	•Impact on healthcare providers	•Culture matters	•Partnerships develop	
•Overprotective is okay	•Sharing of humor		•Cultural competence within the healthcare system		
•Decrease of stress, anxiety and loneliness	•The support affects others		•Bridging the gap		
•Reciprocity of support	•A new resource for professionals				
•Family-centered support	•Overcoming temporal restrictions				
	•Making use of technology to connect				

Reliability. As described earlier, the lead investigator who was familiar with special education and disability research, and one undergraduate completed the reliability calculations for this study. The undergraduate student recorded reliability data for at least 33 percent of all interviews across participants. Once the lead investigator and the research assistant independently completed the four-step coding process of the Modified Grounded Theory approach described above, inter-coder reliability was calculated by dividing the total number of agreements by the total number of disagreements plus agreements, then multiplied by 100. Following the guidelines of reliability literature, the criterion of at least 80 percent reliability was required for all measures. (Kottner, Audige, Brorson, Donner, Gajewski, Hrobjartsoon, et al., 2011). Agreements were defined as the coders recording identical codes (as denoted within the Dedoose © qualitative software program) for each line or section of the interview transcript. Agreement was counted when both coders attached data were the same. A disagreement was counted when one coder attached a section of interview data with differing codes from the other coder. The lead investigator and the research assistant discussed all disagreements until agreement was reached. The average percent agreement for all twenty-four interviews completed for this study was calculated at 89.5 percent (with a range of 76.9 to 95.5 percent).

Member checks. Lincoln and Guba assert that utilizing member checks is crucial to establishing the credibility of a study (1985). Member checks involve sharing data and interpretations with participants in order to get confirmation of their credibility (Creswell & Miller, 2000). Member checks test the data, analytic categories, interpretations and conclusions with members of those groups from whom the data were originally obtained (Cutcliffe & McKenna, 2002). These checks were completed in this study as opportunities arose during the normal course of data collection, such as during a conversation in an interview. Member checks provided participants the opportunity to correct errors and challenges to what may have been perceived as wrong interpretations by the lead investigator (Morse, 1994). In addition, member checks also presented participants with the chance to volunteer additional information, which may have been stimulated by the checking in process. Moreover, member checks provided respondents with the opportunity to assess adequacy of data and preliminary results as well as confirm particular aspects of the data with the researchers (Fereday & Muir-Cochrane, 2008).

Multiple Perspectives. In this qualitative study, the researcher examined data from multiple perspectives via qualitative interview data from sources across different settings, both rural and urban, in the Midwestern state within which this program is currently taking place, and even outside of the state. For example, two of the large medical clinics currently collaborating with the parent-to-parent project serve families within highly populated cities including low-income and culturally and linguistically diverse families, such as families from the Somali and Hmong populations. Many of the smaller remote clinics serve families in medium-sized cities to extremely rural, sparsely populated locations in the countryside including families from Native American populations. The lead investigator interviewed participants being served by these types of medical clinics and the parent-to-parent project in general. Moreover, the data collected for this study included data from a wide age-range of participants, from age 20 to over 60-years of age. In addition, these data have been collected over a four-year period, that is, since the program began.

IV. RESULTS

This study addressed the following key research questions: (1) Do parent volunteers trained under the auspices of a structured Parent-to-Parent program help outreach medical clinics realize a major value that has been widely agreed upon by stakeholders in the system establishing a medical home where families receive family-centered care? (2) What are parents' perceptions of the differences in the kinds of social and informational support provided by trained peer supporters as compared to other sources of support? (3) Are there similarities between the perceptions of culturally and linguistically diverse families compared to those perceptions from white Anglo majority culture regarding the type and efficacy of the support? (4) How do family members of children with special needs perceive, if any, the differences in discourse when speaking to professionals in the medical field as opposed to speaking to another parent with shared experiences? (5) In what ways, if any, do parent-to-parent programs contribute to establishing family-centered care for families of children and youth with special healthcare needs for families? (6) What challenges do the differences in parent-to-parent and clinic functions and organizational contexts raise for implementation of a joint parent-to-parent and medical clinic service model and how have they been addressed?

As a reminder of the four different roles of the participants in this study described earlier in the methods section of this study, a participant was considered a healthcare provider (HP) if the individual was a physician, nurse, mental health therapist, health insurance representative, social worker, school psychologist, teacher, etc., and referred clients to the parent-to-parent program. A participant was considered a program coordinator (PC) and parent support navigator (PSN) if the individual was working directly with the parent-to-parent program, recruited and trained parent and healthcare providers, matched families together, and worked on the overall day-to-day details of the project. A participant was considered a parent support volunteer (PSV) if the individual had been trained in parent-to-parent protocols and provided peer support to help-seeking families. Finally, a participant was considered a referred parent (RP) if the individual had been referred to the parent-to-parent program through a HP, had been connected with a PC, and had been matched with a PSV to receive social and informational support.

Qualitative Interview Themes

The subsections below of this results section will first introduce the master themes and subthemes that developed through the data analysis of the interview data followed by a description of how these themes related to the original research questions of this study.

Following Grounded Theory analysis of the qualitative interview data as described in the previous chapter, themes identified in the interviews were reduced and grouped into six master categories, which included: 1) *Trust and Empathy*; 2) *Resources and Accessibility*; 3) *Awareness and Understanding*; 4) *Cultural Competence;* 5) *Partnerships and Mutual Respect*; and 6) *Empowerment and Advocacy*.

Trust and Empathy

Trust and empathy make up essential components of parent-to-parent programs. Trust can be the belief that someone or something is reliable, good, honest, or effective (Tschannen-Moran & Hoy, 2000). Whereas empathy may be characterized as the feeling that one understands and shares another person's experiences and emotions without having to fully communicate these feelings, thoughts, and/or experiences to the other person (Hakansson & Montgomery, 2003). When participants were initially asked about their experiences with the parent-to-parent program, a majority spoke about how the program gave families a way to connect with another veteran family that they could trust with their feelings and questions. Many of these participants also found the experienced parents to be empathetic towards their experiences.

Similar others. All types of the parents interviewed in this study (21 of the total 24 participants) discussed how connecting with another parent with shared experiences is like connecting to a similar other. One parent interviewed for this study discussed how, prior to becoming a PSV with the parent-to-parent program, she had not been able to find another parent whose child had the same diagnosis as her own: “Just connecting with other people…is really hard to do on your own,” the support parent expressed. “It's a big world out there,” the parent continued, “and just trying to find someone similar to you is almost impossible… After all these years, I am finally getting connected with families [through the parent-to-parent program] despite years of trying.” This ability to connect with other families and/or caregivers for the first time can help establish a “sense of belonging.”

One PSV explained that talking with similar others (Thoits, 1986) gives her “a greater sense of community and… not feeling alone….” Some respondents described a sense of relief being connected with another family member who has “walked the same path” and that someone was “actually listening” to them for the first time. One referred parent (RP) expressed how speaking with an experienced parent was unique compared to other forms of support available such as group therapy, marriage and family therapy, support provided by family members and physicians, etc.:

> The other types of support actually backfire. Normal avenues backfire when you get in these crisis situations [when your child has a medical emergency] and you need someone who has been there… and can give you what you need in order to strengthen

> you instead of making you feel more torn down or confused or helpless and alone too.
>
> And someone who has been there can make you feel less alone.

Another PSV reiterated this decrease of feelings of loneliness upon being connected with another veteran family, especially as a parent of a child who may be at an increased risk of having serious medical crises. Families may share a common experience with medical emergencies and all they entail:

> I felt that there was something that was missing when we went through [the experiences with my child [during his medical crisis] and had nobody else to connect with because we didn't know anyone else in a similar situation. And when we started connecting with families [as support parents], that's when I started to feel not so alone.

When describing the contacts they had made through the program, all of the 21 parents interviewed used phrases like “these families just get it” and they “have been through the same things that we have”. As one Referred Parent (RP) expressed, “it's something that's unspoken where you can let your guard down and the anxiety level just decreases when you know that somebody just gets it.” One parent support navigator (PSN) illustrated how often family members who have lived through the day-to-day process of caring for a child with special healthcare needs and disabilities may be more empathetic towards another family as compared to professionals who are responsible for the treatment decisions of the child:

> Well, I think it's the empathy from [the families] that is special. [The family members] know what my emotions are better than a doctor who hasn't done that or a social worker who hasn't [been a parent of a child with a disability].

One PSV described how frustrated she was because often individuals within the community reveal how they “feel bad” for her for having a child with a severe disability:

> Our daughter… has many [health] problems and she has Down Syndrome. And I don't want sympathy for that. And it's wonderful when I talk to parents [from the parent-to-parent program] because… it's empathy, not sympathy. They know how you feel and how everything goes. And it's nice to be able to speak to people [from the parent-to-parent program] that know what you're talking about.

The parent went on to explain that, not only does she not feel bad for herself or for her daughter, she is in fact quite proud to be the parent of a child with a disability.

No judgment. When speaking with another parent with shared experiences, oftentimes there is little to no fear of judgment. Current literature has indicated that families of children and youth with special healthcare needs and disabilities regularly feel judged or stigmatized by others without children with special needs within their communities (Goffman, 1963; Green, 2003; Green, Davis, Karshmer, Marsh, & Straight, 2005). Gray (2002) reported that often parents of children with disabilities experience both felt stigma (i.e. instances of overt rejection or discrimination experienced by stigmatized individuals) and enacted stigma (i.e. an individual’s feeling of shame or fear of rejection from others) (p. 737). Families report that often parents feel judged about their child’s behaviors and/or appearances, or even parenting abilities by friends, individuals from their community, doctors and other healthcare professionals, teachers, and even from their own family members. Twenty two of the participants interviewed in this study, including one healthcare provider, discussed how the social connection or bond of families with children with special needs can be dissimilar to those in other relationships, including relationships with family members. “I can talk with my friends or even my family members. But when I talk with another family [parent] I just know that she gets it,” said a RP, “and you're not being judged ‘cause you know that they're going through the same exact thing”.

Another RP described how she was surprised because she felt the support provided by her PSV was often more helpful than the support she received from her own mother, who had usually in the past been her main form of social support, but who also made her feel judged at times:

> I expected my family to respond differently [towards me] as a mother… of a special needs kid. I really… expected my family to be more of my support, like they've always been. And what I've found out is there's just a lot that people can't understand about a situation until you're *in* the situation. My mom didn't even believe the diagnosis for a long time. And in a way I get it… when I look at it through her eyes I understand that. But in another way it is really frustrating that my main form of social support thinks I'm being… a little bit ridiculous.

One PSN described how she felt more trust for other families with similar experiences than toward her own parents and other family members due to a lack of understanding and experiences of caring for her daughter’s disability:

> Sometimes even the closest family members do not understand. As a parent or caregiver [of a child with a disability] in the back of my head I am judging [my family members] because do they really get it, do they really understand? Even if it is our own parent, we are already thinking, “you don't know, you don’t really get it.” Talking to another parent [of a child with a disability] you don't have that negative

> conscious you get because they do get it and is reassuring to me, which then evolves into empathy.

Fewer than half of the interview participants (11 of 24) reported that they sometimes experience feelings of guilt about their child with special needs (Solomon, Pistrang, & Barker, 2001), which can be exaggerated by their heightened sense of responsibility for the wellbeing of their child (MacGregor, 1994). A small body of literature suggests that some parents of children who are chronically ill or have special needs may experience a sense of loss, grief, or guilt at the time of diagnosis of the disability, illness, or injury to their child (Fraley, 1990; Rolland, 1990). Moreover, parents' perception of being judged by others within their community may exacerbate these feelings of guilt or grief. One referred parent (RP) exemplified the need for caregivers to feel there is no judgment from others, especially when one is responsible for the care of a child with a special healthcare need and/or disability:

> When you have a child… with [disabilities], you have so much guilt and so many feelings every single day about everything, you just know that you're not being judged when you talk with another family. It's just a comfort level, an unspoken comfort level immediately. And that's just a bond that we all have.

One mother who came from the Hmong community of a large city expressed how she was able to let down her guard and be herself when talking about her daughter with special needs with other families with similar experiences:

> I always have all of my walls and all of my protectors around me. But I can let it down around another parent [of a child with a disability] because I know they won't judge me, and they will understand me. It is a burden lifted off of me and I can

> really talk about what is really in my heart. From there we can go from figuring out our emotions to our struggles because when you have a child with special needs you are already in a ball of emotions … When you have another parent you can talk to and put down your guard, you can look at things and reassemble them and help your family. Just having someone who understands you makes a difference.

Comfort level: coming down to the personal. All three healthcare providers reported that the HPs who have partnered with and have been trained by coordinators from the parent-to-parent program have come to understand the need for families to connect with other experienced families. One HP described her appreciation for the trustworthiness of information from other sources outside of a professional context and the need to get answers from someone that the family is comfortable with:

> This program allows the caregivers, the parents, to talk with somebody outside of the medical profession. I think it's easier for them to sometimes come down to a more personal level in regards to being able to talk with another parent who is experienced and lived through some of the same situations. In the midst of a clinical appointment [families] just don't go into that depth with medical providers.

As described earlier in the literature review of this study, HPs often speak in a specialized dialect using technical and procedural terms and/or information in the medical context. Family members of children and youth with special healthcare needs and/or disabilities may or may not be able to understand this type of specialized medical dialect, especially when the family members experience stress in the face of tough medical decisions for their child (Ahrens, Yancey, & Kollef, 2003). A vast majority of the family members interviewed for this study (19 of 21) reported that often they felt as though the medical discourse used by HPs causes the family member to feel left out of the decision-making process for their child with special needs (Case, 2000). Most of the interview participants, including the HPs (22 of 24) reported that when parents with shared experiences are connected via a parent-to-parent that the discourse between the family groups consisted of narratives and storytelling, which allowed families of children with disabilities to feel more at ease and better able to ask and answer questions regarding healthcare decisions for their children with special needs (MacNeil & Mead, 2005). One healthcare provider (HP) described how she could understand why it would be important for parents to connect on a personal level with other families who have similar experiences outside of the offices of healthcare professionals because, often in a medical context, professionals use jargon that may make a family feel less comfortable:

> I think it's just more of a comfort level connection where [families]… can relate to each other. They can talk on more layman's terms and be able to tell stories back and forth, to get… support.

One parent support volunteer (PSV) described how he felt he could be a resource and be able to communicate effectively for another parent who is going through similar experiences:

> We can talk about our children and… [parents] understand what you're saying, and if they have questions… I know I can answer them [in a way] that they understand.

Overprotective is okay. Interestingly, one subject that arose from a number of the interview participants was the idea of being overprotective. Two of the HPs and a number of the family members (*n* = 15) spoke of how caregivers of children and youth with special healthcare needs and disabilities often may be perceived as overprotective and may be labeled as controlling or domineering over their child's daily life (Holmbeck, et al., 2002). When others brand caregivers as being overprotective, the caregiver may be stigmatized and may feel further isolated from the community (Coleman, 1986). Research has shown, however, that families of children with disabilities often report that, despite the perceived stigmatization from others within their communities, being cautious about their child's daily activities and overall wellbeing may be a deliberate strategy to provide their son or daughter with more time and energy for school and friends, which may decrease their child's vulnerability to a medical crisis (Antle, Mills, Steele, kalnins, & Rossen, 2007). Those 15 families reported that connecting with other veteran parents via the parent-to-parent program may help to offset some of the feelings of being labeled as overprotective. One PSN discussed how, after she was linked with another family with shared experiences, she realized that being overprotective was not necessarily a bad thing:

> You know, when I talk to other parents who go through the same thing, who say, 'you know you have to be very overprotective of them, and if they [healthcare providers, professionals, teachers, etc.] don't like it, tough!' It makes me feel better.

One PSN, who had immigrated to the United States from Ethiopia late into her high-school years, described how prior to meeting another family with similar experiences through the parent-to-parent program, she often felt other people were labeling her as over-protecting her son who had significant healthcare needs:

> People who [see my] situation don't understand… even if they are family they don't get it. "You are overprotective," [they tell me]. No I am not… I am just being cautious because I know there are certain things [that my son] cannot do. He is

> not even supposed to get upset and cry. How do you tell a kid to stop crying because you have a shunt [in your brain] and could build too much pressure up in your head? Other families who have been there, they get it.

Decrease in stress, anxiety, and loneliness. Once the connection and the bond between families and/or caregivers is established, all of the parents interviewed for this study (*n* = 21) and two of the HPs reported that the feelings of anxiety, stress, loneliness, and the sense of being at a loss or out of control decreased for the parents taking part in the parent-to-parent program. For instance one parent support volunteer (PSV) described the feeling of how the empathy from another parent can be “a stress reliever just to be connected with someone who understands what you're going through [because] you don't have to define every definition or every word that you're saying ‘cause they know what it means.” Another parent support navigator (PSN) described her appreciation for the program’s ability to help others decrease their levels of stress, and felt that being connected with an experienced family could have benefited her family when her child was first diagnosed had it been available:

> I wish we would have had something like [the parent-to-parent program]. It took us a long time to get to a point to let go of that anxiety and of that fear [of another medical crisis and the future outcomes for my child]. I wish I had just had a parent to talk to [when my son was diagnosed]. And so I think it's really good that… there is this program that gives support to parents that need it.

One grandmother discussed how caring for her granddaughter, who had recently been diagnosed with a disability that involved a number of behavioral challenges, caused her to feel isolated and, often alone. When this grandmother was connected with PSVs through the parent-to-parent program, her feelings of isolation and loneliness decreased:

> [Being connected with another family through parent-to-parent] made the world of a difference for me. It lifted me out of depression; isolation is a killer of my health. I am usually a very outgoing person. It is just so lonely facing the unbelievable challenges of raising a child with such significant disabilities… and [this support] means everything to me. I would be so *(sigh)* so lost if I didn't have this [parent-to-parent] program… I mean it really contributed to my health, and wellbeing, and my emotions, and everything by having the [parent-to-parent] support.

One Ethiopian RP of four children discussed how her feelings of loneliness and sadness due to her daughter’s challenging diagnoses, living in a remote part of the Midwestern countryside, being a single mother, and her challenges understanding others due to linguistic differences changed drastically when she was matched through the parent-to-parent program with a trained PSV who happened to have a different cultural background:

> I didn’t even know [my closest neighbors] so it was really isolating. I had no one except for my four children. I mean it was really hard…. I thought I was the only person [going through this] and that no one could understand me. I couldn't understand the doctors because I am a second-language person. All of this process was very new to me. It was really hard. Every day I cried. I mean every day I cried. It was so lonely and I was so alone. I was so sad. Then one day I came to [my daughter’s hospital] and that is when I learned about [the parent-to-parent program]. This is how I got connected with this program. My matched family and me got connected right away. We talked for hours; we were just talking, talking, talking. I

> felt like I had family and there were people who had the same lifestyle as me. People who understand me and understand each other. They know what I am going through and everything. I started being happy.

One African-American mother talked about how her support parent validated her feelings of isolation and sadness, thereby giving her strength that she needed to care for her daughter's significant and ambiguous needs:

> It was a relief to talk to [my support parent] because… somebody finally understood… because everybody around you don't get that you have this question mark over you [i.e. is my daughter going to be okay? Will she survive?]. Because when you say my daughter has a *rare disease*… I had this question mark that was over my life…. So it was comforting for [my support parent] to say to me, "it is okay for you to feel this way… It is normal for you to feel that way." That is what my [support parent] did for me– she validated my feelings when everyone around me was invalidating them.

Reciprocity of support. All of the parents interviewed ($n = 21$) discussed how, if a match between families is successful, the support provided from one family to another often can be bi-directional. Even though the PSV may have been recruited to assist and answer questions from the RP, often the support parent will benefit from the RP as each side shares a similar parenting background. One PSV explained how often when she assists a family, she finds that she is receiving assistance in return:

> [Our relationship works] both ways– not just me helping them. I'm connected [with a mother] now…. and she's got information for me. There are some things that

> she's been through I haven't been through and I know that we're gonna go through that.

One PSV, who coincidentally happens to be a HP also, discussed how she wanted to support other families living through similar experiences. She explained how it was only after being connected with a help-seeking family that she realized she would receive support in return from them; that is, she both gave and received support. When asked about why she decided to become a support provider, one parent explained:

> I knew for sure... that I wanted to help where I could, and I knew that the experiences [my family] had gone through could be helpful to somebody else. And once I got into it, I found the families that I've met give me as much as I give them, if not more. It really is kind of a reciprocal thing, and you have support of one another. If I'm… in the hospital [with my child] other people…say, 'Oh yeah, I've been there, I've done that. Don't worry… this is what you can expect.'

Moreover, a majority of the parents (*n* = 17) reported that there was a sense of satisfaction when an individual felt that his or her experiences and expertise were valued and appreciated by another. One PSN illustrated her gratifying experience assisting another family. "It helps give me purpose," she said, "and I love helping other people. It's a passion of mine… to help people go through things that I've been through. It's very satisfying." One program coordinator (PC) illustrated this type of satisfaction in knowing she could support other families and emphasized how beneficial it could be sharing in this journey of other family members of children with special healthcare needs and disabilities:

> When I look at my son and I can share my story and I… hear other parents' stories, what they've been through, I always learn something new. It is so rewarding

> to be able to give back and hear other parents' comments saying you know, 'I really took something away.' Or even, I could say just for myself, hearing other parents give their experiences, I take something away from it. So it's always a learning tool for me when I hear their stories. It's a win-win for me.

Connecting the data to the research questions. The preceding six subthemes (i.e. similar others; no judgment; comfort level: coming down to the personal; overprotective is okay; decrease in stress, anxiety, and loneliness; and reciprocity of support) under this Trust and Empathy master theme relate to question two and four in this research study. Question two asked, "What are parents' perceptions of the differences in the kinds of social and informational support provided by PSVs as compared to other sources of support?" Question four asked, "How do family members of children with special needs perceive, if any, the differences in discourse when speaking to professionals in the medical field as opposed to speaking to another parent with shared experiences?" The data from the interviews described under these subthemes show that families do perceive differences in the kinds of social and informational support, and also perceive the differences in discourse, when speaking to PSVs as compared to other sources of support (e.g. HPs and other community resource professionals). The interview data suggest that families identify the following differences:

- When families receive social support from PSVs, many parents feel they are connecting with another individual with perceived similarities as opposed to connecting with HPs with whom parents may feel few similarities;
- Families may feel more comfortable, connect on a more personal level, and be able to speak in more of a natural, layperson's manner with a PSV compared to a HP or other community resource professional;

- Families may feel more open to discussing topics with PSVs as compared to HPs and others in their communities because the families are not afraid of being labeled overprotective or crazy from other families with shared experiences; and
- e) Families may feel a decrease in levels of stress, anxiety, and loneliness when connecting with a PSV as compared to connecting with an HP because of the perceived similarities and understanding.

Family-centered support. Another distinctive and important component of a parent-to-parent program is recognizing that families are very different, with varying levels of need. Every interview participant in this study (*n* = 24) discussed in some manner how the parent-to-parent program provided family-centered support. In parent-to-parent programs, PCs, PSNs and PSVs will fit the level of support as specified by the help-seeking family (i.e. RPs). One parent may be seeking ideas about what types of food to buy for her child with severe allergies, while another parent may be looking for guidance on what to ask for during the annual Individualized Education Plan meeting for her child, and yet another parent may be seeking support for himself and his family as his infant child awaits a heart transplant in a Neonatal Intensive Care Unit. One PSN explained how each RP is supported differently:

> The way we approach things [in the parent-to-parent program]… it doesn't feel overbearing. [We don’t] just inundate the parents with too much information. It's really centered around what the family needs, and I think that's the most important part because it's about the [help-seeking] family, whatever their needs are. And so we get very specific in their needs… when we do their intake, because ultimately who we're trying to help is the family.

The parent-to-parent intake process is an integral part of this support program because it involves a number of important steps to ensure family matches are made appropriately. First, help-seeking family members are referred to the parent-to-parent program by healthcare providers (HPs) who complete an electronic or paper-based referral form and return it directly to the program Coordinators (PCs) of the parent-to-parent program. Then, PCs contact the help-seeking family (who then are called RPs) within 48 hours of receiving the referral from the HPs to learn about what type of help the RP is looking for in order to create a person-centered support program. Next, the PCs search the statewide, national, or international Parent-to-Parent Program database searching for an appropriate PSV to match with the RP. Most often, RPs are connected with a PSV within their own state, but sometimes it is necessary to search in the national or even international database if a child's diagnosis is very rare. Once the PSV is chosen as a match, the PSV contacts the RP to initiate the support. Finally, after two weeks of contact between the two families, the PSNs contact both the RPs and PSVs individually to determine the effectiveness of the match.

Person-Focused Care. One African-American mother, who served first as an RP and then became a PSV for the parent-to-parent program, described how she felt the support was focused on her as a person needing support, not just as a mother of a child with a special need:

> When you use the word "family" that is what [we are all] thinking about. Parent-to-Parent] is not just about special needs, it involves the parents, too ... When you are a parent, you are always looking for support for your child [with special needs]. [But Parent-to-Parent] is a place for me. It's a place for *me* to be able to go back to. It is a release for me because it gives me a chance to have [time for myself].

This mother continued to describe how speaking to her matched family from the parent-to-parent program in fact did not feel like support at all; it felt more like speaking to someone very familiar, someone like family:

> You know it is just like family to me in a way. We are like family. We talk, we share, we support each other. And when you talk with people so many times, and share everything, it becomes personal. You get to know each other very well and it is more like family.

Moreover, unlike many other referral resources available to families of children and youth with special healthcare needs and disabilities, one distinctive facet of the parent-to-parent program is that PCs make the first contact via a phone call to RPs after the referral has been made from a HP or other referral source. More than half of the interview participants (20 of 24) discussed how great it felt to have the initial contact come from the parent-to-parent coordinators. A RP explained how rare it was to receive a call from an individual looking to provide her with support:

> That was the first phone call that I got from somebody reaching out to *me* to see if *I* was okay and to see if *I* needed anything. When I had [my child with disabilities], it's like I'm not even thinking about myself. And that was nice for somebody to call me and say, ‘How are you? Is there something that I can help you with?’ That was great.

Connecting the data to the research questions. The previous subtheme titled Family-Centered Support directly relates to question one and five of this research study. Question one asked “Do parent volunteers trained under the auspices of a structured Parent-to-Parent program help outreach medical clinics realize a major value that has been widely agreed upon by stakeholders in the system establishing a medical home? Question five asked "In what ways, if any, do parent-to-parent support programs contribute to establishing family-centered care for families of children and youth wish special healthcare needs and or disabilities for families?" The data from the qualitative interviews described under this subtheme suggest on a small scale that parent-to-parent programs can help to establish a medical home by providing family-centered support for families parent-to-parent programs by

- Recognizing that families are different from one another, with varying levels of need;
- Offering a level of support as specified by the family; and
- Providing a person-centered focus in that it is support designed for the individual as a person, not for the child with a disability.

Resources and Accessibility

After successful matches of help-seeking families with trained support families have been made and positive bonds have been developed, information that may be regarded by some families as more reliable is shared and a process of learning may begin.

Reliability of information. Interview data suggest that experienced families can provide other families with knowledge or information that may be regarded as more reliable than the knowledge that comes from healthcare professionals, other members of the community, and even from family members of the help-seeking families. Sixteen of the 21 family members interviewed indicated that information coming from another parent with shared experiences may be perceived as unique, and therefore may feel more trustworthy compared to the information received from perhaps a healthcare professional or another individual who does not have the same experiences as the caregivers themselves. One PSN characterized this phenomenon by saying:

> A lot of times the information that comes from a parent has a little bit more validity because… they can tell you about how [a resource] actually works. You can read about it, but then you don't know how [the resource] is going to work in your life. [The family member] can tell you about an experience they had with their child that you might be getting into and you can get a much more valid opinion than you can from a physician. I think [families] come at it with a perspective and an insight that no one else can provide.

Additionally, some caregivers often have found that information from other sources, such as from popular instructional parenting books, cannot supply the much-needed answers to vital questions because much of the information provided is for typically developing children and youth, not for those whose children have special needs. The information within these types of books, therefore, was irrelevant. One referred parent (RP) described how she was finally able to locate the answers she was seeking for her child with special needs, not within these types of books, but from an experienced parent:

> I think it's so scary when you walk into the special needs world and you don't know what the heck to expect. All of the parenting books out there … really don't tell you what to do when your child doesn't sit up and he’s seven years old. They don't take into account those things. So, it's learning … and being able to share some of those experiences [with another parent] and help each other. They can tell you what's worked for them, what hasn't worked for them. It doesn't mean it will work or won't work for you, but they can give you some ideas.

Sharing of resources. Interview respondents described how once connections with other experienced families with help-seeking families are established and become strong, some RPs may learn about new resources available within their communities, allowing them greater access to what is needed. Information shared between families can be about complex subjects like navigating the healthcare system, and how to apply for state and federal aid for family members. All of the RPs in this study (*n* = 9) reported that they experienced an increase in self-confidence related to accessing healthcare and coordinating the care of their child's special healthcare need or disability. Further, some families learned how to more navigate the healthcare system effectively. This could include many different areas of special needs according to what parents wanted to know including, for example, how to access better medical equipment, the benefits and drawbacks of different types of medical procedures, or the differences between an Individualized Education Plan (IEP) and a Section 504 Plan in the educational context. One parent support navigator (PSN) described different types of useful information that one can learn about when speaking with a veteran parent:

> [Parents] know resources. What types of foods to buy or where I can find certain kinds of foods … Or going to school and 504 plans. We know about resources online for 504 plans. We know resources for who could come sit with you and just be a support when you go in to do your 504 plan. And things like that.

Information shared between families can also be about rather simple, everyday topics such as: where to find clothes for children with special healthcare needs, what types of healthy snacks to take to school, which movie theaters are better equipped for children with special needs, and what parts of a particular region of a state are best to live in. One RP explained how her support parent assisted her with these straightforward inquiries:

> Just navigating where to live, where a good school district is. Because that's really important when you have a child with [disabilities], any child really, is that you want to have them in a good school district. Not every school district is strong with the IEPs and those kinds of things that kids [like my daughter] need. So [my support parent] was great, she was very helpful with that.

A parent support volunteer (PSV) also discussed how often families share experiences about uncomplicated subjects:

> Sometimes [the other family member and I] just talk about basic information. For instance [my husband and I] didn't know how to change our house to make it accommodating for our son. He's in a wheelchair and that kinda impacts everything … and we built a ramp. Our first ramp was really a very steep slide (*laughs*), not much of a wheelchair ramp. And so it's trial and error, and so hopefully we can help people so they don't build a slide on their home.

Through to the other side. When information that is perceived to be dependable is transferred back and forth between families with shared experiences, some families reported (n = 16) that they experienced a regained sense of hope within themselves, including RPs and PSVs. That is to say, these data suggest that families connected via a parent-to-parent program can provide support that will help guide families from one side of an experience that may be perceived as challenging to another side of an experience that is perceived as positive. One PSV expressed her experience with the way in which speaking with another family can restore a caregiver's optimism:

> Reaching out to [other parents] to get answers and finding out all the information that we can helps give people hope … because I think that sometimes when you're

> about to go through something with your child or thinking about the future can be stressful. And to talk to someone who's already been through it and see that they got through to the other side and things are good– I think it gives them hope.

Sharing of humor. A number of the families reported (18 of 21) that not only do they discuss and learn information about resources and other forms of support for their children with special healthcare needs and disabilities when talking with a family they have been matched with, but they can also sometimes share humor in situations that may often seem grim or overwhelmingly emotional. One PSV described how, when sharing stories and ideas with other families with shared experiences, laughter is common.

> Being able to [share] some concrete strategies and reassurances that all the behaviors are typical, all the struggles with school are typical… That way you kind of relax a little bit and at some point you can laugh at the things that your kids do. You know. Even though in the heat of the moment it's like, 'oh my gosh I can't believe my kid just did that!' But as we look back at it [together] we can laugh about it.

One grandmother (who had adopted her granddaughter with special needs and was the main caregiver) explained about how she was able to joke with another veteran parent about how frustrating and isolating Individual Education Plan (IEP) meetings can be for a parent given the number of professionals that generally attend meetings:

> I was joking with my support parent that the next time I go back [to the IEP meeting] I am going back armed with many people and every advocate that I can with a group as big as the one they put around me. 'I see you have 15

> people…Okay well hold on let me go find some people…. get somebody off the street. Here are my 15 people.' *(Laughs)*

Connecting the data to the research questions. The preceding four subthemes (i.e. reliability of information, sharing of resources, sharing of humor, and through to the other side) directly related to research question two that asked what parents perceived as different when comparing the kinds of social and informational support provided by the PSVs as compared to other sources of support. In fact, there was a high level of agreement across the diverse sample of the interviews participants suggesting that families do perceive a number of differences in the kinds of support when talking to another family with similar experiences including:

- Families may perceive that the informational support from a PSV as more trustworthy and reliable and there may be little to no fear of judgment as compared to other sources of support;
- Families may perceive that this reliable informational support from PSVs can be provided in a more personal and humorous manner that helps to provide social support compared to the support from HPs and other community resource professionals; and
- The support from PSVs is ongoing and based on positive attitudes and outcomes instead of negative-based challenges on which HPs and other sources of support often focus.

The support affects others. When families gain insight while speaking with one another, the RPs and PSVs are not the only individuals who benefit. In fact, the interview data show that the information gained when similar others communicate may have a trickledown effect for all stakeholders involved in a parent-to-parent program. Twelve of the interview participants, including PSNs, PCs, and two HPs, reported that the information exchanged amongst their patients' families who have been connected via the parent-to-parent support program may be advantageous for others as well. One HP explained how she had come to consider some of her patients' families as experts on caring for a child with a disability. This HP also described how both PSVs and RPs frequently shared what they had learned when linked with one another, which had unexpectedly informed the HP about many new facets of the medical world she had not previously learned about via previous medical trainings or from other trained professionals:

> What's unique about [the parent-to-parent program] is that these families who are able to and will share their stories teach not just other family members, but they teach me. I like to have that information from other families, to have them as a resource and to have all of these experts sitting down with us.

A new resource for professionals. In addition to providing professionals with new information, all three HPs reported that having a program that offered families support solely as a new referral resource was valuable. Data show that the parent-to-parent program gave some HPs a new resource that could provide a unique form of confidential support outside of the healthcare industry where nothing similar had existed, which may help decrease the amount of workload on a provider's practice. A mental health HP discussed how the program supported her patients' families:

> I think where [parent-to-parent] helps is being able to offer families…a resource to seek out help themselves. That's where it makes the biggest impact for us [in our practice] is that, instead of leaving the [families] helpless… there's something I can

> do. At least we can connect them with something that might be able to make things better.

Further, twelve of the parents also suggested that experienced caregivers may be able to assist help-seeking family members through the challenges of reaching a medical diagnosis for their child with special healthcare needs and disabilities, when HPs may often be less aware of the symptoms based on limited exposure to the child, lack of communication with family members, or even from a lack of knowledge of certain types of diagnoses. One RP gave details of her journey through the diagnosis process for her child with a pediatrician that had previously been unaware of all of the child's symptoms despite the parent's attempts to communicate these symptoms:

> I had frustrations because my son's primary [doctor] hadn't mentioned at all any concerns that [my son] might be [name of diagnosis] and I had actually been asking my son's doctor at his well-baby visits. I had been going through those checklists [doctors] give you now and I'm checking these things I see my son has all of the symptoms. And [the doctor] just didn't … suggest that we get my son tested or anything. And it was just really nice to hear [an experienced parent] say, 'yeah even primary care physicians [are not] completely … as invested [in our child's welfare] or as aware.'

Overcoming temporal restrictions. Another unique component of the parent-to-parent program is the accessibility of support. Compared to other types of help available (i.e. support groups, individual counseling, medical clinics, doctor appointments, etc.), parent-to-parent support is available whenever it is needed. There is no set time that families must appear in order to get emotional or social support, or vital questions answered. Unlike other support resources that begin and end at very specific times, there is no time limit to a parent-to-parent resource. All of parents interviewed (21 of the 24 participants) and two of the HPs explained that, due to the often quite limited amounts of time available for clinical appointments, family members of children with special healthcare needs and disabilities repeatedly feel that they are not able to get much-needed answers to their vital questions. “We [parents] need to talk,” said a PSN, *“*I need to ask questions. I need to not … have [the doctors] giving me this look like ‘Oh my goodness, she's asking me 20 questions”. One PSV described how an experienced family member frequently does not have the time constraints as compared to professionals:

> [Parent-to-Parent Support] is very much more personalized and there's not really a set time frame … When I call the other mom, sometimes it's a five-minute phone call, sometimes it's an hour-long phone call … A doctor, someone that's going to be on a real rigid time table and sometimes they only have five or ten minutes to give you and then it's ‘I gotta move on’ kind of thing. And so they can't sit and listen to everything … I think it's just that piece [where] we're able to connect for as long or as short as we need.

Making use of technology to connect. Interviewees also reported (*n* = 21) that parent-to-parent programs are unique in that they allow individuals to contact their support family members via phone, text, email, Facebook, or other types of social media without having to physically travel anywhere. One RP described the differences in parent-to-parent support compared to other forms of assistance:

> One thing that makes this program so special is that you can pick up the phone. You know there are [other support] groups ... But the thought of dragging myself out

> and meeting a room full of people that I've never met before just to try to get a little support -- it just never happened .... The idea that I could pick up the phone to talk to someone one on one ... that's special.

One parent support volunteer (PSV) reiterated this accessibility of parent-to-parent support via modern-day technology:

> The match [with the help-seeking family] that I've had, sometimes we have a hard time … connecting [via phone], so we're texting cause it just works for both of us. It sometimes takes a while to really connect with [the other family], just because of what we're all living through. With the doctor's appointments, and hospital [visits], or kids being sick, or the holidays. Texting makes it easier to make that connection.

The three HPs also recognized that the accessibility of the parent-to-parent support may be a benefit to their patients' families. One HP explained how being able to connect via phone allowed many families to get support because it can be very challenging to travel to appointments:

> Having to get somewhere to meet with someone is … I think it is really difficult. I think for a lot of our parents, even if being on the phone is hard, it's harder to get there in person. So having that option to have a … phone connection, I think is really good.

Connecting the data to the research questions. The preceding four subthemes under the Resources and Accessibility master theme (i.e. the support affects others; a new resource for professionals; overcoming temporal restrictions; and making use of technology to connect) relate to question one that asked if parent-to-parent support can help to establish a medical home for families of children with special needs. The data from the qualitative interviews described under this subtheme suggest on a small scale that parent-to-parent programs can help to establish a medical home by

- Providing HPs with a referral resource as part of comprehensive medical care that can help provide continuous support to families;
- Providing families informational support through PSVs that will help hold HPs and the medical clinics more accountable in the medical care that is provided;
- Making the informational and social support from PSVs more accessible for families by utilizing multiple forms of modern technology to connect at any time of day or night.

Awareness and Understanding

The beneficial outcomes from the parent-to-parent matches may stretch beyond the RPs that have been matched to other individuals involved in the program including support parents, PCs and PSNs, and even to the HPs through awareness and understanding.

Becoming more open-minded. Participants including both family members and HPs reported (*n* = 15) that there are many different types of diagnoses, and the effect of a diagnosis on a family member may vary for each individual, which is not solely dependent upon the severity of that diagnosis. Rather, family members may respond to diagnoses in very different ways no matter the severity (Kazak, Simms, & Rourke, 2002). Further, informants described how the PCs and PSNs who make the matches for the parent-to-parent program (*n* = 6) continued to learn from the individuals they are assisting, even well after the match had been created. One PSN stated that when she first became linked up with other families, she was well aware and even was bothered when the diagnosis of another family's child was less serious than her own child’s, but then learned that a diagnosis may be challenging for family members, no matter the severity:

> I think that [working for] the parent-to-parent program has done a good job of helping me gain some perspective …. Sometimes [families who are referred to the program] may have a lesser diagnosis [compared to my family or other families], but it’s all about how you interpret it. For some people it can be devastating that you have a diagnosis at all associated with your child. And for some it's more about trying to figure out how you deal with very severe disabilities.

Individuals also may become more open-minded when families of children with special healthcare needs and disabilities share their journeys with others. More than half of the informants (*n* = 14) indicated that the parent-to-parent program gave stakeholders a new perspective about the differences in families. One VSP described how being connected with RPs provided her with a new understanding of the diversity of the families living within her community:

> There’s a huge variety [of people]…. there's lots of different people out there raising different kids…There are the adoptive parents, but they're also the grandparents to the child. But now this child is calling [their grandparents by the name] mom and dad… I've heard about all of those situations before, but now it's real life even to me.

Ripple effect. One PSN who originated from Somalia described how being matched with another veteran family helped her to become more open and positive about her experiences with other members of her own Muslim community. This mother then explained that her candidness and positivity then encouraged other families within her community to be less guarded and even more optimistic about their own experiences with disabilities:

> People [from my community] are starting to share good things that they did with their kids. One lady [from my mosque] said she never took [her son with disabilities] to the mall. But she says now she does take him to the mall ... he likes to play but he doesn't like too loud stuff. But he likes to play with the toys and stuff. She [has become] really good at sharing [her experiences] now and getting out now with her son. I feel good about that.

Impact on Healthcare Providers. Through trainings conducted by the parent-to-parent program coordinators (PCs) and through their own experiences referring their patients' families to the program, some healthcare providers (HPs) reported becoming more aware and having an increased understanding of the needs of their patients and their families. Each of three HPs reported that just being trained in the goals of the parent-to-parent program, and knowing how and when to refer families for peer support, make providers more aware of the needs of their patients and of the patients' families. For example, one HP said that solely having the parent-to-parent program as a referral resource made her more conscious of the needs of families of children with disabilities:

> I think … just even having that opportunity to make a referral [to the parent-to-parent program] … I think just availability of it makes me think a little bit deeper into the needs of our families.

Interestingly, all 21 of the parent interview participants reported in some way that often HPs often did not understand, or overlooked, how stressful life can be for a caregiver of a child with disabilities when creating treatment plans for the child, and may not have been aware that compliance with providers' orders can sometimes be challenging for the families. (Hodgkinson & Lester, 2002). One mental HP explained how being connected with the parent-to-parent program made her more aware and understanding of the day-to-day demands of her patients' families:

> I think that the big thing I have learned through [parent-to-parent] is it doesn't matter how much experience I have [as a professional], I don't have a child with special needs. And I think [for] a parent, everyone's telling them to do this, that, and the other. And then [the professionals] get to leave at the end of the day to go home. I think talking to a [another] parent that doesn't get to walk away is special. There's that 'you know what I'm going through' [when talking with another parent] is very important.

Interview data also suggested that the parent-to-parent program can help HPs become more attentive and sympathetic to the frustrations family members can at times experience with the providers' advice and professional therapies that have been prescribed. One HP explained how she came to understand that parent-to-parent support could offer an arena for families to relieve the demands created by providers:

> To have [a professional] come in and say, 'Oh if you changed this to this, your child might make different choices', I think is really hard [for a family member]. So to have [a veteran parent] who is just kind of an ear and can empathize and know where you've been, and understand why you might be frustrated. Where you can vent about a provider that you have. Because sometime that's all you need to do is to get it off your chest and say you know 'this [provider] really irritated me today.' I think that's important.

Cultural Competence

As described in an earlier section of this study, culturally and linguistically diverse families of children with special healthcare needs and/or disabilities may be at an increased risk of experiencing bias towards their family members from others within their own cultural communities, outside communities, and healthcare professionals (Anderson & Fenichel, 1989). A relatively small body of literature dedicated to the importance of examining cross-cultural perspectives in disability research suggests that stigma levels vary within different types of ethnic communities based on cultural beliefs and norms. That is, different attitudes toward individuals with a wide range of disabilities exist across different cultures throughout the world. Data reveal that members of the majority white population expressed the highest level of acceptance of individuals with disabilities, while members from the Asian community expressed the least amount of acceptance and the greatest amount of pessimism (Westbrook, Legge, and Pennay, 1993). The current change in demographics in the United States continues to push parent-to-parent programs to incorporate cultural and linguistic considerations into family matching and program coordination given the sheer range of needs in help-seeking families. The topic of diversity was a common theme among most of interview participants and there seemed to be a high level of agreement across the diverse sample in this study suggesting that parent-to-parent programs may be capable of providing culturally competent support. One referred parent (RP) described her experience of connecting with many different types of families of children with disabilities within her community and how each family comes from a different background:

> I would say [help-seeking] families of children with disabilities come from a broad range of cultural differences in terms of income, what we've experienced,

> what we have been deprived of, what we have been given, what we have been stuck with. There is a wide range of intellect of parents from quite intelligent … even to those who are marginalized intellectually. Those who have educational degrees and those without degrees, those who are married, those who are single, those who had their own issues with things that are difficult in their life and others that do not. I would say … we are all very different. We probably wouldn't have crossed paths if we did not have a child with a disability.

Felt stigma from own community. Contemporary research has shown that parents from the same ethnic and linguistic groups facing similar challenges are likely to have information and emotional support that is highly salient to help-seeking parents (Banerjee, 2011; McCabe, 2008). Although perceived sameness (Singer, et al., 1998) is important for many families of cultural and linguistic backgrounds in order for trust to develop, some interview respondents indicated that even within their own cultural communities, they felt judged and isolated based on disability-based misconceptions. For example, one PSN who self-identified as living in a predominantly Hmong section of a large city talked about how she felt judged and stigmatized by her own community members because she had a daughter with a significant disability:

> My life revolves around the [Asian] community. Special needs in the Hmong community … is such a taboo topic. It is such a shameful taboo to talk about with others. When you talk about special needs in my community, [others say it is] karma and "it is because you did something horrible from your past. You deserve a child like that." Or "maybe your child did something horrible to deserve that." It is something very naïve in my Asian community. Because of all the stigma that is being

> placed on us within our culture all of these years. I don't think my daughter is in a horrible karma right now or in a past life for what she did. This is part of life we are trying to survive and be happy, but these stigmas … what everyone says in the public and behind our back, even immediate families would say it too. It doesn't help us and it hurts us.

One Ethiopian PSN, who came from a community in which many multi-national families of predominantly Muslim faith lived together, discussed how members of her close-knit community did not talk about issues regarding family members or other individuals with disabilities because it, too, was considered inappropriate to discuss in public:

> I know we have a culture problem [in regards to disability]. You know when you go out you see it … Sometimes if you have, like Autism kid or special kid, it is hard to talk to each other in our Muslim culture. They just hiding [the disability] and you don't even get the kind of information you need within our culture. I just feel so bad and no one wants to talk to you about those problems.

One RP described a similar sentiment within her predominantly African-American community of friends and, even, her own family members:

> Not everybody has [support from] family members because when you have a special child your relationship with friends and family … just kind of diminish. Because you kind of busy. And my own family members … don't understand it. You're talking to people who just don't know where you are coming from and don't accept it, especially in my community.

Disability is its own community. One common theme that many of the interview participants reported was how disability itself can be its own community. Twenty of the 24 interview participants described in some manner that when a family is intentionally linked with another trained support family with shared parental experiences via a parent-to-parent program, families may develop trust in and friendship with the family they are connected to, often regardless of the cultural differences that may exist between the matched families. One RP illustrated this point when describing her experiences with being matched to a family of a different cultural and linguistic background:

> It is not the color of my skin that matters because the problem is the problem and we [as parent's of children with disabilities] need support. There is a need for support in special needs, and disabilities do not have a color on it. … We are sitting at the same table with all kinds of differences, all different languages. Even if I don't understand the language of the parent, I can understand the issues they are going through.

One RP who self-identified as Hmong illustrated how lost she felt when her daughter received a serious diagnosis and how she found comfort in the similarities of her daughter's facial features compared to those of the face of her VSP's child, despite the differences in their racial and ethnic backgrounds:

> At the time when my daughter was first diagnosed with Trisomy 13 … it was important for me to talk to *anyone* who had a child with special needs. I didn't care about the diagnosis or anything of the other families' child. [My daughter] had high medical needs and I needed someone to talk to … I was actually really depressed and somewhat suicidal because everything I had to care for was very overwhelming. Then I was connected to another mother [through the parent-to-parent program], she was from a different culture …. She shared her story with me. When I heard she had a child that has Trisomy 13 just like my daughter it really touched me (*sigh*). Even

> when I think about it now … because of the diagnosis her [daughter’s] facial feature looks so similar [to my daughter]. It was really warming and it touched my heart because I wasn't the only one. There I was in a state with this rare disease. When you know someone who has a child with [Trisomy 13] and looks exactly the same [as your child] it is really reassuring.

Some families also reported (*n* = 8) that simply connecting with another parent via the parent-to-parent program can create a unique, diverse community and sense of belonging when families of children with special needs come together. One African-American mother described how the relationship with her support parent developed quickly even though she was not informed of her support parent’s race and/or cultural background prior to first connecting on the phone:

> I felt that as mothers we automatically bonded, especially as mothers of children that have rare illnesses … we bonded immediately. I don't think the fact that we come from different backgrounds had anything to do with [our friendship]. Because initially when we spoke on the phone, nobody gave us a bio of who we are talking to anyway. I know that she knows that I am African American because I told her. But for me it doesn't make a difference anyway. You are a mom with children that have special needs and that is what to me makes us our own community.

Another parent talked about how cultural diversity can have multiple meanings to some and that the support from parents of children she receives as a parent of a child with a disability can come from any form, diverse or not:

> I feel that from my experiences [with my support family], I don't mind what background we come from. When we have the common challenges [of having

> children with disabilities] the support is important to me. It doesn't matter their cultural differences, their intellect differences, the financial differences, for me it is all important support.

This same mother went on to explain that with other types of friendships, she may seek out companions with whom she perceives she shares more in common, which may have nothing to do with disability in general:

> In my other types of friendships, I may want more in common. If we are going to spend time together I wouldn't want to spend time with someone scrap booking who didn't want to scrap book. I find people with more common interest who have the ability to participate. But in the world of disability, it doesn't matter if we are diverse or not.

Culture matters. Interestingly, two of the parents interviewed for this study discussed how, even though both individuals stated that they themselves did not feel being matched to another parent of the same cultural and linguistic background was important, culture may, in fact, matter to other families in order to provide culturally competent support, especially when families first initiate contact with a program like parent-to-parent. For example, parent number one below who was a PSN explained how perceived sameness of culture may be an important step to trust for some families of diverse populations:

> I think culture is important and that it does sometimes matter [for families of children with disabilities]. Even the people born and raised in America that I interact with are still looking for the same culture and ethnic need [in others that support them]. There is more of a relationship that can develop with those similar to their culture. It is important and it is a need. Talking to someone who understands the

> culture or religious culture, or practices, or behavioral needs within that culture, it plays a part. If someone is not aware of how to carry themselves within another's culture then it may be hard to even have some kind of communication with that person. We try our best not to separate [the different cultural groups] because we are all a bigger group together [as family of children with disabilities]. But sometimes separating is good because that is what the community may need at that time. This is why [parent-to-parent] should provide them [culturally competent support] for their needs so they can grow beyond that.

When asked whether or not culture was important for families of children with disabilities, another PSN from Ethiopia reported that families from her own culture may not be initially as willing to share experiences with other families who are not from the same cultural background, even though this parent herself was willing to share her own experiences with any families of children of disabilities, regardless of cultural background:

> African people ... They just want to keep everything to themselves. They don't want to go outside of the culture. It could be trust a issue, it could be a misunderstanding, it could be that the culture is different.

This type of cultural consciousness characterized by the two interview respondents above can demonstrate the need for parent-to-parent programs to incorporate parent support volunteers (PSVs) from diverse populations to serve as cultural informants or guides. These diverse parents may then help provide appropriate support for all families of children and youth with special needs and/or disabilities within the framework of the parent-to-parent program. This value of including culture into the program will be discussed further below.

Cultural competence within the healthcare system. One component of the medical home model of care that is a condition set by the American Academy of Pediatrics (AAP) is cultural competence. The parent-to-parent program and this study defines cultural competence as a set of congruent behaviors, attitudes and policies that come together as a system, agency or among professionals and enable that system, agency or those professionals to work effectively in cross-cultural situations (Cross, Bazron, Dennis, & Isaacs, 1989). In order for a healthcare system to be culturally competent, it must demonstrate high levels of knowledge-based skills required to provide effective clinical care to patients from a particular ethnic or racial group (Betancourt, Green, & Carillo, 2002). That is, HPs and systems must include considerations of the individual social, cultural, and linguistic needs of patients for effective cross-cultural communication. The goal of cultural competence in health care is to reduce health disparities and to provide optimal care to patients regardless of their race, ethnic background, native languages spoken, and religious or cultural beliefs. The AAP (2016) states that cultural competence is the capability to respect the beliefs, languages, interpersonal styles, and behaviors of individuals and families receiving services, as well as staff who are providing such services.

Cultural competence within the healthcare system is a required component for the medical home model of care; to date, however, many healthcare systems and the providers within those systems have not been able to reach a level of cultural competence required by the AAP (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003). To provide culturally sensitive patient-centered care, physicians should treat each patient as an individual, recognizing and respecting his or her beliefs, values and care seeking behaviors (Like, Barrett, & Moon, 2008). However, many HPs lack the awareness of or training in cultural competence. With the constantly changing demographics within the United States, patients of HPs are increasingly becoming diverse as well, creating even more barriers for HPs to achieve cultural competence within their practices (Galanti, 2014).

As an example of how these cultural barriers between HPs and family members may negatively impact the overall emotional well-being of a family member, one Ethiopian RP described her experiences of going to see her daughter's busy primary care physician:

> Imagine a mom that doesn't speak any [English] language and has an interpreter … maybe the parent only gets 70 percent of the information [from the doctor] and the other 30 kind of falls away … When I go to the doctor sometimes I have a lot of questions and I feel like the doctor are always on their own time. You know like they are time rushing they don't give you that chance, especially when my English is bad.

Even with an interpreter to assist her with the linguistic challenges, this mother and her daughter's HP still encountered communication and informational barriers that ultimately denied this mother access to appropriate care for her child.

These communication gaps caused by language barriers, and social and cultural differences between HPs and family members of children with disabilities may be detrimental to the individual child's and families' needs (Harry, 1992; O'Connor & Fernandez, 2006).

Bridging the gap. Based on feedback from parents and current research on cultural competence, many parent-to-parent programs in the United States, such as the one examined in this study, have initiated incorporating cultural and linguistic informants as an effort to bridge the gap of communication and cultural misunderstandings many families of diverse populations face when working with healthcare professionals (Dong, Chang, Wong, and

Simon, 2011). These cultural guides are parents that serve as PSNs or PSVs, are a) parents of children with special needs, b) at least two years into their journeys as parents of a child with a disability, and c) trained by parent-to-parent PCs in research-based support practices. These cultural informants differ from the other support personnel in a parent-to-parent program in that these individuals counsel and guide the coordinators and project leaders of the program in ways to offer more culturally responsive support to all families of children with special healthcare needs and/or disabilities. That is, parent-to-parent programs attempt to recruit and train family members from diverse populations to ensure that culturally and linguistically diverse families who are struggling and need support in a healthcare system that may seem daunting and culturally unresponsive, may find comfort from a PSV that is of a similar cultural background. A number of the families reported (15 of 24 interview participants) found this attempt by the parent-to-parent program to provide a more culturally competent level of support to be both rare and important. One PSN, who also served as a cultural informant for the program, explained how she considered the support from the parent-to-parent program to be effective because her family match was methodically completed in order to include cultural and linguistic considerations:

> I think [the parent-to-parent program] is unique in that they don't just match you with anybody. Parent to Parent doesn't just go, “your child has such and such diagnosis, we are going to connect you with a parent with a similar diagnosis.” It is more meticulous. They learn about your child’s diagnosis, your child's age, your age, your marital status, your financial background, [whether you live in an] urban or rural environment. They match you based on socioeconomic levels… so many things. You get almost that perfect match, and Parent to Parent, they take that time to listen

> to you so they can match you with someone who truly understands you. Because having a child's diagnosis affects you in other ways… you are a single mom, or you have five other kids, or your child has so many services and your family is struggling financially. That is an even bigger connection between the two families because they know now they don't just have a special needs child in common; they both are struggling financially living in an urban city. You have that understanding of many aspects and that is what is unique about Parent to Parent.

Including cultural and linguistic considerations when matching families via the parent-to-parent program can help to alleviate some of the fear of stigma families may encounter when seeking support. One Ethiopian PSN explained how her presence at the parent-to-parent help desk located in some medical clinics has helped encourage some new diverse families, who may not have otherwise had the courage or desire to stop by the table, sign up for the program.

> I think when I am at the [parent-to-parent table] … families are more comfortable sharing with me. I think they feel comfortable because … they see someone dressed up like them or speak the same language, see someone from their culture. I would say 'hi how are you doing' …. These families then would feel comfortable to stop by. Before [I worked as a support navigator for parent-to-parent] I felt like these [diverse families] were walking by our table and not looking. And [once they became connected with parent-to-parent] they would become more comfortable sharing with others … with anyone from different cultures and different languages.

These deep cultural connections with families described above may help to foster stronger, more effective and positive relationships with families of children with special needs, which can lead to a decrease in stress, anxiety, and loneliness while increasing access to resources described earlier in this results section. One Somalian referred parent (RP) illustrated how, once she was connected with a parent support volunteer (PSV) from the parent-to-parent program, she was able to better communicate her daughter's needs with the physician and made better use of the limited amount of time the healthcare provider (HP) had available:

> Some times I have questions for my daughter's doctor and I am trying to get an answer to one question and then I forget the other one because we speak different languages. I think the doctors don't have time and they are rushing me …. I get frustrated …. But then a few months ago [my support parent] gave me this binder [that helps me organize] all of my daughter's information and can add notes to help me keep track of my questions for her doctor. My support parent gave me this binder and it is helping me get what I need from my child's doctor.

The binder this mother was referring to in the previous quote is one of many types of resources the parent-to-parent PCs and PSNs have created to assist both PSVs and RPs. These support materials are examples of another unique component of the parent-to-parent program that have been developed for families of children and youth with special healthcare needs and/or disabilities. In table 3 below, please find a list of examples of a few of the program materials created by parent-to-parent and a description of each resource.

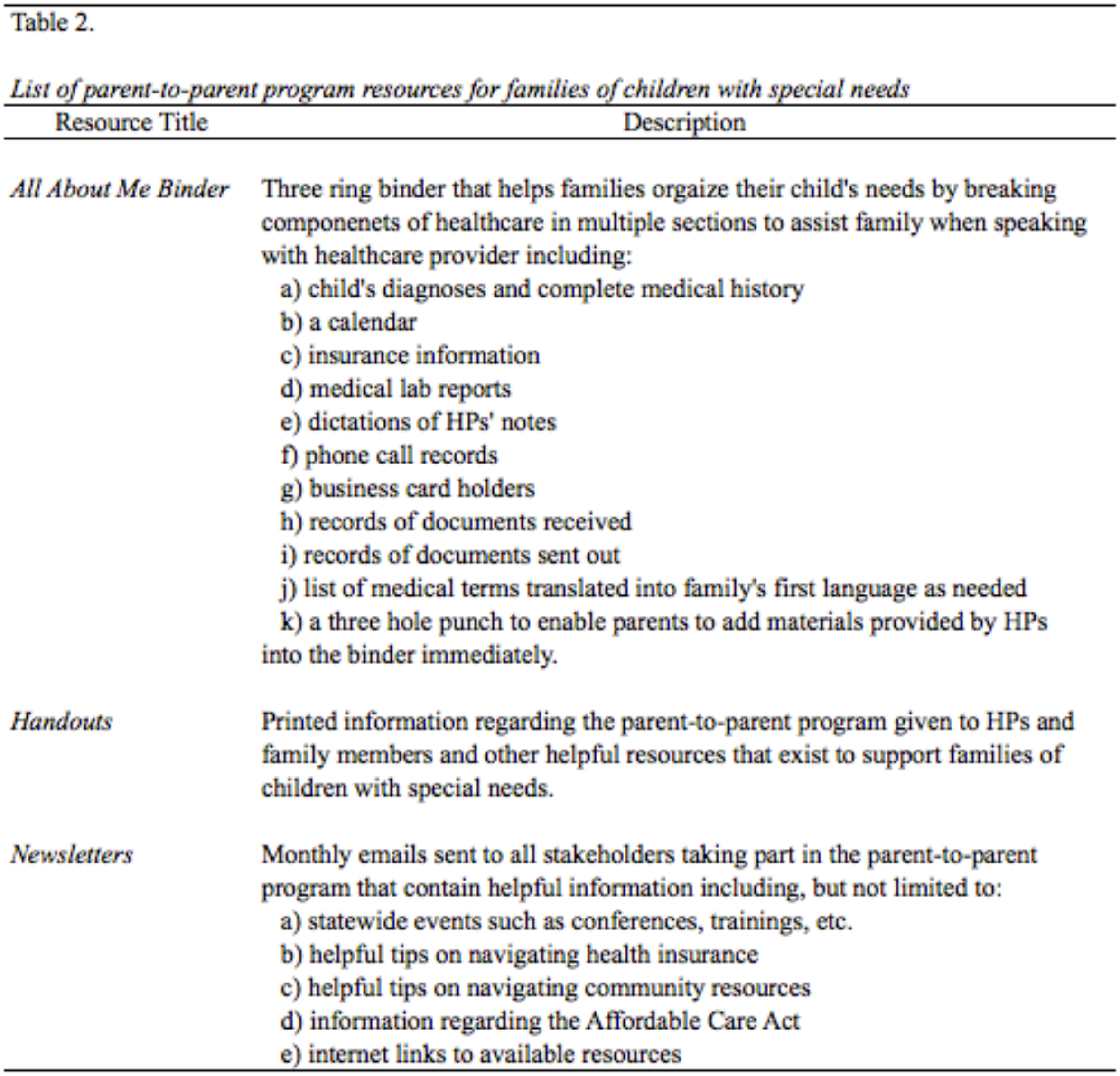


Table 2.

List of parent-to-parent program resources for families of children with special needs

Resource Title	Description
All About Me Binder	Three ring binder that helps families orgaize their child's needs by breaking componenets of healthcare in multiple sections to assist family when speaking with healthcare provider including: a) child's diagnoses and complete medical history b) a calendar c) insurance information d) medical lab reports e) dictations of HPs' notes f) phone call records g) business card holders h) records of documents received i) records of documents sent out j) list of medical terms translated into family's first language as needed k) a three hole punch to enable parents to add materials provided by HPs into the binder immediately.
Handouts	Printed information regarding the parent-to-parent program given to HPs and family members and other helpful resources that exist to support families of children with special needs.
Newsletters	Monthly emails sent to all stakeholders taking part in the parent-to-parent program that contain helpful information including, but not limited to: a) statewide events such as conferences, trainings, etc. b) helpful tips on navigating health insurance c) helpful tips on navigating community resources d) information regarding the Affordable Care Act e) internet links to available resources

One African-American RP described how her PSV encouraged her to seek assistance from other specialists related to her daughter's chromosomal abnormality, which in turn gave this RP the nerve to advocate for her daughter's very specific and serious needs:

> Getting help from my daughter's doctors was very emotional and I needed guidance from [my volunteer support parent] because even though [my support parent's] son had a chromosomal 16 abnormality just like my daughter, the

> breakages were in different places and so the symptoms were different. [My support parent] was the one who encouraged me not to just have a pediatrician, but that my daughter also needed to see specialists. She was telling me, ‘your daughter needs to see specialists because they are specializing in that one thing where your doctors are just kinda focusing on everything and it's easy to miss stuff.’ When she told me, I then told my daughter’s doctor, ‘you need to send me to specialists!’… That is how we got started with the endocrinologist, ear nose and throat doctor, and so on …. Now my daughter goes to specialists pretty much for everything. That was because she gave me that information when before I thought just seeing the general doctor was okay. I am glad that [my support parent] was there because there is no tellin' how long it would have taken for us to get to the specialists and how much time would have been wasted.

Connecting the data to the research questions. The preceding five subthemes (i.e. felt stigma from own community, disability is its own community, culture matters, cultural competence within the healthcare system, and bridging the gap) under this Cultural Competence master theme related to question three in this research study that asked, “Are there similarities between the perceptions of culturally and linguistically diverse families compared to those perceptions from the white Anglo majority culture regarding the type and effectiveness of the parent-to-parent support?” The data from the qualitative interviews described under this master theme suggest that families from diverse backgrounds believe culture should be considered an important component of any support program but that these diverse families do perceive a number of similarities regarding the impacts of parent-to-parent support compared to white, Anglo families including:

- The support provided from PSVs and PSNs via a parent-to-parent program can help create a sense of belonging and community within a community of families with children with special needs regardless of racial or ethnic background;
- The social and informational (including program material resources) support from PSVs is perceived to be family-centered and can help guide RPs in advocating for their child's needs with HPs;
- Parent-to-parent programs incorporate cultural informants or guides as PSNs and PSVs in order to help achieve cultural competence; and
- The support from PSVs is easily accessible via the telephone or other modern technology with few temporal restrictions as compared to the support provided by HPs.

Mutual Respect and Partnerships

When families of children and youth with special healthcare needs and disabilities connect and share similar experiences that are culturally competent that may lead to new awareness and understanding for other stakeholders, mutual respect may begin to develop between family members and professionals. Respect is the feeling of admiration for someone elicited by an individual's abilities, qualities, or achievements (DeLellis, 2000). Once respect is established, family members and professionals may be able to form constructive and meaningful partnerships, which may lead to more effective medical decisions and better overall outcomes for the child with special healthcare needs and disabilities (Bailey et al., 2006; King, Teplicky, King, & Rosenbaum, 2004).

In order for effective partnerships amongst individuals to develop, respect must be reciprocated and shared between both parties (Gallant, Beaulieu, Carnevale, 2002: Labonte, 1994). Nearly all of the interview participants (22 of the 24 participants) reported that the parent-to-parent support programs could help provide individuals with understanding and respect between families with shared parenting and family experiences, and between parents and HPs.

Ease of communication. The building of respect between two parties may be evident by examining the ease of which each party is able to communicate (i.e., the ability to ask and answer questions, share information, raise problems and concerns, check for understanding, reach an agreement, etc. (Makoul, 2001). Interview data suggest that once there is new awareness and understanding for one another, healthcare providers (HPs) and family members may begin to feel more comfortable, which can enable each party the ability to communicate more effectively and able to ask and answer questions unreservedly, which may lead to better healthcare outcomes (Street Jr., Makoul, Arora, Epstein, 2009). One HP explained how her patients' families were able to communicate their needs more effectively, ask better questions, and embark on a more bi-directional conversation with the HP after the family became linked to the parent-to-parent program:

> I feel like the people who I have referred [to the Parent-to-Parent Program] ... are more effective and more activated [in making healthcare decisions] ... and I feel like they're more engaged in a conversation with me as opposed to ... waiting for me to tell them the right thing.

One overall theme many interview participants reported (*n* = 17) was that when families and HPs begin to have mutual respect, they may feel more comfortable and may be able to communicate more effectively with one another, both parties may become increasingly motivated to support one another (Orchard, Curran, & Kabene, 2009). In fact, interview data indicate that caregivers may be more willing to offer their support to HPs if the family member perceives that the professional values their expertise in how to better support other family members of children and youth with special healthcare needs and disabilities. One HP discussed how she became more inclined to request guidance and assistance from caregivers as the family members became better at communicating their needs and how significant the parent's perspective can be when it comes to the healthcare needs of a child and in regards to how to assist other patient's families:

> I think when families continue to say, 'remember that we as the family have incredibly important view points and can be a resource for you' has really helped me trust and let go of some of that 'I don't know if I want to ask them [for help] when I don't know how to assist another patient's family.

One Hmong PSN, who spoke English as a second language, discussed how the parent-to-parent program encouraged some families to advocate for their children's and families' needs with medical professionals and take a leading role in their child's medical home:

> The parent-to-parent program can give family members the tools to become team members with the professionals for their child's care. A lot of the time they are following orders from the physician and they don't realize that they are valuable team members. We [as family support volunteers] can give them the tools they need and let them know they are a valuable team member. The physicians can benefit as well because they will have another team member, which is the family, versus [the medical professional alone] trying to figure out what is the need. [The medical professionals] don't know what is going on in [the families'] daily lives like

> the caregiver or parents. So Parent-to-Parent can help the family understand their role in a medical home.

Professionals value parents' expertise. Moreover, a few of the families (*n* = 8) reported becoming more sensitive and appreciative of the increased amounts of pressure facing many HPs today and became willing to assist professionals in their daily practice. One program coordinator (PC) discussed how, as a mother of an adult child with a severe disability, once her relationship with her son's healthcare professionals (HPs) had been established and she perceived that the respect she felt for the HP was reciprocated, she recognized that her learned expertise in caring for a child with a disability could benefit other hard-working HPs:

> My impression is that providers are … overwhelmed sometimes partially because of the types of families that they serve, but also I think by the complexity of the needs of a lot of the children that they see. [The providers are] so busy that they don't necessarily have time for creative ideas … of how to do things in their practice. So we [the families] are ones that need … to come up with the ideas and say, 'Well, how about if we try this? ... And then [the providers] are very excited about it.

The help or assistance to which this PC referred in the previous quote can be both informational and social support. One example of how parents could provide guidance to HPs would be when families suggest to help-seeking HPs that the doctor a) talk with parents who may speak a different language in more simplified terms and b) provide their patient's non-English speaking family with a handout that has been translated into the appropriate language.

Seven families and all three of the HPs interviewed for this study reported that when HPs respected the experience family members had in regards to caring for a child with special healthcare needs and disabilities, providers recognized that the expertise families could provide to other families with similar experiences might be invaluable. “[When family members take part] in my hospital,” exclaimed a HP, “hearing that voice as a consumer, hearing that voice as a parent is always invigorating … and so helpful.” One PSN illustrated how she initially became linked and eventually friends with a help-seeking parent when her child’s pediatrician was the one who made the connection between the two families, not the parent-to-parent program:

> My child’s pediatrician called me once and said, ‘I have this mom who has got a kid that's newly diagnosed … and she's at a loss as to what to do. Can you call her and talk to her?’ And so I did and now [the mom] and I have become good friends.

One HP explained how she recognized that over time parents become experts in navigating the healthcare insurance system because the parents had devoted so much time on the phone and filling out paperwork in order to qualify for the services their child needs. Some of the parents may be then able to educate the professionals in the complexities of these types of systems to help other patients’ families in the future: “I haven't walked all of these roads,” explained the physician, “I haven't navigated all of these systems.” The HP then explained that, she understood that her knowledge in the insurance arena was limited and therefore was able to refer her help-seeking family to another family who had the extensive experience navigating the ins and outs of the insurance system:

> It was like referring somebody to a specialist. I could say [to my patients’ families], ‘I don't really know for sure how to do this, but I know people who do.’ And so it made

> a huge [difference], it really takes a load off of me, you know [not having to] reinvent the wheel, when I know there are people out there who are doing it [navigating insurance and other bureaucratic systems] successfully.

The quote above from the physician is significant because these interview data suggest that some HPs are beginning to perceive family members of their patients as experts in obtaining effective care for their child in an often convoluted healthcare system. Moreover, these data also indicate that HPs are starting to perceive parent-to-parent programs as a referral resource of family specialist that can connect their patient's families to knowledgeable, helpful individuals.

Partnerships develop. Interview data show that following the development of mutual respect between HPs and families, sometimes the relationship may then transform into a partnership (Orchard, Curran, & Kabene, 2009). Fourteen of the interviewees reported that they felt a sense of a partnership with HPs when they were invited by the HPs to a) participate in the medical professional offices to inform other parents of the benefits of a parent-to-parent support program or b) join medical advisory boards in order to assist other families as part of a larger medical team. One PSN explained that she had been invited by her daughters' HP to set up a booth every week inside the professionals' medical center so that she could directly inform other parents about the benefits of parent-to-parent support just before or after help-seeking families go to clinical appointments:

> I work with the parents in the clinic … And I actually [was invited to set a booth] at the medical center where I'm working with the pediatric clinic to inform the parents that are [there with their child] about the [benefits of speaking to a support family]. I actually set up in the clinic and talk to parents, to recruit parents as PSV. And also

> parents who need the referral program that we offer for support– those [who] may have children with special health care needs or disabilities.

Another PSN described how she became invited to join a panel of experts in the healthcare industry supporting children and youth with special healthcare needs and disabilities as a representative of the voice of families:

> [The healthcare professionals] bring cases ... it's a group of public health nurses, doctors, psychologists, state workers, county workers, anybody [healthcare professional] that wants to be part of this team … People will bring cases for us when they're stumped, they don't know where to go, don't know how to help a family and they are just asking for ideas. [The healthcare professionals] have asked me to stay on their team as a resource.

The development of mutual respect and the formation of partnerships between families and professionals may be perceived as an influential phase in a families' journey with a child with a special healthcare need and/or disability. One HP described how important this phase could be perceived:

> [It is] just very powerful to me to see … how a relationship [a healthcare provider] is able to have with the families, that degree of partnering and partnership. We enjoy partnering with … families. [The parent-to-parent program] helps because it is another resource for our patients, which is … a multi-team effort to meet all of [the families'] needs, both medically, emotionally, and physically.

Connecting the data to the research questions. The preceding three subthemes (i.e. ease of communication, professionals value parents' expertise, and partnerships develop) under this Mutual respect and partnerships master theme related to questions one, four, and five in this research study. Question one asked, “Do parent volunteers trained under the auspices of a structured Parent-to-Parent program help outreach medical clinics realize a major value that has been widely agreed upon by stakeholders in the system establishing a medical home? Question four asked, “How do family members of children with special needs perceive, if any, the differences in the discourse when speaking to professionals in the medical field as opposed to speaking to another parent with shared experiences?” Question five asked, “In what ways, if any, do parent-to-parent support programs contribute to establishing family-centered care for families of children and youth wish special healthcare needs and or disabilities for families?” The data from the qualitative interviews described under this theme suggest on a small scale that parent-to-parent programs can help to establish a medical home by providing family-centered support for families parent-to-parent programs by

- Helping families learn to communicate more effectively with HPs;
- Helping HPs learn to communicate with family members in more of a natural, layperson’s manner;
- Creating more effective, bi-directional communication between family members and HPs;
- Helping to establish mutual respect and partnerships between families and HPs;
- Encouraging families to advocate for their child and themselves with HPs and other professional resources; and
- Encouraging HPs to incorporate parents into their medical practices to help create more family-centered care.

Empowerment and Advocacy

All 24 of the interview participants in this study discussed in some manner the theme of empowerment and advocacy. Interview respondents reported that, after the establishment of mutual respect and a strong partnership had developed among professionals and caregivers of children and youth with special healthcare needs and disabilities, a number of the family members then moved to a new stage in their journey from needing to care for their own families, to become empowered to support others through advocacy (Anderson, McIntyre, Rotto, & Robertson, 2002). One referred parent (RP) explained how the parent support volunteer (PSV) she had been linked with was able to encourage and empower her to speak up for the needs of her child with disabilities when communicating with other families and with professionals. This RP learned how to advocate for her child during her son’s medical appointments and was able to encourage her son’s HP to prescribe the appropriate assistive technology her son needed in order to be able to take part in his school and community setting:

> [The PSV] was very good about encouraging me, affirming me about being assertive with my needs, my family’s needs, my son's needs and … taking ownership of being the point person for his services and for the whole, the big picture of what his life will be like as [we] navigate through the healthcare system ... and I really liked that … it felt really great to have another parent say, ‘You gotta take the reins and go with it.’ It's a lot of responsibility and yet I know it’s important.

Discovering a purpose. More than two-thirds of the family members interviewed for this study (16 of 21) discussed the theme of discovering a purpose. As some caregivers grow more comfortable with “taking the reins” and develop into more effective advocates for family members with special healthcare needs and disabilities, some caregivers may begin to appreciate their own unique parenting experiences (Murphy, Christian, Caplin, & Young, 2007). Reflecting many families of children and youth with special healthcare needs and/or disabilities (Gibson, 1995), one PSV explained how she believed there was an extraordinary reason she had become a mother of a child with special needs and wanted to grow to a place in her life where she could support others in similar situations:

> I feel like I've been put in this position as [my child's] mom for a reason and [I] try to reach out and help other people … so they don't have to have such an uphill battle trying to figure some things out, whether it's medical or what doctor to go to, or getting help through the county. I had to do that all on my own and it was a lot of work and a lot of time. For all these years, I've been saying '(*sigh*) I wish I'd connect with someone.' And when the opportunity came up [to support parents] it was … just what I had been wanting for years .… I wanted to be able to help other families, to make it easier for them. And I knew I could help.

The sense of fulfillment that can develop when caregivers support others may expand the level of empowerment, which may in turn further motivate some individuals to continue collaborating with others with shared experiences (Wickham-Searl, 1992). One PSV illustrated this point:

> Not only does [supporting other parents] give you a sense of belonging, and a sense of hope, and a sense of community, and a sense of understanding, it gives you a purpose here and maybe you're put into this position [as a parent of a child with a disability] for a reason … knowing that you can affect other people's lives and make them better or easier for them.

Offering to support others. Once family members have succeeded in becoming the voice of their child and their family as a whole, ten of the parents interviewed talked about becoming more willing and able to turn to other families to offer their support (Panitch, 2008). One PSV described how he had arrived at a point in which his family life had stabilized into a steady and predictable schedule and found suddenly he had the desire to take on the responsibility of becoming a PSV so that other families may not have to experience the same trials he had to endure early on when his children were first diagnosed:

> I started advocating for other people at Individualized Education Plan [IEP] meetings … because I knew it needed to be done. And to me it meant actually helping out, and people were really appreciative of it. It's necessary in so many ways to have somebody that's there sitting on your side of the table even if, and in the beginning especially, I really didn't know what I was doing, but was just there for moral support … Because, you know it's really tough [in an IEP meeting], you feel daunted by all the people against you. It seems [that] just having a person there to hold your hand … and to have a different frame of mind is important.

One African-American RP explained that when the parent-to-parent program could not provide her with a direct match to another parent whose child had the same diagnosis as her daughter's extremely rare disorder, she became empowered to advocate for her daughter's unusual needs and to be that support person for another future parent whose child may have the same rare condition in the parent-to-parent program:

> My [support parent] was telling me how impressed she was at how knowledgeable I had become [about my daughter's condition] .… I am [my daughter's] mom, I am her voice, and this is what I need to do. I was telling

> [my support parent] that I had been looking for a child or an older adult that has the same [chromosomal] breakages … that my daughter has, to support me. I said if you [parent-to-parent] can't find a person for me… then add me to the matching database and then when another family comes along later that needs help I don't mind helping. At first I was really secretive about what was really going on with my daughter. Now I am not going to be secretive because somebody may have the answers that I need or I may have the answers that somebody else needs.

Once family members reached this point of taking on the responsibility of supporting others through a parent-to-parent program and advocating for those who have challenges advocating for themselves, 13 of the interviewees, including all of the program coordinators (PCs) and parents support navigators (PSNs) reported that some family members moved towards leading others and advocating at the local, state-wide, and even federal levels (Panitch, 2008; Wickham-Searl, 1992). One PC described a sense of satisfaction in helping to empower families by saying, "I like the fact that we're focused on supporting and helping families in the broad sense, but I particularly like to see the growth of individual families in becoming leaders." Some families may even continue towards working to help change current policies for individuals with special healthcare needs and disabilities (Munson, Hussey, Stormann, & King, 2009). Another PC described how a parent can evolve from having little to no confidence in how to care for his or her child, to being able to effectively advocate for their child and their family:

> It always makes me smile and amazes me how when … you talk to a parent that you never met that is caring for a child with special needs, they all say the same thing

> about what they need to do for their child and how they figure out how they have to be an advocate. They figure out how to piece things together. And when somebody who wasn't real outgoing learns to be outgoing when [his or her] child is involved. So I just think it's such a study in resiliency you know. I feel like I meet that with each parent. What wonderful spokespeople they are for their children.

Connecting the data to the research questions. The preceding two subthemes (i.e. discovering a purpose and offering to support others) under this empowerment and advocacy master theme related to both question one and question three in this research study. Question one asked, “Do parent volunteers trained under the auspices of a structured Parent-to-Parent program help outreach medical clinics realize a major value that has been widely agreed upon by stakeholders in the system establishing a medical home where families receive family-centered care?” Question three asked, “In what ways, if any, do parent-to-parent programs contribute to establishing family-centered care for children of families of children and youth with special healthcare needs for families?” The data from the qualitative interviews described under this theme suggest that parent-to-parent programs can help to establish a medical home by providing family-centered support for families’ parent-to-parent programs by

- Providing parents with a type of person- and family-centered support that is focused on empowering the individual parent to advocate for themselves and their family members with HPs and other professionals;
- Encouraging parents to discover a greater purpose within themselves relating to being a parents of a child with special needs; and

- Encouraging parents who have become empowered to advocate for themselves and their family members to support other parents in need.

The Benefits are Evident

The interview data from the six master themes from this research study (i.e. trust and empathy, resources and accessibility, awareness and understanding, cultural competence, partnerships and mutual respect, and empowerment and advocacy) suggest on a small scale that supporting the journey of family members with a child with special healthcare needs and/or disabilities through the guidance of a veteran family through a culturally competent parent-to-parent program may be beneficial for all stakeholders (Leake, Longworth-Reed, Williams, & Potter, 2012). One PC described the evolution a family may experience through the guidance of a parent-to-parent program that begins with trust and empathy, and culminates in empowerment and advocacy that begins within the family itself:

> [There is an evolution] of family leadership that happens beginning with the idea that the family first has to learn how to cope with their own situation and have some control over their own family and family situation. And then … when families have that sense of being able to cope well in that situation, … they expand out to being able to look at their community a little bit more broadly and maybe look at other families within their community. They're able to look at their community and then look at the needs of families in their state, then at the needs of families in the country and at what the policies that are … impacting families at all of those different levels. But it is truly … an evolution of leadership that happens and has to start at that very centerpiece; within the family itself.

Finally, one PSN described how her identity within her community transformed from that of family of a child with a disability within her own cultural community, to the family disability community at large because of her involvement with parent-to-parent:

> When I say *we,* I mean special needs. When I say *we*, it is our own families in the community of special needs. When I say *we*, I mean the entire special needs family everywhere. Now it is not just about the culturally diverse families anymore, it is a bigger community, and it is a bigger system. Within the mainstream system of disability, we have made progress since the 1960s, but there is still more room to grow and more things to do. If we support one another and support smaller pockets of all communities and make others realize that there are other groups of people out there that can help us, we can become a bigger support to all families.

Barriers to Successful Integration

Despite the overall beneficial impacts described in the results section of this research study of integrating a parent-to-parent program within comprehensive medical care, in order to achieve a medical home model of care for families of children and youth with special healthcare needs and/or disabilities, currently there are still a number of barriers that exist that seem to be getting in the way for these two concepts of care to function together effectively. Two of these barriers are a) the challenges of navigating the delineated, highly structured medical system protocols doctors perceive as more important to follow than developing effective partnerships with families; and b) the challenges of incorporating a non-profit volunteer organization into a for-profit medical care system that functions on a well-organized billing system. When asked directly what challenges in parent-to-parent and clinic functions and organizational contexts raise for implementation of a joint parent-to-parent and medical clinic service model (i.e. question six of this research study), one program coordinator (PC) who has been working with HPs to incorporate the parent-to-parent program into medical clinics for over four years had this to say:

> I think healthcare professionals typically believe that parent-to-parent support is important, helpful, and actually valuable. However, they don't routinely incorporate it into their work with their patients and their patient's families. Professionals have a preset agenda, often times created by the ‘medical system’. Parents aren't typically involved in creating this agenda and relating it to the overall healthcare of the child. Because of this highly technical agenda, I think there is a specific ‘workflow’ followed by most healthcare providers. This typically does *not* include offering peer support or connection to a peer support program, despite the fact it is a recommended best practice by the American Academy of Pediatrics. Moreover, parent-to-parent programs are not restricted by healthcare coverage and third-party billing of services needed. Unfortunately, health insurance companies determine a lot more than families do in terms of the way medical professionals do business.

These challenges described above that parent-to-parent program developers and coordinators currently face when attempting to successfully integrate the support program within the context of a medical clinic service model as part of comprehensive medical care and the steps that may address these challenges will be discussed in the following section.

Summary

This chapter discussed evidence from 24 interviews that examined the impacts of integrating a parent-to-parent peer support program to primary medical home clinics along with outreach specialty clinics serving low-income, diverse families, including underserved and underrepresented families, of children and youth with special healthcare needs and disabilities. The results of these data suggest the following: 1) parent-to-parent programs can provide a unique form of support for families of children and youth with special healthcare needs and disabilities; 2) many parents do perceive differences in the tonalities and casualness of parent-to-parent support compared to other sources of support; 3) many parents perceive differences in the forms of social and informational support provided by trained peer supporters as compared to other sources of support; 4) parents do perceive differences in discourse when speaking to professionals in the medical field as opposed to speaking to another parent with shared experiences; 5) there are similarities between the perceptions of culturally and linguistically diverse families compared to those perceptions from white Anglo majority culture regarding the type and efficacy of the parent-to-parent support, but cultural competence still remains important for diverse families; 6) parent-to-parent support programs can help contribute to establishing family-centered care for families of children and youth with special healthcare needs for families; 7) parent-to-parent support may be used as an adjunct to health services for families of children and youth with special healthcare needs and/or disabilities, which may then help amplify the benefits of traditional medical care, but challenges still arise for implementation of a joint parent-to-parent and medical clinic service model.

The following chapter will discuss the implications for current parent-to-parent peer support programs serving families of children with disabilities and future research in this field of family support.

CHAPTER V: DISCUSSION

The purpose of this research study was investigate the impacts of adding a peer support program into comprehensive medical care in order to help achieve a medical home for families of children with special healthcare needs and/or disabilities. Twenty-four key stakeholders taking part in the parent-to-parent program were interviewed for this study. Following Grounded Theory procedures as described by Charmaz (2006), six themes emerged including trust and empathy, resources and accessibility, awareness and understanding, cultural competence, partnerships and mutual respect, and empowerment and advocacy.

As previously peer-reviewed literature has indicated, parent-to-parent support can help create a community of similar others who trust one another with their life experiences, concerns, thoughts, and hopes (Ainbinder, et al., 1998). Findings of the present qualitative research study support on a small scale that the approach of integrating parent-to-parent support into primary care medical home clinics and outreach specialty clinics helping underserved and underrepresented families can be an effective program in supporting families of children with special needs and help achieve a medical home model of care.

Much of the data from this research study is consistent with previous research, but also new data have emerged from these interviews that are unique to the current body of existing literature on parent-to-parent peer support and the medical home model of care. Both interview and survey data from the present study suggest that parent-to-parent support may 1) help family members of children and youth with special healthcare needs and disabilities establish trusting and empathetic relationships with other families with shared experiences, which may help create a sense of belonging and acceptance for the family members (Nicholas & Keilty, 2007); 2) provide families with an easily accessible program that will help families access previously unknown and/or unattainable resources within their communities to assist their child or their family as a whole (Altman & Bernstein, 2008; Berrick, Young, Cohen, & Anthony, 2011); 3) help raise awareness and provide a better understanding of the individual needs of families of children with special needs for healthcare professionals and other professionals (Nilsen, Affronti, & Coombes, 2009); 4) encourage culturally and linguistically diverse families to join a community of similar others, while training HPs to create a more culturally competent environment for all patients and their families (Saha, Beach, & Cooper, 2008); 5) help foster relationships built on respect between family members and HPs that can develop into effective partnerships, which may increase the benefits of traditional medical care (Anderson, McIntyre, Rotto, & Robertson, 2002; Hamilton, Begley, & Culler, 2014); and 6) help empower family members of children with disabilities by increasing levels of parental self-worth, which may lead to increased ability to advocate for self and others on a local, state-wide, or federal level (Wickham-Searl, 1992).

The interview and survey data from this study show parents perceive a number of differences in the kinds of social and informational support provided by trained peer supports as compared to other sources of support, including formal support systems, which both corroborates previous research (Singer, et al., 1999) and adds to the current body of literature. Some of these differences in social and informational support include 1) the quality of the support (i.e. mutual understanding with similar others; no judgment; support is based on empathy, not on sympathy; casual, not technical level of discourse; reciprocity of support between stakeholders; family-centered support, etc.) and 2) accessibility of support (i.e. one-to-one support based on shared experiences; support not provided in a group setting; no time constraints of support, availability of support whenever it is needed, etc.) Although these data substantiate previous findings, they also extend the existing knowledge of the accessibility of support to include current social media. Families' ability to connect by phone, text, email or other social media is an important finding indicating further research is needed in order to examine the advantages of support by text, email, Facebook, Twitter, etc. versus support provided over the phone, especially in emergent medical crises when information may be required urgently.

Further, the findings reported in this study substantiate and further extend the research on HP-patient discourse analysis. Interview and survey data from this study suggest that many family members of children and youth with special healthcare needs and disabilities do perceive differences in discourse when speaking with professionals in the medical context as opposed to speaking with another parent with shared experiences (Barry, et al., 2001). As discussed earlier, parents of children with disabilities reported that HPs often have a technical attitude when discussing a child's diagnoses and prognoses using medical jargon that creates a sense of uneasiness and isolation for family members (Barry, et al., 2001; Case, 2000). The findings from this study show that when parents are intentionally linked to families with shared experiences through a parent-to-parent program, the feelings of uneasiness and isolation may be ameliorated, allowing a space for casual discussion and storytelling regarding their child's disability when communicating with one another. Healthcare providers (HPs) reported an understanding of the need for families to be able to discuss serious medical issues regarding a child's condition "on more layman's terms" with other experienced parents. HPs also reported that some RPs that had received support from other veteran families showed more active and effective communication skills regarding their children's and families' needs. The data from this research study suggest that parent-to-parent PCs should take into account the perceived differences in professional discourse for families of children with special needs when completing program trainings with healthcare professionals and parent support volunteer (PSV). Healthcare and other professionals should be directly instructed to be aware of their use of jargon and the technical voice when speaking with families of children with special healthcare needs and disabilities, and to focus on the use of lifeworld dialect. Not only do these findings align with the principle that increased use of lifeworld discourse can make for better outcomes and more humane treatment of families and children with disabilities as unique individuals (Barry, et al. 2001; Balint & Norell, 1973), these data also allow the researchers to examine more closely how discourse can help establish more respectful parent-professional collaboration. Future research should examine how direct training of the use of lifeworld discourse for professionals and other service providers can help support families of children with special needs especially those from diverse cultural backgrounds.

Results from this study also suggest on a small scale that HPs and other professional stakeholders in the medical field perceive that parent-to-parent programs can help promote partnerships with families of children and youth with special healthcare needs and disabilities. These data corroborate the findings of Singer, et al. (1999) that show that when parents are linked with veteran families with shared experiences through a parent-to-parent program, parents may become more knowledgeable and confident in taking care of their child's and family's needs (i.e. increased knowledge of child's diagnosis/diagnoses, available treatments, navigating and accessing health and insurance systems, and accessing community resources). Although these data are consistent with previous research, the data from this study also show that some of the parents' increased knowledge and confidence in navigating healthcare systems through trained peer supporters (Farmer, et al., 2004) can assist in empowering parents to be more active and effective in advocating for families' needs and wants with HPs. Additionally the findings also suggest that, due to the training HPs receive from PCs and volunteer support navigators regarding parent-to-parent policies and philosophies, healthcare professionals can have a greater understanding of the needs of families with children and youth with special healthcare needs and disabilities. Moreover, as parents' ability to advocate for their families' needs, and as HPs' understanding of the families' needs commonly increases, bi-directional communication can be established, which may lead to reciprocated trust. These data substantiate previous research that show, through trust, partnerships may form between HPs and families, which may lead to better healthcare decisions and more successful overall outcomes for the child with a special healthcare need and/or disability (Case, 2000). Future research should examine the effectiveness of healthcare decisions and overall outcomes for children with disabilities when families who have been linked with veteran families via a parent-to-parent program collaborate effectively with healthcare and other service professionals versus those families who have not been linked with another family.

Results from this study also show on a small scale that some culturally and linguistically diverse families of children with special healthcare needs and/or disabilities have similar experiences with the type and efficacy of support provided by the parent-to-parent program. That is, interview data suggest that some families of diverse backgrounds who have been intentionally linked with another family with similar experiences described parallel experiences with the support, regardless of the race or cultural background of their linked family member. These data suggest that parent-to-parent programs may be able to provide a form of support that can incorporate cultural informants or guides to ensure families of all cultural and linguistic backgrounds will be served appropriately. Furthermore, the results of this study also suggest that parent-to-parent support can provide an avenue for HPs and healthcare systems in general to become more culturally competent for their families of culturally and linguistically diverse backgrounds. Interestingly, some families indicated in the interviews that, even though the respondents themselves did not feel the need to be linked with a family that has a similar cultural background, these family members felt that culture was still important. Future research in parent-to-parent support should examine if support provided is more effective if families connected have similar culturally and linguistically diverse backgrounds compared to those families who do not have similar backgrounds. Moreover, future research should investigate whether families perceive the differences of HPs' levels of cultural competence after HPs receive direct training from parent-to-parent programs regarding culture.

The findings from this study also indicate on a small scale that integrating parent-to-parent programs within medical clinics can assist in contributing to establishing family-centered care, and can help to achieve a medical home for families of children and youth with special needs. First and foremost, the basic principles of the parent-to-parent program itself subscribe to the philosophy of family-centered care in that it a) regards the family as the main focus of care, b) involves parent and professional collaboration and partnership, c) addresses the needs of the families, d) provides family-specified support, e) relies on family decision making, f) emphasizes the strengths of the family, g) attends to families' individual needs, and h) empowers families (Allen & Petr, 1996). Incorporating parent-to-parent support within medical clinics can help establish family-centered support within the daily practice of healthcare professionals with families of children and youth with special healthcare needs and disabilities by encouraging families to advocate for, and to train HPs in incorporating the values of, family-centered care mentioned above as a part of comprehensive medical care. Moreover, parent-to-parent programs can help to establish a medical home for families of children with special needs by promoting the philosophy that care is accessible, continuous, comprehensive, family centered, compassionate, and culturally effective (American Academy of Pediatrics, 2015) when training HPs and other professionals. Future research should examine if parents and professionals perceive that parent-to-parent has helped to achieve a medical home and, if so, how?

Finally, in the differences between parent-to-parent and clinical functions and organizational contexts, the data from this study suggest a number of challenges to implementation of a joint parent-to-parent and medical clinic service model. Despite the growing body of literature supporting the use of the parent-to-parent support within the medical home model of care, research has shown challenges with implementing the model (Carrier, Gourevitch, & Shah, 2009; Nolan, Orlando, & Liptak, 2007). Results from this study suggest that some reasons for these challenges with program implementation may be the focus of professionals and health clinics on the few ways in which parent-to-parent programs are incompatible with the medical home model of care. These incompatibilities include, but are not limited to: differences in the levels of training of participants; lack of quality guidelines and empirical research to facilitate program implementation; added paperwork and processes over and above traditional care; challenges with incorporating and misconceptions regarding the responsibilities and roles of participants.

One challenge that continues to impede parent-to-parent support with the medical home is that of HP program buy-in. Perhaps a reason for these obstacles of provider and health clinic buy-in may be the misconception that implementing parent-to-parent programs as part of the medical home model within a practice is costly, time consuming, and confusing, due to the fact that few guidelines exist on program implementation (Antonelli & Antonelli, 2004; Carrier, Gourevitch, & Shah, 2009). That is, healthcare clinics may see parent-to-parent and the medical home as time consuming in that it can pile on more paperwork in an already paper-filled work environment, adding another layer to a complex system.

Another reason why providers may not buy in to the program is apprehension of losing autonomy within health clinics and the fear that parent support volunteers (PSV) will interfere with or even undermine physicians' authority. Additionally, medical professionals may cite diverging skill and training levels of parent-to-parent PSV and other highly trained professionals, despite the training parent-to-parent programs provide to PSVs. Further, health clinics may not perceive the life-experience training that many families have had as a valuable resource to include within their medical practice.

According to the data collected from both the interviews in this study, parent-to-parent programs have started to incorporate strategies for alleviating some of the problems inherent in implementing a joint program with medical care systems described above. These strategies include conducting direct trainings for HPs that discuss current research on the benefits of providing peer support for families of children and youth with special healthcare needs and disabilities, and parent-to-parent and cultural competency best practices based in empirical research.

Future Research

Although the current knowledge about the benefits of incorporating parent-to-parent support into comprehensive medical care, and integrating it within the medical home, is beginning to emerge, further research is needed. Building partnerships through collaborative efforts with healthcare professionals may improve care, cost effectiveness, and health outcomes for a child with special needs, as well as increase a parent's ability to speak for their child and advocate for change for families of children with disabilities.

Future research in the integration of parent-to-parent programs within the medical home model of care should examine larger samples of stakeholders via quantitative avenues of research, especially focusing directly on the perspective of the HPs to understand how providers view parent-to-parent support with the medical home model of care and why or why not it is being implemented within medical clinics. Further, due to the prominence of women in the empirical literature of parent-to-parent programs and in this qualitative interview study, research should recruit more males and even more culturally and culturally diverse participants, and examine how these factors influence the effectiveness of parent-to-parent programs in the medical context. Future research should also examine if parent-to-parent programs amplify the benefits of traditional medicine through trained peer supports; if trained peer support can assist professionals within their daily practice as an adjunct to professional services; and how the factors of socioeconomic status and region of family domicile can influence the effectiveness of parent-to-parent support within the medical context (i.e., limited access to healthcare due to economic status, language and cultural barriers, and extremely rural living conditions, etc.).

Limitations

This study has some limitations that should be considered for future research. First of all, despite the use of the multiple perspective evaluation of this study, the number of participants from each distinct role was relatively small for the qualitative interviews. Future research in the field of the integration of parent-to-parent programs within the medical context should examine a larger sample of stakeholders, especially focusing more directly on the perspective of the HPs. Second, the predominance of women in the sample of participants, and the predominance of Caucasian majority participants are limitations of this study. Future research should recruit more males (if possible, given that most of the family members currently taking part in parent-to-parent programs are female) and more ethnically and culturally diverse participants, and examine how these factors influence the effectiveness of parent-to-parent programs in the medical context. Finally, this study evaluated the parent-to-parent program from the beginning of program implementation, which is a relatively short period of time. It is possible that there are more powerful effects when measured over a longer period of time as the program becomes more firmly established within the medical clinics. Moreover, future research should examine if parent-to-parent programs amplify the benefits of traditional medicine through trained peer support; if trained peer support can assist professionals within their daily practice as an adjunct to professional services; and how the factors of socioeconomic status and region of family domicile can influence the effectiveness of parent-to-parent support within the medical context (i.e., limited access to healthcare due to economic status, language and cultural barriers, and extremely rural living conditions, etc.).

Conclusion

Despite the limitations, this study does allow the researchers to draw some overall conclusions about the effectiveness of integrating parent-to-parent support within the medical context. Overall, the findings suggest that parent-to-parent support can be a valuable source of assistance for many parents of children and youth with special healthcare needs and disabilities. Results from this investigation indicate that individuals who are successfully matched with a reliable ally via the parent-to-parent program showed higher levels of understanding of medical services, increased access to healthcare and health insurance, increased ability to advocate for self and others, decreased levels of anxiety, stress, and loneliness, and an increased understanding of the community resources available. Moreover, parent-to-parent support can help empower parents to advocate for their families' needs and support other families, and help foster partnerships with professionals within their communities, including culturally and linguistically diverse populations. These findings are consistent with previous research that shows connections between families with shared experiences are associated with decreased signs of depression and increases in self-esteem, positive mood and sense of control (Folkman & Lazarus, 1988; Folkman & Moskowitz, 2000; Nezlek & Gable, 2001; Pottie, 2008). These positive connections with other families may lead to feelings of self-worth and empowerment (Ainbinder, 1998).

Results from this present study provide a more complete understanding of the unique qualities of parent-to-parent support and the impacts of adding this type of program to medical clinics for underserved and underrepresented families of children and youth with special healthcare needs and disabilities. Parent-to-parent programs can help families with special healthcare needs and disabilities by offering a unique form of support that can effectively complement and enhance medical care services. As one parent support volunteer (PSV) powerfully concluded. “mostly what [families] need is just to be heard and to just know that they're not alone, and that there are ways to handle [their child’s medical needs and families’ needs] and that life will be okay. You know, your life has changed dramatically, but it's gonna be fine. You're just gonna do things a little bit differently.”

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APPENDICES

Appendix A

Informed Consent for Healthcare Providers

INSTRUCTIONS:
Informed consent. We are evaluating the Parent-to-Parent program from Family Voices of Minnesota. You have spoken to and referred a parent who has received services from Family Voices. We want to learn about your ideas and feelings about this kind of support from a service provider. Researchers at the University of California, Santa Barbara are interviewing medical and social service providers and parents providing and receiving services from Family Voices of Minnesota in order to learn about practices that are helpful to families from your community. The study is based on interviews. The University of California, Santa Barbara is trying to learn how Parent-to-Parent programs operate and how different participants see their roles and their views on what does and does not help families. Dr. George HS Singer, and Louisa Wood who is advised by Dr. Singer in their doctoral and master's programs at the University are completing the research. We are asking to interview you for up to one hour by telephone to ask you about parent-to-parent support. We know that you are very busy and so we will arrange to talk to you at a time and date of your choosing and we will make every effort to keep the interview brief. If necessary to better understand something you say in the interview we may also be asking consent to contact you again one time only for no more than 10 minutes. The interviews will be recorded and then written out. They will be stored in locked files at UCSB. We are asking consent to use some information such as your age, ethnicity, marital status, and also some information about your child's age and illness or disability. There are risks in any research. In an interview study it is possible that someone outside of the research team would hear the recording of your interview or read the transcript so that your confidentiality would be breached. We will safeguard against this by keeping any digital files on a hard disc drive that is kept in a locked cabinet at UCSB. We will not use your name on any written document. We will also protect digital files with requirements for passwords to access them. Any written data will also be kept in the locked cabinet in a locked room. If we quote from the interview in a report or presentation, your name will be changed and no other information will be provided about you. You do not have to participate in this study and there will be no negative consequences if you chose not to. You may ask to skip any question that you don't feel comfortable answering. You can also ask to end the interview at anytime. After the interview you can ask that any part or the entire recording be erased. There will be no negative consequences of these actions.

If you give your consent please read and then sign below.
I am consenting to participate in an interview study about Family Voices and that the interview will be recorded and transcribed. I understand that I can withdraw from the study or refuse to answer any questions at any time. I understand that I can ask that any part of the recording be erased at any time after the interview. I can withdraw or ask for erasure by contacting a researcher at: singer@education.ucsb.edu or at 805-893-2198, by telling the interviewer, or by telling the parent-to-parent helper who works at the clinic.

If you have any questions regarding your rights as a research subject, please contact the Human Subjects Committee at (805) 893-3807 or hsc@research.ucsb.edu. Or write to the University of California, Human Subjects Committee, Office of Research, Santa Barbara, CA 93106-2050.

Name ___________________________ Date ____________________

Signature __________________________

Appendix B

Informed Consent for Project Coordinators and Parent Support Navigators

INSTRUCTIONS:
Informed consent. We are evaluating the Parent-to-Parent program from Family Voices of Minnesota. You have been working on the grant project from Family Voices and have spoken with family members about your child with special needs. We want to learn about your ideas and feelings about this kind of support from another parent and an individual working on the grant project itself. Researchers at the University of California, Santa Barbara are interviewing medical and social service providers and parents providing and receiving services from Family Voices of Minnesota in order to learn about practices that are helpful to families from your community. The study is based on interviews. The University of California, Santa Barbara is trying to learn how Parent-to-Parent programs operate and how different participants see their roles and their views on what does and does not help families. Dr. George HS Singer and Louisa Wood, who is advised by Dr. Singer in her doctoral and master's programs at the University, are completing the research. Please be informed that Louisa Wood is contracted with Family Voices of Minnesota and is receiving compensation for the work she is completing for the project.

We are asking to interview you for up to one hour by telephone to ask you about parent-to-parent support. We know that you are very busy and so we will arrange to talk to you at a time and date of your choosing and we will make every effort to keep the interview brief. If necessary to better understand something you say in the interview we may also be asking consent to contact you again one time only for no more than 10 minutes. The interviews will be recorded and then written out. They will be stored in locked files at UCSB. We are asking consent to use some information such as your age, ethnicity, marital status, and also some information about your child's age and illness or disability. There are risks in any research. In an interview study it is possible that someone outside of the research team would hear the recording of your interview or read the transcript so that your confidentiality would be breached. We will safeguard against this by keeping any digital files on a hard disc drive that is kept in a locked cabinet at UCSB. We will not use your name on any written document. We will also protect digital files with requirements for passwords to access them. Any written data will also be kept in the locked cabinet in a locked room. If we quote from the interview in a report or presentation, your name will be changed and no other information will be provided about you. You do not have to participate in this study and there will be no negative consequences if you chose not to. You may ask to skip any question that you don't feel comfortable answering. You can also ask to end the interview at anytime. After the interview you can ask that any part or the entire recording be erased. There will be no negative consequences of these actions.

If you give your consent please read and then sign below.
I am consenting to participate in an interview study about Family Voices and that the interview will be recorded and transcribed. I understand that I can withdraw from the study or refuse to answer any questions at any time. I understand that I can ask that any part of the recording be erased at any time after the interview. I can withdraw or ask for erasure by contacting a researcher at: singer@education.ucsb.edu or at 805-893-2198, by telling the interviewer, or by telling the parent-to-parent helper who works at the clinic.

If you have any questions regarding your rights as a research subject, please contact the Human Subjects Committee at (805) 893-3807 or hsc@research.ucsb.edu. Or write to the University of California, Human Subjects Committee, Office of Research, Santa Barbara, CA 93106-2050.

Name ___________________________ Date ___________________

Signature __________________________

Appendix C

Informed Consent for Parent Support Volunteers

INSTRUCTIONS:
Informed consent. We are evaluating the Parent-to-Parent program from Family Voices of Minnesota. You have spoken to a parent who has received services from Family Voices about your child with special needs. We want to learn about your ideas and feelings about this kind of support from another parent. Researchers at the University of California, Santa Barbara are interviewing medical and social service providers and parents providing and receiving services from Family Voices of Minnesota in order to learn about practices that are helpful to families from your community. The study is based on interviews. The University of California, Santa Barbara is trying to learn how Parent-to-Parent programs operate and how different participants see their roles and their views on what does and does not help families. Dr. George HS Singer and Louisa Wood, who is advised by Dr. Singer in her doctoral program at the University, are completing the research.

The evaluators are asking to interview you for up to one hour by telephone to ask you about parent-to-parent support. We know that you are very busy and so we will arrange to talk to you at a time and date of your choosing and we will make every effort to keep the interview brief. If necessary to better understand something you say in the interview we may also be asking consent to contact you again one time only for no more than 10 minutes. The interviews will be recorded and then written out. They will be stored in locked files at UCSB. We are asking consent to use some information such as your age, ethnicity, marital status, and also some information about your child's age and illness or disability. There are risks in any research. In an interview study it is possible that someone outside of the research team would hear the recording of your interview or read the transcript so that your confidentiality would be breached. We will safeguard against this by keeping any digital files on a hard disc drive that is kept in a locked cabinet at UCSB. We will not use your name on any written document. We will also protect digital files with requirements for passwords to access them. Any written data will also be kept in the locked cabinet in a locked room. If we quote from the interview in a report or presentation, your name will be changed and no other information will be provided about you. You do not have to participate in this study and there will be no negative consequences if you chose not to. You may ask to skip any question that you don’t feel comfortable answering. You can also ask to end the interview at anytime. After the interview you can ask that any part or the entire recording be erased. There will be no negative consequences of these actions.

If you give your consent please read and then sign below.
I am consenting to participate in an interview study about Family Voices and that the interview will be recorded and transcribed. I understand that I can withdraw from the study or refuse to answer any questions at any time. I understand that I can ask that any part of the recording be erased at any time after the interview. I can withdraw or ask for erasure by contacting a researcher at: singer@education.ucsb.edu or at 805-893-2198, by telling the interviewer, or by telling the parent-to-parent helper who works with Family Voices of Minnesota.

If you have any questions regarding your rights as a research subject, please contact the Human Subjects Committee at (805) 893-3807 or hsc@research.ucsb.edu. Or write to the University of California, Human Subjects Committee, Office of Research, Santa Barbara, CA 93106-2050.

Name __________________________ Date ___________________

Signature _________________________

Appendix D

Informed Consent for Referred Parents

INSTRUCTIONS:
Informed consent. We are evaluating the Parent-to-Parent program from Family Voices of Minnesota. You have spoken to a parent who was matched to you by Family Voices about your child with special needs. We want to learn about your ideas and feelings about this kind of support from another parent. Researchers at the University of California, Santa Barbara are interviewing medical and social service providers and parents providing and receiving services from Family Voices of Minnesota in order to learn about practices that are helpful to families from your community. The study is based on interviews. The University of California, Santa Barbara is trying to learn how Parent-to-Parent programs operate and how different participants see their roles and their views on what does and does not help families. Dr. George HS Singer, and Louisa Wood who is advised by Dr. Singer in her doctoral and master's programs at the University, are completing the research.

We are asking to interview you for up to one hour by telephone to ask you about parent-to-parent support. We know that you are very busy and so we will arrange to talk to you at a time and date of your choosing and we will make every effort to keep the interview brief. If necessary to better understand something you say in the interview we may also be asking consent to contact you again one time only for no more than 10 minutes. The interviews will be recorded and then written out. They will be stored in locked files at UCSB. We are asking consent to use some information such as your age, ethnicity, marital status, and also some information about your child's age and illness or disability. There are risks in any research. In an interview study it is possible that someone outside of the research team would hear the recording of your interview or read the transcript so that your confidentiality would be breached. We will safeguard against this by keeping any digital files on a hard disc drive that is kept in a locked cabinet at UCSB. We will not use your name on any written document. We will also protect digital files with requirements for passwords to access them. Any written data will also be kept in the locked cabinet in a locked room. If we quote from the interview in a report or presentation, your name will be changed and no other information will be provided about you. You do not have to participate in this study and there will be no negative consequences if you chose not to. You may ask to skip any question that you don't feel comfortable answering. You can also ask to end the interview at anytime. After the interview you can ask that any part or the entire recording be erased. There will be no negative consequences of these actions.

If you give your consent please read and then sign below.
I am consenting to participate in an interview study about Family Voices and that the interview will be recorded and transcribed. I understand that I can withdraw from the study or refuse to answer any questions at any time. I understand that I can ask that any part of the recording be erased at any time after the interview. I can withdraw or ask for erasure by contacting a researcher at: singer@education.ucsb.edu or at 805-893-2198, by telling the interviewer, or by telling the parent-to-parent helper who works at the clinic.

If you have any questions regarding your rights as a research subject, please contact the Human Subjects Committee at (805) 893-3807 or hsc@research.ucsb.edu. Or write to the University of California, Human Subjects Committee, Office of Research, Santa Barbara, CA 93106-2050.

Name ___________________________ Date ___________________

Signature _________________________

Appendix E

Interview Protocol for Healthcare Providers

-First all let me start off by saying how much I appreciate you taking the time out of your busy schedule to speak to me today. I know as a mother, a student, and a professional how hard balancing life can be. Thank you.

The parent-to-parent program has received a grant from the federal government to add a parent-to-parent support program to the outreach clinics offered by your organization (give name as you know it). The funders have asked us to study what impact this program has, if any.

-The information from this interview will be used for the purposes of the evaluation of this program. I want to learn about information early on at the beginning of this program from the coordinators to get an idea of how the program is going.

-Now, I want to ask you if it is okay that I record this interview. The only people who will hear the recording or see the transcripts from this data will by myself and the other evaluator, my advisor George Singer, at this point in time. May I have your permission to record this interview today?

-One final question before we head into the interview: We will be asking in the future for consent to use the data from this interview to use in a study. I want to make sure you understand that you do not have to be a part of the study if you do not want to. Would you be okay if I send you a letter of consent in the future?

<u>QUESTION 1:</u> So why don't we start off by telling me a little bit about yourself and what you do professionally?

<u>QUESTION</u> 2: First, when I talk about the parent to parent program what does that mean to you? Who is involved? What do they do as far as you know?

-What interactions have you had with the program?

<u>QUESTION 3:</u> Great. Well let's move on to the next question. Let's talk about how you became connected with the Parent-to-Parent Program. How did you hear about the parent-to-parent program?

-What do you feel that the main goal of the Parent-to-Parent program?

-Do you feel that you have been fully informed or trained into the goals of parent-to-parent?

- (ask if answer above is negative) If not, what can we do to provide you with better understanding of the goals and support of the program?

-What is your relationship with this organization currently?

-Would you call your relationship with the parent-to-parent team a Partnership?

- If not why? If so, can you give me an example of when you have teamed up with them? Do you feel you are getting the support you need from the Voices Team?

-Does your relationship with parent-to-parent make your job working with families different? If so, how?

-What impact does the parent-to-parent program have on your practice?

-Are there key differences you notice between families who are connected with parent-to-parent versus those who are not?

QUESTION 4:

-Do you feel that being connected with the parent-to-parent program has helped you develop a better understanding of the needs of the families you serve? If so, how?

-If not, what do you think the parent-to-parent program can provide you in order to help achieve this goal?

-How has your involvement with the parent-to-parent program affected your understanding of your families' individual backgrounds and cultural needs, if at all?

-Have you developed any different ways of thinking or perhaps different policies within your practice based on what you've learned from your experiences from parent-to-parent?

Have you learned anything new about the families and community you serve as a result working with the program?

QUESTION 5: Now let's come back to you personally I want to ask you about your experiences with Parent to Parent as an individual. My question is this:

-Starting out with a basic question: How many families have you referred to parent-to-parent thus far, if any?

-What characteristics do you see in a family or the individuals in a family that prompt you to refer them to the parent-to-parent program if you do this?

-Does parent-to-parent seem to benefit families you serve? If so, how? If not, what seems to get in the way? If so, can you please give me an example?

-Is there any reason to believe that this program is harmful?

-What characteristics do you observe that indicate that the program is helping these families, or not? Please explain… (What types of families do you find you are referring to parent to parent?)

- Is there something about parent-to-parent that makes it unique in the support that is provided?

-What is it about Parent to Parent that you feel your families are unable to get from other sources, if they are getting something unique?

-What is it that transpires when parents talk to each other? Please give an example.

<u>QUESTION 5:</u> Overall how would you characterize the effectiveness of the parent-to-parent program? Will you continue to refer to the program? (If so, why or why not?)

<u>QUESTION 6:</u> Is there anything else you would like us to know? Anything you would like to add?

Well thank you so much for taking the time to speak with me today. I have really enjoyed our conversation and your input has been invaluable. (Address to send confidentiality form to?) Take care.

Appendix F

Interview Protocol for Program Coordinators and Volunteer Support Navigators

-First all let me start off by saying how much I appreciate you taking the time out of your busy schedule to speak to me today. I know as a mother, a student, and a professional how hard balancing life can be.

-Also, I want to let you know that I am not evaluating ***you*** in any way. We are not in any way judging you. We are only interested in learning about the program in general. The things that you tell me today will be combined with things that other coordinators say. There is no way that the leaders of the program will be able to discern what you say.

-The information from this interview will be used for the purposes of the evaluation of this program. I am wanting to learn about information early on at the beginning of this program from the coordinators to get an idea of how the program is going.

-Now, I want to ask you if it is okay that I record this interview. The only people who will hear the recording or see the transcripts from this data will by myself and the other evaluator, my advisor George Singer, at this point in time. May I have your permission to record this interview today?

-One final question before we head into the interview: We will be asking in the future for consent to use the data from this interview to use in a study. I want to make sure you understand that you do not have to be a part of the study if you do not want to. Would you be okay if I send you a letter of consent in the future?

Question 1: So, tell me about what you are doing? Are you going to be recruiting family volunteers?

-How do you think it's going?

-Do you feel like you're on track?

-What do you think is working well? SCHOOLS- Referrals??

-Are there any things so far that aren't working? If there are, what seems to be getting in the way? Is there anything that could make a difference with those problems?

Question 2: What is your background? What brought you to this point?

-Is it new for you to be in a leadership role like this?

-What's that like for you taking on something that's really new?

-Is it stressful? What part of it is stressful, if so?

-Are you finding it rewarding? If so, what parts?

-What is your relationship like with the people at the clinics?

-Do they seem to understand what you're trying to do and are they supportive.

-How is it that you're learning about community resources for these outreach areas?

<u>Question 3</u>: What are you learning about when you are working with parents specifically to healthcare?

-Have you been learning about possible resources for addressing those problems?

-What else have you learned from the different areas of community outreach you have completed?

-What have you learned from working the parents?

-How have you already, or do you foresee in the future, incorporate what you have learned into your work?

(For Program Coordinators only)

-What is the current status of recruitment of Parent Peer Support Leaders?

-Status of recruitment of Parents from underserved groups as Volunteer Peer Support Parents.

-Status of clinical staff trainings. Do you feel they are starting to develop new policies and practices to better serve underserved groups? If so, how?

-How many families have been matched so far? Have these matches been successful? If not all, have you been able to follow up with new matches?

-Training families in how to participate in care, planning and policymaking.

-How have you adjusted the peer support model to fit local structures and needs?

-Do you feel that families and health providers are aware of parent-to-parent support services? If so, how?

-Do you feel that the parent-to-parent program have been implementing

<u>Question 4</u>: Is there anything that the people that you work for or work with that could be doing that would be helpful to you?

-Is there any type of support that could help you understand or make your job more effective?

-Is there any information that we could provide you with to help you do your job?

Question 5: Now let's come back to you personally. I want to ask you about your experiences with Parent to Parent as a mother. My question is this:

-What do you feel is different about a program like parent to parent as compared to other sources of support (i.e. your child's doctor, your therapist, your family)?

-What is it about Parent to Parent that you couldn't get from other sources?

-What is it that motivated you to become a helper of others in a program like parent to parent?

-What is it that transpires when parents talk to each other? Do you feel it matters what they are talking about?)

-How was that you were able to get to place in your life that you were able to take on that type of responsibility?

(For Program Coordinators Only)

-When recruiting family volunteers to be matches for families:

-How do you know when a volunteer family is ready to take on the

-responsibility of being the match?

-What kind of values do you look for in a volunteer?

Question 6: Is there anything else you would like us to know? Anything you would like to add?

Well thank you so much for taking the time to speak with me today. I have really enjoyed our conversation and your input has been invaluable. (Address to send confidentiality form to?) Take care.

Appendix G

Interview Protocol for Volunteer Support Parents

-First all let me start off by saying how much I appreciate you taking the time out of your busy schedule to speak to me today. I know as a mother, a student, and a professional how hard balancing life can be. Thank you.

-Just to give you a little background on why I am conducting this interview: The (program name) has received a grant from the federal government to add a parent to parent support program to the outreach clinics offered by your organization (give name as you know it). The funders have asked us to study what impact this program has, if any.

-The information from this interview will be used for the purposes of the evaluation of this program. I want to learn about information as we work hard on this program from the family support volunteers to get an idea of how the program is going.

-Now, I want to ask you if it is okay that I record this interview. The only people who will hear the recording or see the transcripts from this data will by myself and the other evaluator, my advisor George Singer, at this point in time. May I have your permission to record this interview today?

-One final question before we head into the interview: We will be asking in the future for consent to use the data from this interview to use in a study. I want to make sure you understand that you do not have to be a part of the study if you do not want to. Would you be okay if I send you a letter of consent in the future?

<u>Question 1</u>: So why don't we start off by telling me a little bit about yourself and what you are doing?

<u>Question 2</u>: When I talk about the parent-to-parent program what does that mean to you? Who is involved? What do they do as far as you know?

-What interactions have you had with the program?

-Do you feel that you have been fully informed or trained into the goals of parent to parent?

- (Ask if answer above is negative) If not, what can we do to provide you with better q understanding of the goals and support of the program?

-Is there anything that the parent-to-parent program team could be doing that would be helpful to you?

-Is there any type of support that could help you understand or make your job supporting families more effective?

Question 3: What is your background? What brought you to this point?

-Is it new for you to be in a helping role like this?

-What's that like for you taking on something that's really new?

-Is it stressful? What part of it is stressful, if so?

-Are you finding it rewarding? If so, what parts?

Question 4: Let's talk about your experiences as a support parent thus far.

-What characteristics do you see in a family or the individuals in a family that you are asked by the Voices Team to contact?

-How many families have you been in contact with thus far, if any?

-How were you able to get in touch with the families? Was it easy or challenging?

-Tell me a little about what the families needed help with? Do you feel you were able to provide the families with the information they needed.

-What characteristics do you see that indicate that the program is helping these families, or not? Please explain…

-Does parent to parent seem to benefit families you serve? If so, how? If not, what seems to get in the way? If so, can you please give me an example?

Question 5:

-Do you feel that being connected with the parent-to-parent program has helped you develop a better understanding of the needs of the families you are in contact with? If so, how?

-If not, what do you think the parent-to-parent program can provide you in order to help achieve this goal?

-How has your involvement with the parent-to-parent program affected your understanding of the individual backgrounds and cultural needs of families you are in contact with, if at all?

-Have you learned anything new about the families and community you serve as a result working with the program?

Question 6: Now let's come back to you personally. I want to ask you about your experiences with the parent-to-parent program as a parent yourself. My question is this:

-What do you feel is that is different about a program like parent to parent?

-What is it about Parent to Parent that you couldn't get from other sources?

-What is it that motivated you to become a helper of others in a program like parent to parent?

-What is it that transpires when parents talk to each other? Do you feel it matters what they are talking about?

-How was that you were able to get to place in your life that you were able to take on that type of responsibility?

Question 7: -Do you feel it is important to provide support/receive support to/from families of similar backgrounds and/or identities? Why or why not?

-Do you notice the differences in the manner of speaking when you connect with someone from your own cultural background or identity as compared to someone from a different cultural background or identity? Why or why not?

-Do you find differences in the type or quality of support you receive when you talk with a family from a similar cultural background compared to when you talk with a family from a different cultural background? Why or why not?

-Do you think the support you receive from medical professionals is different than the support other families from different cultural backgrounds receive? Why or why not?"

Question 8: Overall how would you characterize the effectiveness of the parent-to-parent program?

Question 9: Is there anything else you would like us to know? Anything you would like to add?

Well thank you so much for taking the time to speak with me today. I have really enjoyed our conversation and your input has been invaluable. (Address to send confidentiality form to?) Take care.

Appendix H

Interview Protocol for Referred Parents

-First all let me start off by saying how much I appreciate you taking the time out of your busy schedule to speak to me today. I know as a mother, a student, and a professional how hard balancing life can be. Thank you.

-Just to give you a little background on why I am conducting this interview: The (program name) has received a grant from the federal government to add a parent-to-parent support program. The funders have asked us at the University of California, Santa Barbara to study what impact this program has, if any.

-The information from this interview will be used for the purposes of the evaluation of this program. I want to learn about information as we work hard on this program from the family who have received services from the parent-to-parent program to get an idea of how the program is going.

-Now, I want to ask you if it is okay that I record this interview. The only people who will hear the recording or see the transcripts from this data will by myself and the other evaluator, my advisor George Singer, and my assistant Katie Johnston at this point in time. May I have your permission to record this interview today?

-One final question before we head into the interview: We will be asking in the future for consent to use the data from this interview to use in a study. I want to make sure you understand that you do not have to be a part of the study if you do not want to. Would you be okay if I send you a letter of consent in the future?

Question 1: So why don't we start off by telling me a little bit about yourself?

Question 2: When I talk about the parent-to-parent program what does that mean to you? What do they do as far as you know?

-How did you first hear about the parent-to-parent program?

-How did you come to be connected with the parent-to-parent program? How did you hear about the program and what interactions have you had with the program, if any?

-What initially motivated you to get in touch with the program after referral or heard about the parent-to-parent program?

-Tell me about your experiences with Parent to Parent after you were referred/contacted them? Take me through it step by step, if you would please?

Ask about:

Once you were connected with parent to parent, tell me about who got in contact with you.

-The family you were connected with.

-How long did it take to get in touch with them?

-How did they get in touch with you?

-Please describe your experiences with the family member you spoke with.

-How did you feel when talking with the family member? Please tell me about your conversation.

-What did you talk about with the family member?

Self-Efficacy in managing child's disability:

-Can you tell me what you gained, if anything, from the parent-to-parent program as it pertains to the following: access, engagement, information, communicating with physicians, managing child's condition, understanding the system, navigating the system

-Parents perceptions of social/emotional support re child and family

-Parents perceive clinic as medical home.

-Can you tell me what you gained, if anything from the parent-to-parent program as I pertains to the following: accessibility, cultural competence, continuity, coordination, comprehensiveness, communication/compassion

Question 6: Now let's bring it back to you. I want to ask you about your experiences with the parent-to-parent program as a parent yourself. My question is this:

-What do you feel is different about a program like parent to parent?

-What is it about Parent to Parent that you couldn't get from other sources?

-What is it that motivated you to get in touch with the parent-to-parent program?

-What is it that transpires when parents talk to each other? Do you feel it matters what they are talking about?

Question 7: -Do you feel it is important to provide support/receive support to/from families of similar backgrounds and/or identities? Why or why not?

-Do you notice the differences in the manner of speaking when you connect with someone from your own cultural background or identity as compared to someone from a different cultural background or identity? Why or why not?

-Do you find differences in the type or quality of support you receive when you talk with a family from a similar cultural background compared to when you talk with a family from a different cultural background? Why or why not?

-Do you think the support you receive from medical professionals is different than the support other families from different cultural backgrounds receive? Why or why not?"

Question 8: Overall how would you characterize the effectiveness of the parent-to-parent program?

Question 9: Is there anything else you would like us to know? Anything you would like to add?

Well thank you so much for taking the time to speak with me today. I have really enjoyed our conversation and your input has been invaluable. (Address to send confidentiality form to?) Take care.