Parent To Parent Support For Parents Of Children With Autism Spectrum Disorders: Perspectives Of Parents And Program Staff

Nina Nelson
University of South Carolina

Follow this and additional works at: http://scholarcommons.sc.edu/etd
Part of the Social Work Commons

Recommended Citation
PARENT TO PARENT SUPPORT FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS: PERSPECTIVES OF PARENTS AND PROGRAM STAFF

by

Nina Nelson

Bachelor of Science
University of the West Indies, 1996

Master of Science
University of the West Indies, 2000

Submitted in Partial Fulfillment of the Requirements
For the Degree of Doctor of Philosophy in
Social Work
College of Social Work
University of South Carolina
2015

Accepted by:
Arlene Bowers Andrews, Major Professor
Terry Wolfer, Committee Member
Robert Hock, Committee Member
William Brown, Committee Member
Lacy Ford, Senior Vice Provost and Dean of Graduate Studies
DEDICATION

I dedicate this dissertation to:

My parents, Gloria and Ralston Nelson, for your unending love, sacrifice, and investment in me and my education;

the parents of children with autism spectrum disorder - like every good parent, yet extraordinary; and

the memory of Christopher Peter Aluah and to all international doctoral students who study in the USA. May this successful completion encourage you to persevere with your dreams.
ACKNOWLEDGEMENTS

I thank God for this opportunity, strength, wisdom and all the persons He has put in my way to have made this possible. I thank my immediate family – my parents Gloria and Ralston for their long-life investment in my education and my siblings Donovan, Genieve, and Ryan for their encouragement, financial support and practical assistance.

I am especially grateful to my study’s participants- parents and program staff who graciously allowed me to become a part of their lives and shared their stories with me. I thank the agency director for granting permission to conduct this study and the parent to parent program coordinator who recruited the parents. I thank my dissertation committee especially my chair Dr. Arlene Andrews, and other committee members, Drs. Robert Hock, Terry Wolfer, and William Brown for guiding me so expertly through this process, for their generous patience, encouragement, and quick turn around with drafts. I am grateful for the assistance with editing and formatting from Kaylene and Kevin Cox, Kevin Fletcher, Michelle, Amy, Deborah, Genieve, Ryan, and also to my transcriptionists.

I thank my church and extended family in Jamaica for their support especially those who have helped me oversee the caregiving of my Dad and Aunt while I have been away. I am grateful for the support of friends and church families here in the USA at Maranatha (Tallahassee) and Ephesus (Columbia) Churches.
I extend my gratitude to fellow doctoral students who have been a great source of mutual support throughout this doctoral journey, especially Meredith, Lynn, Candace, Sunny, Joi, Claudius, Constance, and Joan. I extend my gratitude to Drs. Neil Abell, Scott Rutledge, Darcy Siebert, and Bruce Thyer for their unwavering support and belief in my abilities and success.

Finally, I am especially grateful to the College of Social Work’s faculty and staff. I thank Dr. Naomi Farber, administrators and colleagues at the Center for Child and Family Studies and the Institute for Families in Society (IFS) where I completed my graduate assistantships for their generous support for my education and opportunities to acquire additional research and teaching expertise. I especially thank the administrators, staff, and my supervisors at IFS, who gave me flexibility as well as access to their conference room to conduct my phone interviews.
ABSTRACT

This short-term longitudinal qualitative study used grounded theory methods to explore how parents of children with autism spectrum disorder (ASD) benefit from one-to-one support (P2P), factors affecting success, and how these relationships evolved. In-depth interviews were conducted with 6 staff, 12 referred parents, and 11 support parents.

Most referred parents found P2P helpful, deriving informational/practical, emotional, and a few social benefits. Six interrelated factors affected success including a) parent-support relationship; b) program level; c) support parents’ experiences with P2P and the disability community; d) practical/logistical factors; e) psycho-emotional factors; and f) referred parents’ expectations relationship program level. The relationship was the most crucial factor, and both parents perceiving similarity was the central process leading to success. These six factors affected the helpfulness by facilitating or inhibiting matched pairs’ ability to perceive and use similarity to meet referred parents’ needs.

Perceiving similarity contributed to helpfulness by fostering emotional connection, causing both parents to see the support parent as a credible helper and to open up to each other. It enabled the support parent to understand concerns, provide useful information, and be a non-stigmatizing source of social interaction.

Matching referred parents to someone with similar but longer experience with their type need and children’s functioning was critical to both parents perceiving similarity and subsequently to the match’s success. Also, training and support parents’
P2P experience gave them the relationship skills to communicate similarity, build rapport, and use their lived experience to meet their referred parents’ needs.

Mutual openness was essential for perceiving similarity and meeting referred parents’ needs. Parents’ choices about making contact, what they disclosed, and how they responded to each other’s disclosures affected the success of the match. This was important because the benefits of P2P accrued from the mutual exchange of information and stories that allowed referred parents to conduct social comparisons to their support parents. Comparisons to parents who had similar difficulties but had experienced improvement provided hope, normalized their experiences, validated their emotional reactions, reduced their sense of isolation, and yielded practical information for problem-solving. Both parents continually assessed similarity and each other’s relational qualities. Referred parents chose to continue contact and accept assistance when they perceived support parents as similar, open, genuine, non-judgmental, and empathic. Their readiness was also a major factor influencing them to disclose and accept help. Support parents chose to continue offering help based on referred parents’ receptiveness. Practical issues such as busy lives, along with poor emotional well-being undermined success by preventing contact. Also, incongruence in parents’ expectations for the match was a barrier to success.

Most relationships were short-term, remained primarily unidirectional with support parents providing support and referred parents receiving support. Over time, contact decreased in frequency and length but was increasingly initiated by referred parents.
Overall, the findings suggest that P2P can be a viable approach for providing support to parents of children with ASD. Implications for optimizing beneficial outcomes and advancing research are discussed.

Keywords: qualitative research, grounded theory, parent to parent support, autism spectrum disorder
# Table of Contents

DEDICATION ................................................................................................................... iii  
ACKNOWLEDGEMENTS ............................................................................................... iv  
ABSTRACT .................................................................................................................... vi  
CHAPTER 1 INTRODUCTION ...................................................................................... 1  
CHAPTER 2 LITERATURE REVIEW ........................................................................ 16  
    PART I: CONCEPTUAL FOUNDATION .................................................................. 16  
    PART II: RESEARCH FINDINGS ON P2P ......................................................... 25  
CHAPTER 3 METHODOLOGY ..................................................................................... 50  
CHAPTER 4 FINDINGS: CONTEXT FOR PURSUING P2P ...................................... 80  
    PART I: CONTEXT FOR HELP SEEKING ....................................................... 80  
    PART II: TYPE OF SUPPORT SOUGHT ......................................................... 89  
CHAPTER 5 FINDINGS: BENEFITS, FACTORS, AFFECTING HELPFULNESS OF P2P AND CHANGES IN RELATIONSHIPS OVER TIME ........................................ 92  
    PART I: BENEFITS OF P2P .............................................................................. 92  
    PART II: BARRIERS AND FACILITATORS OF BENEFICIAL OUTCOMES .... 102  
    PART III: CHANGES IN RELATIONSHIPS OVER TIME .................................. 158  
CHAPTER 6 DISCUSSION, STRENGTHS AND LIMITATIONS AND IMPLICATIONS .... 168  
REFERENCES ............................................................................................................. 200  
APPENDIX A: RECRUITMENT SCRIPT FOR REFERRED/SUPPORT PARENTS ........ 214  
APPENDIX B: RECRUITMENT FLYERS ................................................................. 215
CHAPTER 1

INTRODUCTION

There is an urgent need for studies on how to enhance social supports for parents raising children with autism spectrum disorder (ASD). As noted by the Interagency Autism Coordinating Committee (IAAC)\(^1\), in its *2011 Strategic Plan for Autism Spectrum Disorder Research*:

> Community supports that address quality of life (as opposed to core symptoms) for people with autism and their families have almost no traditional evidence base to support them. Yet these types of services are some of the most requested and most needed (IAAC, 2011, p. 45).

Parents caring for children with ASD experience considerable challenges beyond those of parents of typically developing children and different from those of parents coping with non-ASD disabilities or special health care needs (Karst & Van Hecke, 2012). To cope with the demands of caring for their children with ASD, parents tend to seek information and support more frequently from other parents of children with ASD than from other personal and professional relationships or autism-related group gatherings (Mackintosh, Myers, & Goin-Kochel, 2005). Yet little is known about the

---

\(^1\) The US Congress established the IAAC in 2006 to advise the Health and Human Services’ (HHS) Secretary and to coordinate HHS’ efforts pertaining to ASD. It is comprised of federal officials from agencies engaged in ASD research and services, public participants including persons with ASD and their parents, ASD researchers, and advocates. The IAAC is mandated to create and yearly update a strategic plan for and a summary of advances in ASD research.
helpfulness of supports that parents of children with ASD receive from similar parents and there is no known study about the effects of interventions based on peer support. More research is needed to discern whether parents helping parents is effective and meaningful as parents confront the challenges related to ASD. This qualitative study contributes to filling gaps in this area by exploring how participation in an intervention using a one-to-one parent-to-parent match (P2P)\(^2\) benefits parents of children with ASD and the factors that promote and inhibit beneficial outcomes. It also explores how P2P relationships change over time.

**Background**

According to the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V)*, ASD is a developmental disability characterized by impairments in social interaction and social communication, and restrictive and repetitive behavioral patterns that begin in early childhood resulting in limited and impaired functioning. ASD diagnoses have been dramatically increasing with the most recent estimate of 1 in every 68 US children in 2010 - an increase of 30% from 2008, 60% from 2006 and 120% from 2002 (Centers for Disease Control and Prevention [CDC], 2014)\(^3\). Because of this high and increasing prevalence, the CDC declared ASD as an urgent public health concern (CDC, 2009).

\(^2\) Throughout this paper I use “P2P” as a generic term to refer to one-to-one parent to parent support and not as a reference to any particular model.

\(^3\) CDC estimates are based on surveillance data from 2010 and are based on the DSM-IV-TR definition of ASD. The DSM-IV-TR included five subtypes of ASD: autistic disorder, PDD-NOS, and Asperger disorder, Retts disorder and childhood disintegrative. Because of their rarity, Retts and childhood disintegrative disorders were not included in the prevalence data.
Impact of ASD on Families and Society

Associated with the increasing prevalence are concerns about the costly impact of ASD on affected families and society. The estimated lifetime incremental costs (i.e., additional costs solely due to autism) to U.S. society for a birth cohort of persons with ASD are $35 billion and $3.2 million per capita (Ganz, 2007). Using national data about families of children with special health care needs (CSHCN)\(^4\), Kogan et al. (2008) examined the family impact of children with ASD compared to that of CSHCN with other emotional, behavioral and development problems (EBD), and CSHCN with non-EBD problems. They found that families of children with ASD were more likely to report that their children’s health care led to financial problems, needing additional income to cover children’s medical expenses, reducing or ending employment because of their children’s condition, and that they paid, at least, $1000 for their child’s medical care in the previous year. They also were more likely to spend more than 10 hours weekly in caregiving or coordinating care for their children (Kogan et al., 2008). Using national data, Cidav, Marcus, and Mandell (2012) estimated that families of children with ASD on average earned 28% less compared to those of CSHCN and 21% less than of non-CSHCN, and worked 5 hours less per week than those of non-CSHCN.

Caring for children with ASD is extremely challenging because of multiple impairments and comorbidities, unclear etiology, varied presentation, and a plethora of treatments with no consensus on optimal treatment or criteria for evidence-based efficacy (Rogers & Vismara, 2008; Lord & Bishop, 2010). This often entails coordinating a

\(^4\) CSHCN are children with developmental, emotional, behavioral or physical conditions that require health and related services beyond that typically required by children (McPherson et al., 1998).
complex assortment of treatments and therapies that may include drugs, specific diets, and behavioral and educational interventions with multiple professionals in diverse settings (Goin-Kochel, Myers, & Mackintosh, 2007). Parents from the USA and other countries have reported using an average of seven types of treatments per child (Goin-Kochel et al., 2007). The number of treatment types ranged from 0 to 15 (Goin-Kochel et al., 2007) to as much as 47 (Green et al., 2006). Further, comprehensive interventions (those targeting core ASD symptoms) usually require up to 25 hours per week for one to two years, and focused interventions (those targeting a specific behavior) typically necessitate weekly caregiver support or daily involvement in direct teaching (Lord & Bishop, 2010).

Parents must continually respond to an abundance of ever changing information about intervention options, decide on which to pursue, and attempt to access selected options while providing daily care to their children (Karst & Van Hecke, 2012). The treatment process is not only time-consuming and costly but often frustrating due to difficulties in accessing health care for their children as indicated by higher rates of unmet need for specific health care services (Kogan et al., 2008) and lower access to family-centered care and care-coordination when needed (Schieve et al., 2011).

These financial and time burdens and other difficulties associated with caregiving and seeking services often leave parents with fewer resources and time for self-care and attention to other relationships in and outside their immediate families (Hock, Timm, & Ramisch, 2012). Social interaction with extended family, friends and especially in other settings is often difficult and embarrassing because of children’s behavioral oddities, rigidities and sometimes aggression (Ryan, 2010). These parents report relational
consequences including social isolation, stigma, loss of social support from extended family, friends, and faith communities (Altiere & Von Kluge, 2009; Nealy et al., 2012; Ryan, 2010) and on average higher rates of marital dissatisfaction and divorce compared to parents of children without disabilities (Hartley et al., 2010; Hartley et al., 2012).

Given these challenges, it is unsurprising that parents of children with ASD tend to experience higher rates of issues related to physical and mental well-being. These include depression, anxiety, fatigue, and physical health issues (Karst & Van Hecke, 2012). These parents also tend to report higher levels of parenting stress and are more likely to feel that their children are harder to care for compared to those of children with other EBD needs, other special needs, and non-C SHCN (Schieve et al., 2011).

**Implications of Parental Well-being on Children’s Treatment and Development**

Although there is no known cure for ASD, intervention, especially when implemented early, can lead to improvements in the children’s functioning (Virués-Ortega, 2010; Vismara & Rogers, 2010). The financial costs associated with ASD can be substantially reduced with even minor improvement in the independence and adaptive skills of children with ASD through intervention services (Reichow & Wolery, 2009; Rogers & Vismara, 2008). Also, since the low adaptive functioning of children with ASD is associated with increased parenting stress (Hall & Graff, 2011), these improvements may likely lead to lowered stress. Given this, attention to parents’ well-being is important because as caregivers, they play perhaps the most the central role in their children’s treatment and ultimate development (Rao & Beidel, 2009). With respect to children’s receipt of services, “parents are seen as key ‘gateway providers’ in terms of recognizing their child’s need for help and taking steps to obtain help” (Shanley, Reid, &
Evans, 2008, p.136). They also play a pivotal role in participating in, complying with, and monitoring the effects of children’s treatment. Therefore, their participation in this process may affect the treatment’s potential effects on their children’s functioning.

There are concerns that the comparatively elevated levels of parenting stress and mental health issues among parents of children with ASD can undermine their treatment help-seeking efforts for their children and subsequent treatment compliance and efficacy (Jackson, 2007; Rao & Beidel, 2008). Parenting stress and mental health issues have been associated with parents’ non-compliance and withdrawal from parent-training (Allen & Warzak, 2000; Jackson, 2007) and with negative impacts on children’s development. Even in the presence of parental nurturance, parenting stress has also been linked to “negative impacts on the child, such as lower levels of cognitive school readiness and personal maturity” (McGroder as cited in Schieve et al., 2011, p. 144).

Elevated levels of parenting stress and mental health issues are not inevitable for parents of children with ASD as parents show wide variations on these outcomes (Karst & Van Hecke, 2012). Given the high and increasing prevalence of ASD and its costly impact, attention to enhancing parents’ well-being is important not only for their sake, but also for their children’s adjustment. Research has identified parental social support as an important factor for parental adjustment with implications for their ability to be engaged in their children’s treatment.

Social Support. Research has identified social support as an important coping resource and a factor associated with more positive adjustment among parents of children with ASD. It has been associated with lower perceived negative impact of ASD (Bishop, 2007), lower levels of anxiety (Bitsika & Sharpley, 2004), depression and stress
proliferation\(^5\) (Benson, 2006), and reduced risk of elevated parenting aggravation (Schieve et al., 2011). Social support also promotes parental adherence to mental health treatment for their children (Allen & Warzak, 2000). Conversely, a low level of social support is a strong predictor of depression and anxiety (Boyd, 2002) and less emotional support is associated with greater daily negative mood (Pottie et al., 2009).

In light of the central role that parents play in assisting their children with ASD to acquire adaptive skills, social support is being promoted as a necessary complement to and consideration in their children’s treatment process (Bloch & Weinstein, 2010; Rao & Beidel, 2009). However, while much scholarly attention has been given to etiology and to a lesser extent treatment approaches for ASD and their efficacy, much less has been given to social support services for affected families (Karst & Van Hecke, 2012; IAAC, 2011). The 2011 IACC Strategic Plan for Autism Spectrum Disorder Research identified community supports for persons and families affected by ASD as an area in which research is urgently needed (IAAC, 2011).

Among personal and professional relationships, parents of other children with ASD are the most used sources of information and social support (Mackintosh et al., 2005; Twoy et al., 2006). A survey of 55 parents of children with ASD found that 93% used parents of children with similar diagnoses as sources of information and support (Twoy et al., 2006). Another survey of 1005 caregivers found that two-thirds had ever participated in support groups specific to autism and 50% were currently active participants (Mackintosh et al., 2005). Support from other parents occurs through various forms: online discussion forums or email discussion lists (Huws, Jones, & Ingledew,

\(^5\) Benson (2006) defined stress proliferation as “the tendency of stressors to engender additional stressors in other life domains” (p. 685)
2001; Jackson, 2007); group gatherings – support groups, conferences, workshops (Macintosh et al., 2005; Mandell & Salzer, 2007); and personal relationships between parents which may be through organized matches or through informal relationships (Singer et al., 1999; McCabe, 2008). These informal relationships may develop as spontaneous by-products of outreach programs or interventions where children and/or parents receive services (McCabe, 2008).

Despite the high frequency of parent peer support use among parents of children with ASD, literature in this area is sparse. Studies have examined the extent of and factors associated with use of personal relationships and/or group-based support (Macintosh et al., 2005; Mandell & Salzer, 2007), needs and expectations of those who use support groups (Papageorgiou & Kalyva, 2010), how parents use online ASD forums (Jackson, 2007), and the functions of an email group (Huws, Jones, & Ingledew, 2001). Only two known studies have investigated the benefits of peer support to parents of children with ASD (Clifford & Minnes, 2013; Weidle, Bolme & Hoeyland, 2006) with both exploring group-based support. None of these studies, however, explored the factors affecting beneficial outcomes of group-based support or how and why these relationships change over time. Also, there are no known studies on P2P relationships including its benefits, factors influencing its helpfulness and how they change over time.

**Specific Aims**

This study seeks to build knowledge in this area by exploring how participation in a volunteer-based (P2P) program impacts parents of children with ASD. It utilized a qualitative methodology with in-depth, semi-structured interviews with a sample of referred parents of children with ASD, their matched support parents, and P2P staff.
Guided by grounded theory methods, this study explored how P2P matches benefit parents of children with ASD, factors affecting helpfulness and how P2P relationships change over time.

**The P2P Intervention**

P2P programs seek to provide informational and emotional support to parents of CSHCN (referred parent) through a one to one match with a trained and experienced parent (support parent) of a child who has similar needs as the referred parent’s child (Santelli, Turnbull, Marquis, & Lerner, 1998). The first formal P2P program, the Pilot Parent model founded in 1970 in Omaha, Nebraska, originally served families of children with mental retardation. The program spread rapidly and a few years after its inception, its founders received a grant to replicate the model in the Midwest. By 1974, the program began training parents of children with diverse disabilities and special health care needs (Santelli, Poyadue, & Young, 2001) and, after that, spread throughout the United States. Today, there are P2P programs in every state.

P2P relationships are highly individualized in their duration and mode, number and frequency of contact between matched parents and typically use volunteer support parents. There is a less prevalent model, the Ireys model, that uses paid support parents with fixed and intensive training hours and duration for the intervention (Ireys, Chernoff, Stein, DeVet, & Silver, 2001; Sullivan-Bolyai et al., 2004; Sullivan-Bolyai et al., 2010). The proposed study will be focused on the volunteer-based model.
Rationale for the Study

There are several reasons that make P2P a worthy social support intervention for ASD research. First, social support from other parents of children with ASD is a highly desired and used source of support among parents of children with ASD (Mackintosh et al., 2005; Tway et al., 2006). This is especially so for emotional support and information needs (Mackintosh et al., 2005). Furthermore, parents of CSHCN who participate in P2P tend to highly recommend their use as a coping resource for other parents of CSHCN, especially those of children with a recent diagnosis (Rearick, Sullivan-Bolyai, Bova, & Knafl, 2011). Second, volunteer parents are less costly and more widely available source of support compared to professionals or paid parent aides. Third, parents of children with ASD may find P2P to be a more timely, efficient, accessible and convenient way to have their concerns addressed compared to peer support groups since the one to one relationship does not require having to find other parents and fit the schedules of multiple parents and/or the support group meeting time, waiting for the group to meet, and/or waiting one’s turn during group meetings to seek and receive help. It may also be cheaper due to less or no worries about child care and transportation to facilitate group meeting attendance. Parents who participate in ASD specific focus groups are more likely to be Caucasian, middle-income, and more educated (Mackintosh et al., 2005; Mandell & Salzer, 2007), which may be an indication that they are less accessible to minorities and those with lower socioeconomic status. Fourth, because support parents have experienced the issues for which referred parents are seeking help, P2P provides a unique form of support based on a “been in their shoes” expertise and empathy that cannot be provided by professionals, friends and family members who do not have such
experiences (McCabe, 2008). Finally, as a form of peer support among parents, P2P mitigates the potential issues of power inequity that may be present in professional-client interactions (Dunst & Dempsey, 2007).

Although P2P programs have been in existence since 1971 and are prevalent nationwide, they have received very little empirical study regarding their impact on the stress and adjustment of parents of CSHCN. Most of the few extant P2P studies are based on samples of parents of children with acute, chronic and/or terminal physical conditions, for example, chronic lung disease (Nicholas & Keilty, 2007). Only three studies have included parents of children with disabilities (Iscoe & Bordelon, 1985; Shilling, Bailey, Logan, & Morris, 2014a, 2014b; Singer et al. 1999). Although two of the study samples included parents of children with ASD along with other disabilities (Shilling et al., 2014a, 2014b; Singer et al. 1999), they did not specifically identify how P2P impacted recipients and what influences impact for parents of children with ASD.

Nevertheless, extant studies using samples of parents with other diagnoses generally indicate that receiving P2P may enhance parents’ capacity to respond positively to the stressors associated with caring for a CSHCN (Abinder et al., 1998; Singer et al. 1999; Rearick et al., 2011). These studies suggest that not all parents who receive P2P find it helpful. Therefore, it is important to understand the factors that influence outcomes to optimize the benefits of P2P for parents of children with ASD. Unfortunately, even fewer P2P studies provide insight into the factors that influence outcomes (Abinder, 1998; Nicholas & Keilty, 2007; Shilling et al., 2015a, 2015b), and none of these are specific to ASD. In addition, these few studies that have investigated influential factors have taken a one-sided approach – from the perspective of referred parents - with one
exception. An evaluation of a P2P program in the UK by Shilling and colleagues (Shilling et al., 2015a, 2015b) included perspectives of the parents providing support and professionals outside of the P2P program who work with children with disabilities and their families.

Also, to date, there are no known studies that capture the perspectives of the P2P program staff who organize and follow-up on matches and provide consultation to support parents. Since program staff interacts with referred and support parents, they are potentially rich sources of information of organizational and match-level factors that facilitate and inhibit beneficial outcomes, including those that lead to dissatisfaction and disrupted matches.

This study addresses the gaps in the P2P scholarship discussed above in two ways: by using a sample of referred parents of children with ASD, along with their matched support parents and P2P program staff who arrange and follow-up matches. A short-term longitudinal qualitative design was used to examine how participation in a volunteer-based, one-to-one parent (P2P) program benefits parents of children with ASD in South Carolina, and the factors that promote and inhibit beneficial outcomes. The research questions that guided this study were:

a) How, if at all, do P2P matches benefit referred parents of children with ASD?

b) What factors promote or inhibit beneficial outcomes for referred parents from the perspectives of referred parents, support parents, and program staff?

c) How do P2P relationships change over time?
**Importance of the Study**

This study adds to the sparse literature on the processes through which social support interventions in general and specifically peer support interventions help parents of children with ASD cope with caring for their children. It is the first known study of the factors associated with the helpfulness of P2P for parents coping with ASD. Within the broader P2P literature, this study addresses the gap on P2P staff perspectives on factors influencing helpfulness to P2P while adding to the largely unexplored area of support parents’ perspectives. These multiple perspectives may lead to a more comprehensive and layered conceptualization of the factors and processes that promote and inhibit helpful P2P relationships. In particular, the study may identify factors that go beyond describing referred parents and characteristics to explaining dyadic dynamics and program level influences. Such an understanding can be useful to P2P program staff in helping to support or change procedures that can optimize P2P’s benefit.

This study may, therefore, have implications for pre-service training and in-service training and supports for support parents. It might provide P2P staff with information on indicators of when matches may not be helpful and how to intervene to enhance matches. Although this qualitative study cannot verify the efficacy of P2P, it may provide detailed accounts of how and when it helps and does not help and the processes through which these occur. These accounts can lay the foundation for selecting or developing measures and informing the design of studies to test and understand efficacy that can be generalizable to a wider population.
Relevance to Social Work

This study is relevant to social work because it explored an intervention intended to enhance adjustment and coping of parents of children with ASD, a population that is at higher risk than most parents for negative outcomes in several life domains (Kogan et al., 2008; Schieve et al., 2011). Enriching knowledge about how peer support works, particularly among parents coping with similar problems, contributes to the research evidence base that informs social work practice with families coping with children’s disabilities. Positive parental adjustment has implications for their ability to support the treatment and development of their children living with ASD, and to foster family system functioning. This aligns with the social work profession’s mission to enhance the well-being of all persons especially those that are vulnerable (NASW, 2008).

Summary

Parents caring for children with ASD experience considerable parenting stress and caregiver burden (Karst & Van Hecke, 2012) with potential for negative impact on parental well-being, treatment help-seeking, adherence and efficacy for their children (Jackson, 2007; Rao & Beidel, 2008). These challenges and their potential negative impact indicate the need for interventions that can help parents manage parenting stress and caregiver burden. Research (e.g., Bishop, 2007) shows that social support can enhance parental adjustment in this population. Yet there is little attention and research on social support interventions for these parents. Much more focus has been devoted to identifying the cause of ASD and its treatment. Parents most often seek support from other parents of children with ASD (Mackintosh et al., 2005; Twoy et al., 2006) but few studies have examined the helpfulness of approaches using peer-based support and there
is no known study on the helpfulness of P2P, in which trained parent volunteers of children with ASD provide one to one support to their peers. Using a sample of referred parents, support parents and program staff, this qualitative study examines the helpfulness of P2P, a commonly used form of peer support for parents of children with ASD. It also examines how P2P relationships change over time.

The remaining sections are organized in five chapters. In chapter two I present the literature that includes the conceptual foundation guiding this study and a synthesis of the studies on P2P. Chapter three explains the study’s methodology. Chapter four summarizes the study’s findings on the context within which referred parents sought help. Chapter five presents the findings on the benefits of P2P, factors affecting beneficial outcomes, and changes in the relationship over time. Finally, in chapter six, I discuss the study’s findings, implications, strengths, and limitations.
CHAPTER 2

LITERATURE REVIEW

This chapter is organized in two major sections. Part I includes a synopsis of the concepts and theories that inform the study. Part II presents a review of prior empirical research about P2P including benefits to recipients and factors affecting beneficial outcomes.

Part I: Conceptual Foundation

The study was informed by a conceptual foundation that explains how P2P as a form of social support given by others with similar experiences might help parents cope with challenging circumstances associated with caring for a child with ASD. The framework also looks at what might shape helpfulness of P2P. It is based on theories, concepts, and P2P programmatic features that have guided the development and evaluation of various P2P and other peer support interventions (Ireys, Devet, & Sakwa, 2002; Salzer, 2002; Singer et al., 1999). These include concepts and/or theory about stress, coping, social comparison, cognitive adaptation and social learning, social equity, and social exchange. The study is also grounded in ideas from research and theory about the positive and negative dimensions of social support (Tilden & Gayle, 1987) and about social relationships in which others, particularly caregivers, had unmet expectations and/or negative interactions with those attempting to provide them (Horowitz, 2001; Neufeld & Harrison, 2003).
How P2P Is Beneficial

In this section, I review ideas that attempt to explain how P2P as a form of social support is beneficial in helping parents coping with stressors related to caring for a child with P2P. Key undergirding principles are stressors, coping and social support.

Singer et al. (1999) in their multi-site evaluation of P2P programs using Thoits’ (1987) reconceptualization of social support as coping assistance, suggested that P2P enhances and promotes referred parents’ efforts to cope with challenges associated with their children’s health. Thoits integrated coping and support processes within a more general theoretical framework of Lazarus and Folkman’s (1984) stress buffering processes to explain how and when the efforts of similar others to provide social support to a distressed person are efficacious in reducing or buffering the potentially adverse impacts of his/her exposure to stressors.

Social support as coping assistance: definitions and principles. A stressor represents undesirable conditions that disrupt one’s usual activities acutely or chronically and is perceived as a threat to well-being (Thoits, 1987). Caring for a child with ASD can be considered as a chronic stressor because it typically presents high psychosocial and financial costs to parents and is a lifelong disorder (Kogan et al., 2009). Coping refers to constantly changing behavioral or cognitive attempts to manage a stressor (Lazarus & Folkman, 1984). Thoits (1987) argued that social support functions - commonly categorized as instrumental, socio-emotional, informational, and appraisal aid provided by others to distressed individuals - parallel coping functions in the management of stressors. Therefore social support can be “reconceptualized as coping
assistance or the active participation of significant others in an individual’s stress
management efforts” (Thoits, p. 417).

Applying these ideas to P2P, support parents enhance and promote referred parents’ efforts to cope through providing social support. In doing so, support parents suggest techniques of stress management or participate directly in referred parents’ coping attempts, and these techniques help referred parents change threatening aspects of or emotional reactions to their circumstances or both (Thoits, 1987). Support parents may give referred parents suggestions on how to change their situation or information that can facilitate making changes in their situations, for example, practical tips on how to find therapeutic services and negotiate with service providers. As Ireys et al. (2002) have noted, the P2P relationship can act as a “weak tie” that links the referred parent to social groups and social institutions. The relationship may become a channel to novel and varied sources of information. If the relationship is sustained, then these weak ties can also “become effective links to knowledge about upcoming events, unfamiliar institutions, or the rules and procedures within a service system” (Ireys et al., 2002, p.155). Shanley et al. (2008) found that, consistent with social network theories, help-seeking by parents on behalf of their children “involves consultation with numerous formal and informal sources” (p. 143). Thus support parents may be an important consultation source for referred parents in seeking help for their children as they discuss their children’s developmental concerns and look to them for information on whether, where, and how to find services.

In addition to being a link to information for problem-solving, the relationship with the support parent can become a link to others. This leads to decreased social
isolation often experienced by parents of children with ASD and other disabilities (McCabe, 2008).

Social comparison theory. Under threatening, uncertain, or stressful circumstances persons conduct social comparisons with similar others for self-enhancement (i.e., to feel better about themselves), to evaluate their skill-related abilities, to gauge the appropriateness and strength of their emotional reactions and opinions, and for guidance and/or modeling (Taylor, Buunk, & Aspinwall, 1990; Thoits, 1987; Suls, Martin, & Wheeler, 2002). Thus social comparison processes are central to coping with stressful circumstances and to the use of social support towards this end. Referred parents may derive benefits from P2P by using the support parent or other parents whose children have similar conditions as their comparison models (Ireys et al., 2002). These benefits accrue from downward comparisons (comparing themselves to worse-off parents) and upward comparisons (comparing themselves to better off parents). Upward comparisons can provide hope, motivation, and inspiration and models of coping and problem-solving (Salzer, 2002; Suls et al., 2002). Downward comparisons can lead to ego enhancement and positive affect by “providing examples of how bad things could be” (Salzer, 2002, p.360).

Social learning theory. Two important components of social learning theory are that people’s views of their capabilities “influence[s] their behavior, thinking, and emotional reactions in stressful situations” and most behaviors develop through modeling by others (Stewart, 1990). Thus, as Stewart (1990) noted, self-efficacy and modeling are important in understanding how change occurs as a consequence of social support. Applied to P2P, support parents enhance referred parents’ adjustment to stressors by
“model[ing] coping and health-enhancing behaviors” and “enhance[ing] self-efficacy that one can change behavior” (Bandura as cited in Salzer, 2002, p. 360).

**Cognitive adaptation theory.** P2P may enhance referred parents’ adjustment to their children’s disability through the process of cognitive adaptation (Klein & McCabe, 2007; Singer et al., 1999). According to Taylor’s (1983) theory of cognitive adaptation, people’s adjustment to difficulties is mediated by the extent to which they see meaning and purpose in them, attain a sense of control over them and also their entire life, and give selective attention to the benefits in their circumstances or compare themselves positively to other persons (as cited in Klein & McCabe, 2007). Through observation of and conversations with the support parents, referred parents can be helped to find meaning and purpose in their children’s disabilities and even benefits. Even parents of children with ASD often, over time, come to find positive ways in which having a child with ASD impacts them and their families (Green, 2007; Klein & McCabe, 2007).

Much of this cognitive adaptation is facilitated by narrative exchange (Green, 2003). In P2P both referred and support parents exchange narratives about their experiences. Parents of children with disabilities have found such exchanges to be healing, cathartic, validating of their emotions and concerns, and to promote their adjustment through the process of cognitive adaptation (Green, 2003). Orbuch (1997) in summarizing sociological theories on sharing stories or accounts noted the following benefits and ways in which they lead to cognitive adaptation:

- accounts are not merely social constructions to protect the self; they also (a) give individuals a greater sense of control and understanding of their environment, (b) allow individuals to cope with emotionally charged and stressful events, (c)
produce some degree of closure, (d) provide a greater sense of hope and will for the future, and (e) establish order in daily relational experiences (p. 459).

Factors Shaping the Helpfulness of P2P

Empathic understanding and perceived similarity. Referred parents are expected to be more likely to find P2P beneficial when they perceive the support parent as empathic and similar in social characteristics, values and the experience of the stressful circumstances. Using ideas from social comparison theory Thoits (1987) suggested that empathic understanding is the crucial condition for a distressed individual to seek, accept, and find coping assistance (social support) effective. “Others who are socioculturally or experientially similar to a distressed individual are most likely to be perceived (and to be) empathetic” with experiential similarity being more important (Thoits, p. 421). This similarity also enhances the credibility of the supporter. Thus overall, similar others are most likely to be maximally informative comparison models.

The emotionality of the comparison model. Referred parents may be more likely to solicit, accept, and find support parents’ help effective when they perceive their support parents to be relatively calmer than they are. Thoits (1987) suggested that there is a narrow range of emotionality in helpers that may render social support effective. Distressed persons will tend to avoid others who are more emotionally distressed in response to the stressors and those who are “substantially calmer” because much calmer persons may make them feel inadequate; while much more emotionally reactive supporters may increase their distress (Thoits, 1987).

Recipients’ focus in the social comparison process. Comparisons to the support parents are more likely to be beneficial when referred parents focus on the positive rather
than negative aspects of downward and upward comparisons. In an upward comparison where distressed persons compare themselves to a better off target on a dimension of interest, they can conclude that “[they] are not as well off as everyone” that is a negative inference. Alternately, they can focus on the positive inference “that it is possible for you to be better off than you are at present” (Taylor et al., 1990, p. 82.). In downward comparisons where they compare themselves to someone worse off, they can focus on the positive inference – “[their] situation is not as bad compared to others” (p. 82). Alternately they can focus on the negative inference- “that it is possible for you to get worse” (p. 82). Focusing on the positive aspects of these comparisons is more likely to lead to persons to feel better about themselves and/or their circumstances.

Several factors may influence where referred parents focus when making social comparisons, including their locus of control, self-esteem, and the likelihood of improvement in the dimension being evaluated or the stability of the stressful event. Persons with high self-esteem and internal locus of control are more likely to focus on the positive inferences (Taylor et al., 1990). If the possibility for improvement in the particular stressful circumstance is high, then a person’s capacity to gain comfort from downward comparisons and useful knowledge from upward comparisons might be enhanced (Suls et al., 2002). Ireys et al. (2002) suggested that support parents can also influence whether referred parents focus on the positive inferences of their comparisons by encouraging focus or refocus on the positive inferences of social comparisons.

Reactions to offers of assistance. The stress buffering potential of relationships aimed at providing social support is influenced by recipients’ emotional reactions to these offers of help (Ireys et al., 2002; Tilden & Galyen, 1987). These emotional reactions are
shaped by recipients’ perceptions of reciprocity and attributions of the supporter’s motivation in providing aid and implicit messages underlying their offer of aid. Based on these ideas we can expect that the more that referred parents perceive that the P2P relationship is reciprocal the more likely they will be to accept and have positive feelings about accepting a support parents’ help. In the converse condition rejection and negative or mixed feelings about accepting help are more likely to occur. Based on social exchange and equity theories, perceptions of imbalance in social relationships tend to make the over benefited feel guilty and indebted, leading to stress in the relationship (Tilden & Gayle, 1987). It also generally leads to an aversive state driving the recipient to establish equity by seeking to help the helper, minimize the value of the help, or to disparage the helper (Green as cited in Ireys et al., 2002, p.156). It may also lead the recipient to withdraw from or decrease interactions in the relationship.

Recipients are more likely to accept help when their attributions of the supporter’s motives and intentions are positive. Acceptance is also influenced by the recipient’s attributions of the implicit evaluation contained in the supporters’ offer of aid. When the referred parent believes that the support parent views him/her as incompetent or helpless (a perceived attribution of internal difficulties) then he/she is more likely to reject the support parents’ offer of help. While perceived attributions of external difficulties (current circumstances are difficult) are more likely to encourage the referred parent to accept the support parent’s offer of aid (Ireys et al., 2002).

**Match between needs and support provided.** The degree of congruence in needs of the referred parent and the assistance that the support parent provides may influence the referred parent’s perceptions of the helpfulness of the support. Social
support is more likely to help a distressed person cope when it matches their needs and values (Horowitz et al., 2001; Neufeld & Harrison, 2003). Effective supporters as they listen can accurately “judge what the problem-teller wants and react in a way that satisfies that goal” (Horowitz et al., 2001, p. 49).

Summary of Conceptual Foundation

Existing conceptualizations provide a useful foundation for examining how P2P might help parents of children with ASD and what might shape helpfulness. P2P might help parents through providing models for coping, increasing parents’ self-efficacy, instilling hope, and providing linkages to others parents and institutions that become sources of useful information and support. These benefits occur through the related processes of conducting social comparisons, social modeling, and cognitive adaptation as parents in the match share information and exchange stories.

The conceptual foundation also suggests that helpfulness of P2P may be more likely when referred parents’ needs match the assistance the support parent provides and referred parents focus on the positive inferences of social comparisons. Helpfulness is also more likely when referred parents perceive the P2P relationship to be reciprocal and their support parents as empathic, similar to themselves, relatively calmer in comparison to themselves, and as having positive intentions and attributions underlying their motives for helping.

While this foundation is useful in understanding helpfulness of P2P, ideas pertaining to factors shaping helpfulness need more attention to issues that might affect the delivery of the intervention including (a) the experience of support parents with their children’s disability; b) level of experience in being a support parent; c) support parents’
perceived adequacy of training and other preparation for the support parent experience; d) support parents’ adjustment to their own children’s disability; and e) timeliness and adequacy of P2P staff follow-up of matches.

**Part II: Research Findings on P2P**

I reviewed studies that investigated if and how P2P benefitted referred parents and the conditions affecting these outcomes. Because research on P2P is sparse and more so on parents of children with disabilities, I included all studies that met these criteria regardless of research design and type of special need. In addition, although the proposed study is focused on P2P provided by volunteer support parents, I included studies that evaluated P2P provided through paid support parents. The paid support parent approach uses a time-limited P2P, screened selection and training of prospective support parents with extensive hours of training, and regularly scheduled post-match supports for support parents (supervision and debriefing). In contrast, in the volunteer approach, the P2P intervention is usually not time limited, the pool of parents for support parent training and matching are often self-selected, and support parents typically receive fewer hours of training. Unlike the paid approach, support parents usually receive ad hoc post-match supports from the program staff rather than systematic supervision and debriefing.

**Description of Studies**

The search yielded 16 research reports that met the inclusion criteria representing 11 evaluations. Seven reported findings of four programs that used paid support parents (Ireys, Sills, Kolodner, & Walsh, 1996; Ireys et al., 2001; Rearick et al., 2011; Silver, Ireys, Bauman, & Stein, 1997; Sullivan-Bolyai, Bova, Lee, & Gruppuso, 2011; Sullivan-Bolyai et al., 2004; Sullivan-Bolyai et al., 2010). The remaining nine reported findings
from seven evaluations of programs using volunteer support parents (Abinder et al., 1999; Ardal, Sulman, & Fuller-Thomson, 2011; Iscoe & Bordelon, 1985; Nicholas & Keilty, 2007; Preyde & Ardal, 2003, 2007; Preyde, Ardal, & Bracht, 2001; Santelli, Singer, DiVenere, Ginsberg, & Powers, 1998; Shilling et al., 2015a, 2015b; Singer et al. 1998). Five evaluations were of programs that provided P2P to parents of children with chronic illnesses and three for parents of children who had low-weight and preterm babies. The three remaining evaluations were of programs that delivered P2P to parents of children with disabilities only (Iscoe & Bordelon, 1985) or primarily parents of children with disabilities (Abinder et al., 1999; Santelli et al., 1998; Shilling et al., 2015a, 2015b; Singer et al. 1998).

**Impact of P2P on Parents**

**Social support.** Studies that investigated the effect of P2P on perceived social support had mixed results. Among the parents of children with juvenile rheumatoid arthritis diagnoses who received paid P2P support in a 15 month program (n = 20), P2P was associated with an increase in the number of persons that parents perceived to be supportive (Ireys et al., 1996). It had no effect on perceived overall availability of social support, but this may have been because parents already had moderate levels of support at baseline. Neither did P2P have an effect on two other social support indicators: a) the percentage of parents who felt nobody understood their burden, and b) the percentage of parents who had unmet needs for support. Failure to detect a statistically significant P2P effect on these two indicators may have been due to the small sample size. Similarly, Sullivan-Bolyai et al.’s (2010) randomized control trial (RCT) also did not find a P2P effect on social support among mothers of children newly diagnosed with Type 1
diabetes involved in a 12 month program using paid support parents (n = 28). However, the control group (n= 30) participated in other activities that would have provided the same kinds of support as the intervention group received, which the study’s authors surmised may have contaminated the intervention’s effects. The small sample size could have also been a reason for not finding statistically significant differences.

Singer et al. (1999) conducted a multistate evaluation of volunteer-based P2P programs using a two month RCT involving parents of children diagnosed primarily with disabilities and also found no P2P effect on parents’ perceived social support. This however may have been due to a ceiling effect since the majority of parents perceived their pre-study levels of social support to be adequate (Santelli et al., 1998).

In contrast to studies finding no discernible effects, Preyde and Ardal (2003, 2007) using a pre-test post-test design with a comparison group, found positive effects of P2P on perceived social supports among a sample mothers of very pre-term and low-weight newborns (< 30 weeks gestation or birth weight < 1500g) in the neonatal intensive care unit (NICU). At four months post-enrollment in the P2P program mothers in the intervention group (n=32) reported better quality of their listening support versus comparison group (n= 23) (Preyde & Ardal, 2007) and greater perceived social support 16 weeks post enrollment (Preyde & Ardal, 2003). Similarly, Iscoe and Bordelon’s (1985) multisite study of P2P programs indicated that P2P had a positive impact on social support. They found that over 60% of the 17 surveyed parents of children with Down syndrome or cerebral palsy reported that provision of personal support along with feeling understood were the greatest benefits of P2P.
Overall, due to the various design issues and contamination issues of the RCTs and the cross-sectional design of the latter study, it is difficult to conclude whether or not P2P might have an effect on recipients’ perceived levels of social support.

**Social isolation.** Nicholas & Keilty (2007) conducted a mixed-methods evaluation of a four month volunteer-based P2P delivered to 36 parents of children with chronic lung disease and found no statistically significant P2P effect on social isolation. The authors noted that failure to detect a statistically significant effect could have been due to low power from the sample size and decreases in social support from family and friends that participants experienced during the study. However, in in-depth interviews, parents reported that P2P decreased their social isolation. Similarly, in other qualitative evaluations parents receiving volunteer-based P2P (Abinder et al., 1999; Ardal et al., 2011; Preyde et al., 2001; Shilling et al., 2015a) and paid P2P (Rearick et al., 2011) reported decreased social isolation as a benefit. Parents mentioned that the opportunity for ongoing communication with someone who had similar experiences and who could, therefore, understand what they were experiencing led to feelings of connectedness, camaraderie, and that they were not alone and the only family undergoing their experience (Keilty & Nicholas, 2007; Rearick et al., 2011). Overall it appears that reduced social isolation may have been a benefit for parents in these P2P interventions although positive effects were not captured in the tests of statistical significance because of low power, instrumentation, and other design issues.

**Mental health.** Studies using quantitative methods that tested the impact of P2P on multiple mental health indicators including anxiety, worry, depression, cognitive disturbance, anger, stress, and overall psychotic symptoms found mixed results in terms
of statistically significant effects depending on the outcome and the population (Ireys et al., 1996; Preyde & Ardal, 2003; Silver et al., 1997; Singer et al.’s 1998; Sullivan-Bolyai et al., 2010; Sullivan-Bolyai et al., 2011). However, studies using qualitative analyses indicated that P2P seemed to have a positive impact on mental health.

**Anxiety and worry.** P2P was associated with lowered state anxiety among mothers of very pre-term babies in the NICU at four weeks post program enrollment. Similarly, using an RCT with a sample of mothers of children who had been diagnosed with chronic illnesses for at least six months (Silver et al., 1997) found lowered anxiety in the intervention group (n = 174) compared to controls (n = 169) with the P2P effect on anxiety only among mothers with higher levels of stress (i.e., five or more stressful events within the last year). In addition P2P buffered the impact of stressful life events on anxiety.

In other studies, there were no statistically significant effects on anxiety. There was no P2P effect on trait anxiety at 16 months post enrollment among mothers of children in the NICU (Preyde & Ardal, 2003) and on anxiety among mothers of children with JRA once researchers controlled for children’s functional status (Ireys et al., 1996). Similarly, Sullivan-Bolyai and colleagues evaluated the influence of P2P on worry about raising a child with a chronic illness among parents of children newly diagnosed with Type I diabetes using an RCT and found no effect on mothers (Sullivan-Bolyai et al., 2010) but found that P2P increased the worry of fathers (Sullivan-Bolyai et al., 2011). Interestingly, in post study conversations, mothers who received P2P shared that although they found P2P very valuable, it would not have changed their responses to some of the
questionnaire items indicating that the study measures may not have been sensitive to capture the aspects of their adjustment that P2P influenced (Sullivan-Bolyai et al., 2010).

**Depression.** While P2P was associated with lowered depression among mothers of very preterm infants in the NICU (Preyde & Ardal, 2003), other studies found no direct P2P effect among mothers of children with juvenile rheumatoid arthritis diagnoses (Ireys et al. 1996) and with chronic illnesses (Silver et al., 1997). P2P, however, buffered the impact of stressful life events on depression among mothers of children with chronic illnesses (Silver et al., 1997).

**Other mental health outcomes.** Using their sample of mothers of very-preterm babies in the NICU, Preyde & Ardal, 2003 found that the group receiving P2P reported lower stress compared to controls at four weeks post program enrollment. P2P had no direct effect on anger, cognitive disturbance, and overall psychiatric symptoms among mothers of children with juvenile rheumatoid arthritis diagnoses (Ireys et al. 1996) and with chronic illnesses (Silver et al., 1997). It however, buffered the impact of stressful life events on mothers’ overall psychiatric symptoms but not the effects of anger and cognitive disturbance (Silver et al., 1997). Ireys et al., 2001 noted that despite the few statistically significant effects of P2P on mental health in their P2P RCTs, (Ireys et al., 1996; Silver et al., 1997) participant mothers provided anecdotal information of dramatic benefits from the P2P program and that a qualitative evaluation would have helped clarify details of P2P outcomes and processes (Ireys et al., 2001).

In general, although the findings from quantitative studies have not always found statistically significant effects, results from qualitative studies have indicated that parents derive mental health benefits from P2P. For example, a subsample of recipients of P2P
involved in the 12 month intervention for parents of children with diabetes reported decreased mental health symptoms including stress as benefits of P2P (Rearick et al., 2011). They noted that the sense of ongoing availability of support parents (i.e., being able to contact support parents at any time) made stressful circumstances more bearable. Similarly, in the qualitative evaluation of Singer et al.’s (1998) multisite P2P study, parents of children diagnosed primarily with disabilities identified increased emotional well-being (Abinder et al., 1998). Parents of children with disabilities reported increased emotional stability as a benefit of Face to Face, a P2P program in the United Kingdom (Shilling et al., 2015a).

**Coping.** Two studies tested the impact of P2P on coping with mixed results. Singer et al. (1999) tested the impact of P2P on parents’ perceived coping efficacy in a two month RCT using a multisite sample of parents of children diagnosed primarily with disabilities. Results indicated that P2P increased coping efficacy but only for mothers with lower pre-intervention coping efficacy (i.e., pretest coping efficacy scores ≤3.08; maximum score of 5). There was no P2P effect on coping efficacy among mothers with higher pre-intervention levels of coping. However in the accompanying qualitative evaluation, parents in this 2-month P2P intervention reported improved management of their daily challenges as a benefit (Abinder et al., 1998).

In somewhat of a contrast, a 4-month volunteer-based P2P intervention did not have a statistically significant effect on the coping of parents of children with chronic lung disease (Nicholas & Keilty, 2007). Failure to detect a statistically significant effect may have been due to the small size. Also, study authors noted that decreased social support and/or increase in caregiver strain experienced by parents during the study may
have diluted the interventions’ effect. Nevertheless, in accompanying in-depth interviews parents reported enhanced learning about coping strategies as a benefit (Nicholas & Keilty, 2007). Similarly, in other qualitative studies, parents of children with Down syndrome or cerebral palsy (Iscoe & Bordelon, 1985) and very low birth weight babies (Ardal et al., 2011) reported improved coping as a benefit of P2P. Together, the findings from quantitative and qualitative analyses provide some support that P2P is helpful to parents of children with disabilities and chronic illnesses.

**Management of children’s condition.** Sullivan-Bolyai and colleagues tested the effect of paid P2P on parents’ confidence in the daily management of Type 1 Diabetes and parents’ concern about its management in two RCTs using samples of parents of children newly diagnosed (Sullivan-Bolyai et al., 2004; Sullivan-Bolyai et al., 2010). The results indicated that P2P reduced management concerns in the 6 month pilot intervention delivered to mothers (Sullivan-Bolyai et al., 2004) but had no effect on concerns for mothers (Sullivan-Bolyai et al., 2010) or their spouses (fathers) (Sullivan-Bolyai et al., 2011) in the 12 month intervention. However, in the 12 month intervention control parents were also involved in other supportive interventions some of which included peer support that could have contaminated the control condition (Sullivan-Bolyai et al., 2010).

P2P did not have an effect on mothers’ confidence in their daily management of Type 1 Diabetes in either RCT (Sullivan-Bolyai et al., 2004; Sullivan-Bolyai et al., 2010), but had a positive effect on the confidence of fathers who participated in the 12 month intervention (Sullivan-Bolyai et al., 2011). Although the results did not indicate that P2P had a statistically significant effect on mothers’ confidence, mothers and fathers
in the 12 month intervention reported it, along with the acquisition of practical tips for the day to day diabetes management as a benefit in in-depth interviews (Rearick et al., 2011). In contrast, Preyde and Ardal (2007) found a positive P2P effect on confidence in parenting and understanding of the medical condition in their sample of mothers of very pre-term infants in the NICU.

**Empowerment.** In a multisite RCT, Singer et al. (1999) tested the impact of volunteer-based P2P on mothers’ perceived empowerment to obtain services or to effect change involving parents of children with disabilities. At the two month follow-up, they found no P2P effect on parents’ perceived empowerment. However, a closer examination of scores on the measure of empowerment indicated that P2P was associated with increased empowerment in the family domain but not in service systems and community/political domains (Santelli et al., 1998). Additionally, parents in this intervention reported empowerment as a benefit in the qualitative evaluation (Abinder et al., 1998). This might indicate that empowerment in the latter two domains may not be as amenable to P2P influence as the family domain within a two month period.

**Cognitive adaptation.** Four evaluations tested P2P’s impact on parents’ perceptions of family circumstances related to their child’s illness including acceptance of family circumstances (Singer et al., 1999), its perceived negative impact on the family (Sullivan-Bolyai et al., 2004; Sullivan-Bolyai et al., 2010; Sullivan-Bolyai et al., 2011), and its intrusiveness in their family’s life (Nicholas & Keilty, 2007). Tests of statistical significance indicated mixed results on whether P2P increased recipients’ positive attitudes towards their circumstances. Singer et al. (1999) found that P2P increased mothers’ acceptance and positive attitudes towards their family circumstances associated
with their children’s disability. Nicholas and Keilty (2007) tested the impact of P2P on parents’ perceptions of illness intrusion into family life among 36 parents of children with chronic lung disease but found no P2P effect.

Sullivan-Bolyai and colleagues tested P2P’s impact on the perceived negative impact of Type 1 Diabetes on the family in two RCTs. In the six month pilot P2P had a positive effect by decreasing mothers’ perceptions of the negative impact of diabetes on the family (Sullivan-Bolyai et al., 2004). Findings from the accompanying qualitative analyses of this pilot study provide details on how P2P may have led to less negative perceptions of the illness on the family. Mothers in the pilot study reported that support parents helped them put their situations into perspective by enabling them to see that “T1DM [Type 1 Diabetes] was a part of their lives and not its entirety” and to take a child and family centered rather than disease-centered focus, where their “[ill] child was a child first, and not the disease” (Sullivan-Bolyai et al., 2004, p. 481). Also, by listening to accounts of support parents’ experiences and mistakes in handling their children’s illness, the support parent also helped them to put in perspective their judgments of their own management, thus bringing a realization of the human element in caregiving (Sullivan-Bolyai et al., 2004).

However the evaluation of the 12 month intervention did not indicate any P2P effect on perceptions of the negative impact of diabetes on the family among mothers (Sullivan-Bolyai et al., 2010) or fathers (Sullivan-Bolyai et al., 2011). This may have been due to contamination of the control condition mentioned earlier. However, in in-depth interviews, P2P recipients reported experiencing shifts in their perceptions of their family circumstances that ensued from their conversations with and observations of their
support parents and their children. Specifically, parents came to believe that their lives would go on and that they would attain “a new normal” (Rearick et al., 2011, p. 515). Overall findings from quantitative and qualitative analyses of these four evaluations suggest that P2P may help recipients in having more positive attitudes towards their family circumstances as it relates to raising children with a chronic illness or disability.

**Progress on the presenting problem.** Singer et al. (1999) tested whether P2P led to improvement in the problems for which parents of children with disabilities had first sought help from the P2P program. They found statistically significant positive effect with recipients reporting more progress in getting help with the problem they first brought to the P2P program compared to control parents.

**General helpfulness.** Three studies using volunteer support parents reported recipients’ ratings of the overall helpfulness of P2P. The overwhelming majority of parents in these studies found P2P to be helpful or very helpful. In Singer et al.’s (1999) multisite evaluation of P2P, 87% of recipients who were primarily parents of children with disabilities (n=72) rated its overall helpfulness of P2P as helpful or very helpful. While 87.5% (n=24) and 95.5% (n=45) of parents of very pre-term infants in the NICU rated their P2P program as helpful or very helpful (Preyde & Ardal, 2003; Preyde et al., 2001). A small proportion, however, did find it unhelpful ranging from 11% (Singer et al, 1999) and approximately 4% in both NICU programs. Only 1% in both NICU programs reported it did not make a difference.

**Other parent benefits.** A number of other benefits were identified from the qualitative evaluations of P2P (Abinder et al., 1999; Ardal et al., 2011; Iscoe & Bordelon, 1985; Nicholas & Keilty, 2007; Rearick et al., 2011; Sullivan-Bolyai et al., 2004). First,
across all qualitative investigations, parents reported being able to vent, feeling understood, and having their feelings and concerns validated and normalized as benefits of P2P. They felt these benefits ensued because the support parent had similar experiences to theirs (e.g., Rearick et al., 2011). Second, P2P recipients mentioned a vision of and reassurance about their children’s futures as benefits that came from seeing or hearing stories about the support parents’ children and families, especially observing them lead typical lives (Iscoe & Bordelon, 1985; Rearick et al., 2011). Third, parents gained pragmatic tips on parenting and managing their children’s condition, information on resources and medical terminology and processes, reinforcement of information learned elsewhere, and ways to work with professionals (Abinder et al., 1999; Ardal et al., 2011; Rearick et al., 2011; Sullivan-Bolyai et al., 2004). Fourth, participants reported social interaction, friendship and personal growth as benefits of P2P (Shilling et al., 2015a). Finally, parents identified improved family adaptation in terms of learning how to focus on their other children and family members and not just the ill child as a positive impact of P2P (Rearick et al., 2011).

**Factors Affecting the Helpfulness of P2P**

Studies on factors that might affect P2P’s helpfulness are also rare. This question has been explored using quantitative and qualitative analyses. Quantitative studies tested for moderation effects of recipients’ amount of support parent contact, pre-intervention coping, socio-demographic characteristics, the level of stress, and characteristics of their child’s illness.
Findings from studies with quantitative methods.

**Intervention dose/amount of contact.** Results of studies are mixed when it comes to the moderating effect of intervention dose. It did not moderate the effect of P2P on mental health (anxiety, depression, cognitive disturbance, anxiety and total psychiatric symptoms) and perceived social support in the two RCTS conducted by Ireys and colleagues (2001) but did so for family management of chronic disease among parents of children with Type 1 diabetes (Rearick et al., 2011). Mothers with greater participation in the P2P intervention (i.e., more support parent contact) tended to have more ease in their family management of diabetes (Rearick et al., 2011).

**Characteristics of recipients.** Recipients’ socioeconomic status as measured by income did not make a difference in P2P’s helpfulness to parents of children diagnosed primarily with disabilities (Santelli et al., 1998). Similarly, when indicated by receipt of public assistance, it did not moderate the effect of P2P on mental health and perceived social support for parents of children with chronic illness (Silver et al., 1997). Family structure (single parent versus two-parent) did not moderate the effect of P2P on these outcomes for the same group of parents (Silver et al., 1997).

Recipients’ levels of life stress (high versus low) moderated P2P’s impact on anxiety but not on depression, anger, cognitive disturbance and overall psychiatric distress of mothers of children with various chronic illnesses (Silver et al., 1997). In this study P2P lowered anxiety among mothers with high life stress (five or more stressful events in the last year) but did not do so for those with low life stress.

**Characteristics of recipients’ children.** Children’s illness-related factors (absence or presence of functional impairment and time since diagnosis) did not moderate
P2P’s impact on mental health and perceived social support outcomes among parents of children with various chronic illnesses (Silver et al., 1997). Sullivan-Bolyai et al. (2010) surmised that parents’ stress would have been greater if their child with diabetes was the firstborn for mothers and tested for a moderating effect of birth order. They found that birth order did not moderate the effect of P2P on parent concerns about diabetes management, confidence in its daily management, the perception of its impact on the family, worry about raising a child with a chronic illness, or perceived social support.

**Findings from studies using qualitative methods.** Five evaluations used qualitative inquiry to explore factors influencing helpfulness of P2P (Abinder et al., 1998; Preyde et al., 2001; Ardal et al., 2011; Nicholas & Keilty, 2007; Shilling et al., 2015a, 2015b). Findings from these studies provide detailed information on factors promoting and inhibiting helpfulness of P2P.

**Factors promoting helpfulness.**

*Perceived similarity.* Matches were most helpful when referred parents perceived sameness between themselves and their support parents. Two dimensions of similarity were possible although study participants did not identify both as important factors in all studies. These two dimensions of similarity were at the child level (age, diagnoses, experiences, symptoms and care requirements) and at the parent level (personality, values, socio-cultural background) (Abinder et al., 1999; Ardal et al., 2011; Nicholas & Keilty, 2007; Preyde et al., 2001). While some studies found that the greatest helpfulness was perceived when similarity was seen on both levels (Abinder et al., 1998; Preyde et al., 2001), in others the focus was only on similarity at the child-level (Shilling et al., 2015b). Perceived similarity was crucial to creating a sense of shared experience
between matched pairs which enabled emotional connection, comfort disclosing needs and concerns, normalization and validation of feelings, and learning useful information and practical tips. How exactly similar children needed to be to develop a sense of shared experience was not always clear as in some studies parents did not all have the same diagnoses or were matched on diagnosis (e.g., Abinder et al. 1998, Shilling et al., 2014b). For example, in an evaluation of a P2P program serving parents of children with varied disabilities, some referred and support parents felt being a parent of a child with any disability was sufficient to facilitate shared experience, while others felt that matching on diagnosis or similar diagnoses was imperative (Shilling et al., 2014b).

**Positive interpersonal dynamics.** Parents of children with chronic lung disease identified personal compatibility and positive interpersonal dynamics as factors that prompted helpfulness as it made conversations enjoyable and often left parents feeling encouraged and affirmed. Thus, it appears that differences in personality may be overcome if they are complementary (Nicholas and Keilty, (2007).

**Motivation for participation.** Parents whose motivation for participation in the study was their desire to help another parent of a child with a similar condition found that this helped them maintain their commitment to the P2P process. This, in turn, promoted the helpfulness of P2P (Keilty & Nicholas, 2007).

**Mode and amount of contact.** In a study of the impact of P2P among mothers of children with chronic lung disease, Keilty and Nicholas (2007) found that face to face meetings for the initial contact appeared to promote the helpfulness of P2P matches. Face to face contact helped to establish and strengthen peer connection, encouraged engagement in the relationship, and motivated the referred parents to continue contact.
with the support parent (Keilty & Nicholas, 2007). P2P recipients mentioned that being able to visualize each other encouraged more and greater identification with and empathy for each other as well as greater depth and intensity within their communication. Using email and telephone also promoted helpfulness because it “increased convenience and ultimately participants’ ability to engage in the peer support process” (Keilty & Nicholas, 2007, p. 254) and referred parents who had more contact time seem to have been helped more (Abinder et al., 1999).

**Accessibility of the support parent.** A characteristic of helpful support parents was around-the-clock accessibility. This was an “ongoing sense that that the support parents can be called upon as needed that gives referred parents a feeling of dependability” (Abinder et al., 1999, p. 104).

**Bi-directionality of support.** Recipients may be more likely to find P2P beneficial when they also help those providing them with support. In a study of the impact of P2P among parents of children with disabilities and chronic illnesses, Abinder et al. (1999) found that referred parents who felt that P2P was helpful were generally in matches where they also gave support to their support parent. Not only was it important to these referred parents to provide support but feeling that they were helpful to their support parent was itself a benefit to them.

**Qualities and characteristics of the support parent.** Shilling et al. (2015b) investigated the potential role of support parent factors in the helpfulness of P2P to referred parents of children with disabilities. They identified two groups of support parent factors - extrinsic and intrinsic qualities - that helped create a sense of shared experience and a safe environment for disclosure which in turn made P2P helpful.
Extrinsic qualities included the support parents’ P2P training, use of program rules to maintain boundaries and professionalism. While intrinsic qualities included readiness (having the requisite skills and information from training and being emotionally “in the right place” to support another parent), being empathic, understanding, knowledgeable, nonjudgmental and having an altruistic motivation to support.

Organizational factors and processes.

Shilling et al. (2015b) solicited referred and support parents perspectives on the role of formal structures and processes on the helpfulness of P2P. Participants reported support parent training, supervision and the delivery approach of the P2P program as three factors that contributed helpful outcomes. Support parents reported that the training and ongoing support from the support parent network facilitated shared experiences and therefore led to helpfulness as it gave them up to date knowledge and relationship skills especially in listening and maintaining boundaries on how much to disclose. The training contributed to parents’ confidence in supporting which enabled them to make the referred parent feel comfortable. Similarly, the ongoing mutual support from the network of support parents and the support parent coordinator also contributed to their confidence and emotional stability which was critical to them to ensure their continued ability to support other parents (Shilling et al., 2015a). In terms of the delivery, referred and support parents reported that the very personalized, flexible and one to one in-home service created an environment that facilitated referred parents’ trust and confidence in the support parent. It also caused the matched pairs to see the program “as relaxed and informal” which made referred parents feel in control and comfortable disclosing their feelings (Shilling et al., 2015b, p.5).
**Factors inhibiting helpfulness.**

*Practical/Logistical issues.* There were several practical and logistical barriers that led to the premature end of matches by diminishing opportunities for contact and engagement in the P2P process, ultimately undermining helpfulness. These included long distances between matched pairs preventing pairs from meeting, difficulty paying for phone calls, lost phone numbers, scheduling problems, telephone tag, negligent supporting parent follow-up, and referred parents’ busy lives leading to lack of time to talk on the phone and for self-care due to heavy and frequently changing care responsibilities for their child, and other family commitments (Abinder et al., 1999; Keilty & Nicholas, 2007; Preyde et al., 2011).

*Situational and individual differences.* Differences in children’s diagnoses, progress, age and subsequent day to day challenges were the most often reported reasons for matches having no or limited benefit to P2P recipients (Abinder et al. 1999; Keilty and Nicholas, 2007; Preyde et al., 2011). Differences undermined helpfulness in two ways. First, when supporting parents’ children’s challenges were more severe and their children younger this inhibited referred parents’ disclosure about their own children’s progress or development in an attempt to refrain from discouraging the support parent. This difference also led to referred parents spending more of the P2P contact time giving support to the support parent while receiving minimal support. Differences in the other direction (support parents’ child was doing much better) also inhibited helpfulness. In these cases, referred parents felt there was little commonality for a helpful relationship with the support parent. Also, this difference often resulted in referred parents feeling that their own circumstances were worse than they had previously perceived. Second, in
situations where the support parent’s child had not experienced similar issues as the referred parent’s child, then the latter parent felt that there was no common ground for dialogue or that the support parent would be bot able to empathize or provide practical information.

Abinder et al. (1999) also found that even if there was situational similarity, matches were not helpful when parents had different individual preferences and values, specifically in communication and parenting styles, views on the disability, and visions for their children’s future. Similarly, Nicholas and Keilty (2007) found parents’ non-complementary disposition and personality often led to interpersonal difficulties typically leading to parents finding peer support unhelpful and discontinuing contact.

Mode of initial contact. Parents of children with chronic lung disease identified not having an inaugural face to face meeting as a factor inhibiting P2P helpfulness. They noted that in such instances they experienced awkwardness with telephone conversations that led to more difficulty establishing and sustaining contact (Keilty and Nicholas, 2007).

Interpersonal difficulties between matched pairs. Interpersonal problems arising from non-complementary dispositions or personalities of matched peers was a barrier to helpful matches as in these situations, recipients reported the peer support to be unsatisfactory and often did not continue with the match (Keilty and Nicholas, 2007). This included, for example, pairs in which one parent was optimistic and hopeful about their child’s future while their matched parent was pessimistic.

Concerns about the exchange of information. Keilty and Nicholas (2007) identified factors that specifically led to referred parents’ reluctance to engage in sharing
or listening to information and stories from the support parent. Such reluctance inhibited the development of meaningful peer contact, and ultimately the helpfulness of the P2P match. For some parents, this reluctance stemmed from their discomfort with sharing personal information with someone they did not know. In other cases, referred parents avoided contacting support parents to avoid learning about potential medical problems their child might develop or painful reminders that their child was not progressing (when the support parents’ child was ahead). In the converse situation when referred parents’ children were doing better than their support parents’ child, referred parents were reluctant to share personal or health information that they felt might discourage the support parent.

Timing of the support in recipients lives. Shilling et al. (2015b) found that P2P was unhelpful if it was offered or accessed at the wrong time in the recipient’s life. Specifically, it was unhelpful when referred parents were not at the point where they were ready or willing to talk. While referred and support parents felt that receiving help early in their post-diagnosis journey could be beneficial for all families, they felt that for some families it could be dangerous if accessed too early as they needed to have developed the confidence in themselves before they could reach out to another parent. However, participants in the study reported that one could know the best timing to give support and that this was on a case by case basis.

Organizational factors. Shilling et al. (2015b) found that P2P program rules intended to maintain boundaries and to protect both parties in the match in some cases became a barrier to helpfulness in their evaluation of a P2P program in the UK that used in-home visitation. Specifically, referred and support parents reported that these rules
impeded the creation of a safe environment for disclosure and a sense of shared experience. Two particular rules were identified: that support parents should not give their personal mobile number to and especially not talk too much about themselves with the referred parents. While the rules were intended to maintain professionalism by preventing the helping relationship from becoming a friendship, referred and support parents felt that some sharing was not only helpful for parents but was necessary to facilitate the relationship.

**Conclusion**

Although not always statistically significant in tests, based on data trends and findings from qualitative interviews, P2P appears to improve a variety of parent outcomes including anxiety, depression, perceived social support, and stress. Further, P2P appears to have some generic effects across parents of children with varied special health care needs (e.g., validation of feelings, decreased social isolation, and practical tips for managing children’s condition). These studies have also shed some light on factors that influence the helpfulness of P2P to referred parents of which perceived similarity is one of the most crucial factors. Yet, the extant P2P research has several limitations and gaps. First, none of these studies have specifically examined helpfulness for parents of children with ASD and thus have limited generalizability to this population. Research has identified the unique and typically greater psychosocial and financial burdens of families caring for children with autism (Kogan et al., 2008; Lord & Bishop, 2010; Schieve et al., 2011). The etiology of ASD is unclear, its presentation varied, the developmental trajectory uncertain, and a plethora of treatments are available with no cure and consensus on optimal treatment and the criteria for evidence-based efficacy
(Lord and Bishop, 2010; Rogers & Vismara, 2008). These children’s multiple deficits require services from a variety of professional treatments and expensive and time-consuming processes of caregiving and treatment-seeking, participation and monitoring. Understanding how and when P2P may be helpful must be explored within this context as this will more likely identify how some of the generic benefits play out in this population and possibly other benefits that may be unique to this population.

Second, design issues also limit the strength of their conclusions and applicability to parents of children with ASD who use volunteer-based P2P. The majority of studies were RCTs requiring that only parents who were willing to be randomized to a control group were included. This meant that studies excluded parents who may have been in crisis or felt they had urgent needs for this type of support. Also, diverse and insensitive measures, problems in design including in the control conditions, ceiling effects and low power due to small sample sizes, may have led to failure to detect statistically significant positive effects although benefits were consistently reported in qualitative analyses. In Singer’s et al. (1998) study there was concurrence on most outcomes across both types of analyses unlike the other studies. This may have been due to their use of a participatory action research approach in which outcomes tested were based on parents’ identification of the ways that they felt P2P was helpful, and the measures were chosen or developed in part based on parents’ perception that they were valid indicators (Santelli et al., 1998). This suggests that quantitative analyses may be best able to answer questions on P2P effects among parents of children with autism when outcomes to be tested and sensitive measures are identified based on qualitative descriptions from parents. Study authors underscored the value of qualitative inquiry in providing depth to understand how P2P
helps, through what mechanisms, and what factors shape helpfulness (Keilty & Nicholas, 2007; Singer et al. 1999). Others recommended it as a foundation and/or a complement to quantitative inquiry into its effects and in selection of measures that will best capture the ways that P2P helps referred parents (Ireys et al., 2001; Sullivan-Bolyai et al., 2010).

For this reason the present study used a qualitative methodology to answer the question of how P2P helps or does not help parents of children with autism. Obtaining a detailed description can form an important foundation for testing effects in later studies for this population.

Another notable limitation of the prior research is that although P2P involves a match between two parents organized and monitored by P2P staff, the perspectives of support parents with one exception are absent, and that off program staff is completely absent. Support parents are the essence of the intervention and are trained to use their emotional and practical experience and knowledge to help referred parents meet their needs. Given this, their experience with being a parent of a child with a disability and in support parenting, their perception of adequacy of training and post-match supports for the support parenting tasks are factors that need more exploration as these vary across P2P programs. Shilling et al. (2015a, 2015b) identified how training, post-match supports, and program delivery contributed to the helpfulness of P2P. Given that P2P programs vary on these structural aspects, more studies are needed to better explore these areas.

Also largely unexamined in the extant studies are the salience of support parent characteristics that P2P programs are expected to use to screen or to have potential support parent use for self-screening as suggested in the Parent to Parent Handbook
(Santelli et al., 2001, p. 106): a) acceptance of their child and adjustment to their family situation; b) ability to reach out and provide support to other parents; c) ability to cope with other people’s problems and tolerance of values and feelings that may be different from their own; d) willingness to share their family story with others; e) communication skills; f) maturity and empathy; and g) time availability. Programs based on the Ireys model also include likeability and warmth (Sullivan-Bolyai et al., 2010). Also unexplored, is the support parents’ social context including their family structure and other demographic characteristics and how these might affect the P2P process. While Shilling et al. (2015a, 2015b) identified being knowledgeable, non-judgmental, understanding, and empathic, readiness and motivation to support, some of the other factors presumed to be important and used in screening need exploration especially in how they facilitate beneficial outcomes.

Other than the timing of the support and availability or time for self-care, very little focus has been given to how referred parents’ characteristics may contribute to the dynamics of the P2P relationship and its helpfulness. Beyond availability, we do not know what factors might affect emotional readiness and willingness to talk to another parent.

More understanding is also needed on the matching criteria needed to establish a sense of shared experience or perceived similarity. This includes understanding under what circumstances and for what types of supports needs are certain matching criteria important (e.g., age of the child, diagnosis/symptoms, and parents’ personality and social background of the parent).
In addition to soliciting referred parents’ perspectives, this study will seek to capture the perspectives of support parents and P2P staff on factors affecting helpfulness of P2P matches with the aim of providing an understanding of how P2P specifically benefits parents of children of ASD and more comprehensive picture on factors shaping P2P helpfulness.
CHAPTER 3

METHODOLOGY

Qualitative researchers acknowledge that the participants and the researcher impact the research process. Given this, before I discuss the methodology that guided the study, it is important that, as a researcher, I reflect on the identities I brought to the study and how these may have impacted the research process and its outcomes (Bourke, 2014; Dwyer & Buckle, 2009; Kerstetter, 2012). Therefore, in this section, I discuss my identities relative to the study participants, beginning with what I brought to the study.

Researcher Identities

I am a doctoral student and a Black woman from a developing country in the Caribbean. I have been involved in social work practice, education and research for approximately 18 years. Much of my professional experience and interests have been in the areas of child welfare, the emotional and behavioral health of children and adolescents, and parent educational involvement. I did not initially plan to study P2P or the social support needs of parents of children with ASD when I began my doctoral studies in 2008. In fact, before I began this study on P2P, I was interested in studying how foster parents perceive and experience their role in their foster children’s education, especially barriers and supports for their involvement. My aim was to provide policy and practice guidelines to support foster parents’ educational involvement.
In 2011, while working on my dissertation proposal on foster parent’s educational involvement, a faculty member in my department approached me about being involved in and then leading a study about P2P among parents of children with ASD. As I pondered the pragmatics of switching topics, I realized that the proposed study brought me back full circle to what was my original professional interest as I was finishing high school and applying to college - to work as a special education teacher with children with learning, intellectual and developmental disabilities. My interest in special education grew out of stories and information from the media about children and youth with disabilities along with becoming aware of and acquainted with similar children in my community.

Because there were no degree programs in special education at that time in my country, I pursued a degree in social work but maintained my interest in children with special needs. As parents in my social network learned that I was being trained and later practicing in social work, they would solicit my input about educational and behavioral health issues of their children, particularly about assessment and finding treatment. Through these interactions, my personal and professional interests expanded to include support for the parents as well as services for their children. As I transitioned to graduate training in social work and post-graduate employment, interactions with children with disabilities and their families became a part of my professional practice and not just informal conversations with parents. This began in an outpatient clinic where I worked on an interdisciplinary team that provided services to children with emotional/behavioral and developmental issues including ASD.

As a result of my informal and professional interactions with families of children, before this study, I had listened to parents’ stories about grappling with and accepting
diagnostic labels. I had also listened to their struggles with accessing assessment and treatment that continue to be very limited in the Caribbean. I found interactions with these parents satisfying in that I was able to be a listening ear while informing them of what I knew about accessing assessment and treatment. However, I also found it frustrating and even sometimes felt a sense of helplessness because of the very limited resources and, even more, limited access to what existed. So when I was offered the opportunity to become involved in this P2P study, I thought almost immediately about how this program would be particularly useful in the Caribbean. I thought about how parents could receive emotional support and practical tips from their peers while waiting for or as a supplement to formal services. I realized that the proposed study appealed to me on a deeper level because it provided a way to ameliorate some of the concerns of parents of children with disabilities in my country and my sense of frustration and helplessness with limited services.

The proposed study also resonated with me on a deeper level because P2P as an instance of one-to-one peer support captured what I had been doing for 11 years not as a parent but as a caregiver to my father and elderly aunt who had stroke related disabilities. Over the past 11 years, I have talked with and listened to spouses, children and other caregivers of adults with stroke or other illness-induced disabilities. I have often reflected on and felt frustrated about how caregivers in my country still have such limited access to emotional support and information on the practical aspects of caregiving for adults with disabilities. As I thought about becoming involved in this P2P study, I realized that it might also provide a useful model to deliver supports to caregivers as I had been doing for many years.
While neither I nor anyone in my immediate and extended family is a parent of a child with ASD or other disabilities, I nevertheless brought to this study four areas of pertinent professional and personal interests and experiences. These included research and/or social work practice with a) children with disabilities and other special needs, b) involvement of parents/caregivers in the health, mental health and educational involvement of children with special needs, c) parenting interventions including supports for parents of children with special needs, and d) supports for caregivers of adults with illness-induced disabilities. Given than I am not a parent of a child with special needs, I am an outsider to daily lived experiences of parents of children with ASD or other disabilities. Thus, unlike the referred parents, support parents and P2P program staff, I did not share in this experience. On one hand, this meant I could bring less bias to the study through not reading my experiences into participants’ experiences. On the other hand, it also meant that I was at a disadvantage in not having an intuitive understanding as a parent of what it meant to receive and provide P2P. I also did not have a personal experience of what it meant to administer P2P programs, particularly in training. This, however, did not seem to undermine building rapport with research participants. There are several possible reasons for this which I discuss below.

First, it is possible that participants may have found it easy to talk to me because I, like them, am a woman. Oakley (1981), for example, suggested that shared experiences of being a woman may lead to greater rapport when women interview women. Second, beyond gender, I shared varied types of identities with different parents in the matches that enhanced rapport. For example, some like me were students or had an interest in and questions about pursuing graduate and doctoral education. Like me, some
support parents had training in or worked in helping professions and so we shared a common language related to concepts and processes of helping. Third, it is also possible that it was easy for referred parents to build rapport with me because they had already shared their stories during intake with program staff and agreed to do so with support parent who they did not know. Similarly, the role of program staff and support parents involved talking with parents with whom they were likely to be unfamiliar, which may have contributed to my ease in developing a rapport with staff during their interviews.

To prepare for the study, I reviewed the literature on the concerns and experiences of parents of children with ASD. I also reviewed studies on their need for and use of formal and informal support. In addition, I read studies on P2P especially paying close attention to qualitative investigations to get a better sense of how P2P worked. Further, while developing the proposal for this study, I spoke with several employees of FCSC about P2P and read program brochures and descriptions online. I also went to and completed the training for support parents where I observed the training procedures and listened to parents of children with varied special needs tell their stories from pre-diagnosis to present and their ongoing adjustment to caring for their children. I also told my story of being a caregiver of my father and eldest aunt because of their stroke-induced disabilities. Also, I spoke to a couple who has a child with ASD and had also received P2P through FCSC, who shared their story and provided input on my interview guide along with the FCSC staff. Because I did not know anyone else who was caring for a parent who had become disabled, similar to the referred parents of children with ASD, I have an insider understanding of lacking and desiring support from a similar caregiver. I also have parallel experiences to P2P in that like support parents I have an ongoing history of
listening to and giving suggestions to parents of children with ASD and other disabilities as well as caregivers of adults with disabilities. Reflecting on my personal and/or professional experiences with caregivers of children and adults with disabilities and grounding in the related literature prepared me to listen to parents and also gave me insight into the P2P relationships and processes that I was studying.

**Overall Design**

This study used a longitudinal qualitative design informed by modified grounded theory guidelines to answer the research questions. Data was collected via separate, repeated, in-depth and semi-structured interviews with mentees and mentors before and after their support relationship began. Also, P2P staff participated in single individual interviews. A qualitative design was well suited to address the study aims for two reasons. First, qualitative approaches by virtue of their flexible and open design allow for the identification of unexpected phenomena (Maxwell, 2005). This flexible design was appropriate given that the experience of parents of ASD with P2P is unknown, and there is little or no empirical understanding of the perspectives of those involved in P2P delivery- support parents and program staff. Second, qualitative methods are particularly useful in building an understanding of the role of one variable affecting another variable or outcome and the process through which this occurs (Maxwell, 2005). This aligned well with the aim of this study that sought to understand the factors that inhibit and facilitate beneficial outcomes of P2P. A short-term longitudinal design was important for tracking how relationships unfolded over time.
Grounded Theory

Grounded theory methods were developed by sociologists Barney Glaser and Anselm Strauss during the late 1960s through their studies of people who were dying in hospitals in the US (Charmaz, 2006). In their book, *The Discovery of Grounded Theory (1965)*, they first presented the strategies guiding these methods and the promotion of this approach to scientific inquiry in which theory development would occur inductively from data collected in a research study rather than a deductive approach where hypotheses are derived from extant theories and tested. Grounded theory methods provide a systematic approach to the collection and analysis of qualitative data. The central components of this approach as defined by its originators are: a) simultaneous data collection and analysis; b) a data driven (inductive) approach to develop analytic codes and categories; c) use of the constant comparative method—making comparisons throughout the analysis; d) writing memos to define, describe, and elaborate on a category, its properties, dimensions, and connections to other categories; e) sampling for theory construction rather than population representativeness; and f) conducting a literature review following rather than preceding an independent analysis of the data (Glaser & Strauss, 1967; Glaser, 1978; Strauss, 1987 as cited in Charmaz, 2006).

This study was guided by these guidelines except that a literature review preceded as well as followed data analysis. This literature review included prior theories and research that are pertinent to understanding parents’ experiences with P2P and, more specifically, factors associated with its helpfulness. Like Maxwell (2005), I use the term theory broadly to reference any level of abstraction that is a proposition of the connection or relationship between two or more concepts. I deviated from Glaser and Strauss’
timing of the literature review for pragmatic and ideological reasons. Pragmatically, the
development of the research questions, justification of the importance of the study, and
situating its contribution to practice and scholarship necessitated a prior review of the
literature. This included scholarship on the experiences of parenting a child with ASD
and theory and research about how P2P as a form of social support works, barriers and
facilitators to beneficial outcomes, and how relationships change over time. Therefore, I
already came to data collection and analysis with beliefs and expectations about what the
data might reveal. These preconceptions also derived from my experiences and
ponderings of what Maxwell (2005) refers to as “thought experiments” (p. 58).

Ideologically, in accordance with a constructivist-interpretivist paradigm, I believe that
we make sense of our experiences through subjective rather than a neutral or objective
lens and that our apprehension of phenomena is inextricably tied to our interpretations
(Denzin & Lincoln, 2005). Presenting a prior literature review and a conceptual
framework intentionally brought my lens to the forefront of the study that had several
potential advantages. It provided me with sensitizing concepts to help me make sense of
data that may otherwise have appeared unrelated or not salient to my research questions
and illuminated what I saw by drawing attention to connections that I might have missed
or misunderstood (Maxwell, 2005). It also helped me bound the scope of the study, and
thus the design, including what data to collect, and also improved the efficiency of the
research process (Miles & Huberman, 1994).

Of course, potential disadvantages are that it could have blocked alternate ways of
exploring and understanding phenomena and encourage a tendency to force the data into
my conceptual framework. Nevertheless, I believe an articulation of the theories and
research findings that I brought to the study provided an opportunity for my preconceptions to enter the analysis only if supported by the data. This was done through searching for discrepant data and other methods that will be discussed in the data analysis and trustworthiness sections below.

The grounded theory method was used because it is particularly useful in answering research questions that relate to the interactions between individuals or among persons and particular environments (Grbich, 2007). The central phenomenon of this study, P2P, is an instance of social interaction aimed at providing social support through relationships between matched parents. These relationships are embedded in the P2P organization, its actions in the matching, follow-up and support of matched pairs, and in the context of the lives of the matched parents. Thus, an understanding of the P2P impact and what influences beneficial outcomes or not was best understood with these contexts. Grbich (2007) noted that a strength of grounded theory as a method is that it facilitates “teas[ing] out the elements of a setting or the depths of an experience” (p. 70).

**Recruitment**

I recruited participants from Family Connection of South Carolina (FCSC), a statewide organization that provides P2P to parents of children with special health care needs (CSHCN). FCSC operates in three regions and six offices: a) the Upstate with offices in Anderson, Greenville, Spartanburg, and Rock Hill; b) the Midlands with the state office in Columbia; and c) the Low Country with its office in Charleston. I recruited parent participants only from the Midlands office because of its proximity to me to minimize costs that might be associated with the need for face-to-face interviews. I selected FCSC as the site for this study for several reasons. First, its P2P program is a
mature program that has existed for over 20 years. This facilitated being able to access study respondents, particularly support parents and program staff, with lengthier experiences with P2P. Therefore, information was more likely to be rich, with varied factors associated with beneficial and non-beneficial outcomes. Second, it was accessible to the researcher based on its proximity and existing research-related relationship with College of Social Work faculty at the University of South Carolina.

FCSC is one of 32 alliance members of the Parent to Parent USA (P2P USA), a national non-profit organization that seeks to ensure that families of CSHCN have access to P2P nationwide. FCSC connects all statewide P2P programs\textsuperscript{6}. Like other members of P2P USA, FCSC uses trained volunteers as support parents. Founded in 1989, FCSC is a community-based and family-focused non-profit organization whose mission “is to strengthen and encourage families of children with special healthcare needs through parent support” (Family Connection, n.d.). In addition to the P2P program, FCSC offers other programs and services including but not limited to: local family social events; workshops for siblings, grandparents and couples of children with special needs; parent support groups for specific disabilities; statewide advocacy for children with special needs; and a resource and information center. All of FCSC’s programs and services are based on the belief that families with similar experiences are uniquely qualified to assist each other.

\textsuperscript{6} Alliance members are organizations that have a statewide P2P program as a core program that uses trained volunteer parents and have committed to implementing evidence-based P2P USA endorsed practices derived from the multisite study of P2P conducted in the 1990s (Abinder et al., 1999; Singer et al., 1998) and best practices from program coordinators.
The P2P process at FCSC

The aim of the P2P program is to provide informational and emotional support to a referred parent through a one-to-one match with a support parent. An intake interview is conducted with the support-seeking parent to ascertain their specific needs, information about the focal child including demographic characteristics, nature and history of their child’s diagnosis, preferences for mode of communication and characteristics of a support parent, and basic information about the parent and family. Once this is done, the matching coordinator attempts to match the referred parent to a support parent within 24 to 48 hours. Support parents are encouraged to contact the referred parent within 24 to 48 hours. The P2P staff makes follow-up phone calls at two weeks to each parent to see if contact has been made and then follow-up the match at two months. At six months post match, the P2P staff contacts the referred parent to see if they have any other information and service needs or wish to be matched again to another support parent.

Before any match, the P2P staff conducts three to four hours of training with each support parent, giving each trainee a manual on resources for parents of CSHCN and a support parent training manual. At the end of the training session, support parents fill out a data form with their contact information; description of their family structure; places of employment; and description of their children with special health needs (i.e., primary and secondary diagnosis, symptoms and related problems). They also indicate the areas for which they are willing to provide support. FCSC does not screen parents for the support training or readiness as a match for referred parents. Their P2P staff assumes parents are ready to become support parents if they consider themselves ready (J. Richards, personal communication, January 13, 2012).
Recruitment Procedures

I began recruiting participants through FCSC after the USC’s Institutional Review Board (IRB) approved the study’s procedures. The P2P coordinator directly recruited referred and support parents using a telephone script that I provided (see Appendix A). Referred parents who requested or accepted the offer to be matched were recruited during the intake telephone call with the P2P coordinator. The coordinator recruited support parents by phone at the point where they agreed to be a match for a referred parent. She informed parents of the study’s purpose; that their participation was confidential, voluntary, would include one 15 to 30 minute interview before beginning their relationship and, at least, one follow-up interview; and that they would receive a $10 Walmart gift card for each interview. She asked their permission to give me their contact information if they were interested in participating in the study or had questions about the study. She also sent them a flyer (see Appendix B) about the study by email and mail.

Once I received parents’ contact information, I called them and introduced myself and went through the consent procedures (see Appendix D), solicited and answered any questions about the study, and then confirmed if they still wished to participate. The consent procedures reiterated information shared during recruitment and that the interviews would be by telephone or face-to-face by their preference. The participants were told that in addition to a pre-relationship interview there would be up to six follow-up interviews for up to six months depending on how long their P2P relationship lasted and their continued voluntary participation in the study. I informed them that I was recruiting their matched peer and reviewed how the data from their interviews would be used and kept confidential, limits to confidentiality, risks and benefits to participating,
and how they could contact my study advisor and the USC’s IRB director. I explained that participating in the interview would indicate their consent and mailed or emailed them a copy of the consent document.

After explaining consent procedures and obtaining consent, I scheduled the first interview as soon as possible, usually the same day or the next because FCSC policy is that support parents should contact the referred parent within 48 hours of being matched. At the end of each month, I mailed referred and support parents a Walmart gift card with a value of $10 for each interview in which they had participated.

**Participants’ Characteristics**

Participants included referred parents and support parents of children with ASD, who requested and/or agreed to be matched to another parent of a child with ASD as well as P2P program staff involved in matching parents and following up matches. The plan was to follow matches prospectively before matched pairs began their relationship and then during their relationship rather than retrospectively. Parent was defined broadly to include any primary caregiver of a child with ASD seeking support or providing support to a parent of a child with ASD. I excluded persons who were younger than 18 years old and non-English speaking. Parents were eligible if their matched peer agreed to be in the study. Initially, when recruitment was slow, I relaxed this and so the first three study participants were only one party from the match. Once I was able to recruit pairs, I discontinued recruitment of participants where only one party was in the study. I also discontinued additional follow-ups of the first three participants given study expenses. To test emerging ideas about reasons matches were not helpful, I attempted to recruit referred parents who had been matched within the past six months and after at least one
contact and who had ended their match or asked to be re-matched or had reported at follow-up that the match was unhelpful. I also tried to recruit the support parent to whom they had been matched and the support parent, if any, with whom they were now matched. Although I expanded my inclusion criteria, there were no parents during the data collection period that fit these criteria.

Twenty-nine persons participated in the study and all were female. This included 23 parents (11 support and 12 referred parents) and all P2P program staff (n = 6). The 23 parents represented 14 matches. For 11 of these matches, both referred and support parents participated in the study. For the first and second match, only the referred parent participated in the study (one support parent declined participation and the other expressed initial interest in the study but did not return calls to confirm participation). In the third match, the referred parent did not respond to the email and mail recruitment flyer. Once I was able to recruit pairs, I decided to have no further follow-up with the three matches in which only one party was involved in the study. Of the remaining 11 matches, both referred and support parents participated in the study completing, at least, one interview. However, one of these matches never began a relationship (RP8 and SP8) and only completed their pre-relationship interview.

Referred parents (n = 11) were biological mothers who were on average 38.75 years old (range = 32 to 45 years); 10 were married and two, separated; nine were stay-at-home mothers, and three had full-time employment; and five were Caucasian, six, African American, and one, multiracial. Their children with ASD included eleven males and two females and were on average 8.74 years (range = 3 to 16 years). At the time of the first interview, their children had been diagnosed with ASD from 1.5 weeks to 12
years with eight children having been diagnosed less than a year and five children less than four years. One parent had two children with ASD.

All 11 support parents were biological mothers of whom four were Caucasian; six, African American; and one was biracial. Five were married; six were single or divorced; two were stay-at-home mothers; four had full-time employment; three, part-time employment; and two were unemployed. Nine had been supported by a support parent. Their children with ASD included nine males and three females with one parent having two children with ASD. The children were on average 11.25 years old (range = 5 to 20 years) and had been diagnosed on average for 6.58 years (range = 2 to 17 years) with four less than four years and eight for four or more years.

All program staff members were female, five were Caucasian, and one was Hispanic. All were current or past support parents, and four were parents of a child with ASD. They had worked with the P2P program an average of 8.16 years (range = 1 to 20 years). Three were involved in matching, two in conducting follow-ups of matched pairs, and one carried out both functions.

**Data Collection**

I collected data through repeated semi-structured and separate, individual in-depth phone interviews with referred and support parents and a single interview with the P2P staff. I gave prospective referred and support parents the option to interview in person or by phone, but all of them opted to interview by phone. The initial plan was to conduct a focus group interview with staff, but it became difficult to arrange this because the staff was dispersed across different regions of the state. Staff interviews lasted an average of one hour (ranging from 44 to 70 minutes). As planned, I interviewed all parents once
before them making contact with each other except two support and one referred parent. Despite numerous attempts, I was unable to make contact with the referred parent until after she had already begun her relationship with her match. One of the support parents contacted her match immediately after the P2P coordinator gave her the information. The other support parent was a rematch for a referred parent in my study, and I learned of the rematch after the relationship had begun. Pre-contact interviews for support parents lasted an average of 40 minutes (range = 29 to 56 minutes) and for referred parents, an average of 29 minutes (range = 21 to 39 minutes).

I conducted the first follow-up interview for each parent within a week of the pre-relationship interview. I initially scheduled the second and third follow-up interviews for respectively two weeks and four weeks from the first follow-up interview unless the parent requested another time because they would be unavailable or had planned to talk with each other sooner or later than the scheduled time. In a few instances, parents had forgotten or were unable to call each other, and I had to reschedule several times. Thus, I began checking in with parents by text messaging, email or phone call usually one to two days before the scheduled time to see if they had made contact and if they were still able to interview. We rescheduled as needed. I conducted one to four follow-ups with matched pairs except one pair who never began their relationship. Follow-up interviews for support parents lasted an average of 35 minutes (range = 8.48 to 64 minutes) while referred parents’ interviews were an average of 33 minutes (range = 13.07 to 64 minutes).

I conducted staff interviews after I had conducted at least one follow-up interview with the 10th matched pair of parents. Staff interviews lasted an average of about one hour (range = 44 to 70 minutes).
All interviews were audio-recorded and transcribed verbatim. I verified transcriptions before uploading them into ATLAS.ti (version 7) for analysis by listening to each audio recording and made any necessary corrections to the transcription. Also, I removed identifying details and replaced them with pseudonyms or other disguises. I used a contact summary sheet to briefly document date of the interview, key themes, modifications in the sample, questions from the interview guide that I had not asked, responses that needed further explanation, and time for the next interviews (See Appendix C). I later added a log to the contact summary sheet to document the date and content of check-ins and any non-interview contacts I had with parents, which were typically about whether they had contacted and talked with their match and/or reasons for not doing so, as well as any revision in the scheduled interview time. During these check-ins parents sometimes provided unsolicited information on their opinions of the match and judgments they were making about genuineness, readiness, and receptiveness. They also shared their satisfaction with the match or if they were thinking about or had requested a rematch. These check-ins were also important pieces of data. I read and reviewed the contact summary sheet or read the transcript and made notes before moving on to the next interview.

**Interview Protocol**

I used three semi-structured guides, one each for referred parents, support parents, and P2P staff (See Appendix D). I made slight modifications as data collection and analysis progressed to add more specific probes concerning ideas that were emerging about factors affecting helpfulness and influenced changes in matches over time. If more time was needed, I sought participants’ permission to extend the interview.
**Parent interviews.** The first referred and support parent interviews began by asking about what led to their involvement in their match or P2P program (e.g., “what prompted you to become involved with the P2P program?”) and expectations for the support relationship. I also asked questions to elicit a description of parents and their family context including past and concurrent matches; their children with ASD (age, type and time of diagnosis); and demographic information (marital and employment status, age, race/ethnicity). In follow-up interviews, I questioned them about how the support relationship was developing, its helpfulness and factors influencing this, what would have made it more helpful, and recommendations to maximize P2P helpfulness for parents of children with ASD.

**P2P staff interviews.** The staff interview began with questions about their role in the P2P program and whether they had been a referred and/or support parent and their experiences as recipients and/or providers of support in their matches. Subsequent questions solicited their perspectives on the factors limiting and promoting helpfulness based on their experiences as participants in a match and also as a program. I also solicited recommendations to maximize P2P helpfulness for parents of children with ASD.

**Data Management and Safeguarding Participants**

Several steps were taken to safeguard participants. The IRB approved the procedures for this study. Recruitment took place only after first receiving IRB approval and data collection after obtaining verbal consent. I sent a copy of the consent form to each participant. Transcriptionists sent transcripts electronically to me using password protection and signed a confidentiality agreement indicating that they would keep
information locked away, confidential, and would destroy all materials within ten days of sending transcripts (see Appendix E). I checked transcripts against the recordings for accuracy and removed any identifying descriptors, replacing them with pseudonyms or generic descriptors such as “town,” “child,” and “physician.” Transcripts were entered into ATLAS.ti (version 7) for coding and other analytic work. I kept the digital recorder, electronic versions of the recording, and any printed data and information concerning participants in a locked cabinet in my home office when they were not in use. I later destroyed the original digital recordings. Study files could only be accessed by me and only on computers that were password-protected. Also, electronic transcripts, contact summary sheets, and files with contact information for participants were also password-protected.

**Data Analysis**

Analysis began after the first interview and continued iteratively and simultaneously with data collection. I began by listening to the audio recording or reading through the transcript if available and writing a one-page summary of each interview that I kept in individual Word files for each participant. The summary included answers to key questions of the study, descriptive information about the participant and her child, main themes and issues, information on interview questions that the interview did or did not provide hunches, and next field steps suggested by the interview. For example, the pre-relationship summaries for the referred parents included the reasons for seeking help through a support parent and expectations for the match. Follow-up interview summaries included participants’ views on the way the match was helpful and/or unhelpful and factors affecting helpfulness. I also wrote notes about initial ideas.
about emerging themes that needed more exploration and interview questions that I had not asked, or the participant had not answered.

Once I entered the transcripts into ATLAS.ti (version 7), I read each transcript and began open coding chunks of data, which varied from phrases to a line, or sometimes sentences. As mentioned earlier, I came to the study having been immersed in the literature on P2P and peer and support social processes, experiences of parents of children with ASD, and stress and coping. Also, as described earlier, I brought to the study personal and professional experiences with disabilities and interactions with parents and program staff involved in P2P. I used the literature and my experiences as sources of sensitizing concepts as I approached the simultaneous tasks of data collection and analysis. For example, I used concepts of coping, social isolation, shared or similar experience, and social comparisons as a starting points to alert me to potential processes and ideas as I read and analyzed interview transcripts and thought analytically about them (Charmaz, 2006). As Charmaz (2006) noted, while it is not possible to come to data collection and analysis without any biases, I was able to use these sensitizing concepts as analytical tools rather than forcing them on the data. I tried to do this in several ways. First, I kept my interview questions generally broad. For example, although I expected that perceiving similarity in experience would contribute to rapport and helpfulness, I asked parents “What affected how you got along?” and “What made the P2P relationship helpful?” rather than asking whether similarity affected these outcomes. In this way, I tried to stay open to other possibilities. Second, I did not use a predefined list of codes but instead developed my own codes based on reading and interrogating the data, making comparisons between data, and using code names that reflected the language of
participants wherever possible. Second, as I coded, sensitizing concepts and
preconceptions about P2P benefits and factors affecting beneficial outcomes remained
tentative unless they had earned their way into the data. Even when they appeared to
have earned their way into the data, I tried to keep my analysis grounded by comparing
the extent to which my emerging ideas aligned with my preconceptions. In subsequent
rounds of data collection, I subjected sensitizing concepts to further testing and/or
development by adding them as probes. I was able to identify conditions under which
concepts such as perceiving similarity operated differently than expected in leading to
beneficial outcomes.

Where possible, I tried to use code names that were gerunds to identify the actions
and processes that were taking place in the data as recommended by Charmaz (2006). I
wrote memos for ideas that seemed important but for which I was not sure what code
names to apply and in some cases created a tentative code name. I coded new transcripts
using the code list that the software generated from the previous transcripts and created
new codes as needed based on comparisons between data within the interview, existing
codes, and across different interviews from the same and different participants.
Specifically, I made comparisons of themes at several levels: a) individual referred and
support parents’ accounts of their current and any previous matches; b) between parents
in a match; c) across matched pairs; d) between program staff’s accounts about their
general experiences with matching, re-matching and following up matches and also about
their experiences as referred and support parents; and e) across the three types of
participants.
In the beginning, after coding the first two transcripts, I met with two committee members to look at how I was coding. I also went back in and recoded and refined the code list to add some conceptual codes, because my code list at that time consisted primarily of descriptive codes. As my code list quickly became very long, I paused and defined my codes and found that I had several code names that were similar conceptually and merged these codes. In other instances, I expanded the definition of codes so that I could merge codes that had only very slight distinctions. In addition, I began to see and create categories and subcategories. I renamed codes to create stems for the name of the category (e.g., benefits of P2P: information, benefits of P2P: decreased isolation). These steps made the coding more efficient, and I revisited them several times throughout the data analysis.

I also wrote memos about initial ideas about the data and questions and emerging themes that needed more exploration. I initially wrote the latter types of notes on my contact summary sheet and later started also using the memo function in ATLAS.ti (version 7) to record them and make more extensive comments. I however, kept writing brief notes and potential questions and probes on my one-page interview summaries. These notations allowed to efficiently to conduct several layers of comparisons: a) within and between interviews of each participant over time as applicable; b) within and between matched pairs; c) between interviews of participants in each group (i.e., referred parents, support parents and P2P staff; and e) and across the groups of participants. Using these comparisons, I wrote additional and more extensive memos in which I brought in data from the transcripts. Towards the end of my data analysis, I also wrote
summaries of each match to give me a quick picture of how each match evolved and its helpfulness.

Memos and interview summaries drove continued data collections in two major ways: to identify and fill in gaps and to test emerging ideas. For example, initial analysis of early interviews indicated that perceiving similarity and feeling connected seemed important to referred parents finding their match helpful. However, the type of similarity between children and parents that distinguished helpful and helpful matches was unclear. Also unclear was what feeling connected meant and how it developed and affected the helpfulness of matches. Because I was following matches prospectively, I could not know ahead of time if I might have matches that would be unhelpful. In fact, over the course of the study, I only had one match that disrupted which would have been insufficient data to test my initial ideas about the relationship between an emotional connection and perceived similarity. This led me to recruit persons whose matches had disrupted or had reported that the match was unhelpful at follow-up, but there were no persons who had fit those criteria during that time. It also led me to ask referred and support parents and later staff about prior matches they may have been involved in or followed up to see how these factors were related to P2P outcomes, and this allowed me to gather data to test and elaborate upon these ideas.

After the open coding phase, I entered into a selective phase of coding that entailed focusing on the codes that occurred most frequently and categories that seemed most important for summarizing the data. During this phase, I used memos and drew several concept maps to reflect on the relationships among these codes. I revisited my interview summaries and transcripts and integrated these memos about these codes and
earlier ideas about possible relationships. This led to a framework where I was able to identify outcomes of P2P (types of P2P benefits or unmet needs) and to delineate the relationship between the major codes and categories that influenced outcomes. Also, I identified how relationships changed (or not) over time and the factors affecting how they evolved. After I had developed this framework based on my analysis, I returned to the literature and compared my framework and data to research findings and theoretical propositions (including those in the literature review that had informed my study) for similarities and differences. In some instances, comparisons made me aware of concepts that I had overlooked in the data or had not sufficiently developed in terms of how it might be related to other concepts. Contradictions between my framework and those in extant literature, also led me back to the data and sometimes to coding and memo writing to account for the differences by better delineating differences in contexts and conditions.

As discussed earlier, in my role as researcher, I inadvertently became an extension of the intervention and as a result, my interactions with parents paralleled the relationships between parents and between parents and staff. I reflected on these parallels and wrote memos on my reactions to participants and vice-versa during the research process. For example, I wrote memos about instances where respondents seemed somewhat disengaged or distracted during interviews. I also compared my experiences with participants’ accounts of their relationships, including actual and attempted contacts with each other and the content of their interactions. I used these comparisons to help make sense of what was going on in the data, such as how parents contended with practical issues such as scheduling conflicts and other responsibilities in making decisions about making time for P2P interactions.
Data Quality and Enhancing Trustworthiness

Several strategies were implemented to enhance data quality including steps to minimize biases from participants and researcher reactivity. One important strategy was triangulating data sources by interviewing both parents in the match along with program staff. This proved to be helpful as both parties in the match tended to focus more on factors associated with their matched peer when reflecting on issues affecting helpfulness. The program staff was able to identify factors that both parties tended to overlook, such as how referred parents explained their support needs during intake and how staff explained the support parent’s role. Their differing perspectives provided leads for theoretical sampling and even new hypothesizing.

A potential concern was that parents might have feared that I might judge them negatively regarding their contributions to the match. I was concerned they might feel uncertain about how what they shared would be used or anticipate negative repercussions to their relationships with their matched parent or FCSC staff. This could have led them to overstate the positive and/or understate or withhold information on negative aspects of their interactions with each other. I tried to minimize participants’ reactivity to me by stating and restating the purpose of the interview and what will be done with the data and conducting parents’ interviews in an informal and conversational manner (Miles & Huberman, 1994). Other strategies to minimize reactivity included emphasizing to participants that there were no wrong or right answers to interview questions; reminding them of confidentiality procedures and that the study was not the agency’s study; and conducting separate interviews of the three groups of participants – referred parents, support parents, and P2P staff.
To minimize my reactivity to participants, I used Miles and Huberman’s (1994) suggestions to keep my research questions in mind by having a written interview guide and soliciting feedback from peers or advisors. At several points throughout data collection and data analysis, I met with members of my dissertation committee to debrief and to discuss my analysis. Overall these strategies helped me to minimize being overcome by sentimentality, interpersonal concerns, straying unintentionally from research questions, and failure to probe for elaboration or challenging contradictions.

I checked on the meaning of outliers (unusual events, unique matches, or exceptions to apparent patterns) by collecting (more) data on such instances to verify if what occurred in them was different or missing from typical cases. One example of this was in one staff interview where the participant, a program staff member, reported that differences in functioning between her child and her support parent’s child did not undermine helpfulness of P2P. Up to that point in the study, participants had reported that such differences undermined the helpfulness of matches. I followed up on this in other interviews, and it led me to modify my prior conclusions on the role of similarity as a facilitator of helpfulness. Specifically, that similarity in children’s conditions was not important to meeting certain needs for support such as information on general resources for children with disabilities.

I also had peers, committee members, P2P program staff, and a former P2P recipient reviewed my interview protocol to identify biased questioning and areas that needed more elaboration and exploration. Finally, recording interviews and developing verbatim transcriptions allowed for more accurate and detailed data for analysis.
Anticipated and Actual Researcher Involvement in the Study

My expectations for involvement as a researcher were that my role would be to collect data from the participants in the study through interviews as a neutral and uninvolved observer of the P2P process. As an outsider to parenting a child with ASD, I expected that I would have no or very limited practical information or experiences with caring for a child with ASD that would be helpful to participants. I saw myself as someone who parents would see as an intruder into very intimate spaces of their lives and so during the informed consent process I tried to emphasize how short the interviews would be.

Once the interviews began, I soon discovered that it was not possible for me to be an affectively neutral and uninvolved observer for several reasons. First, by listening to parents during the interviews, I myself became an extension of the intervention as a source of emotional support, similar to the role of the support parent. Both referred and support parents seemed to enjoy talking to me and opened up quite considerably about their experiences. For example, SP6, a support parent, said that talking to me, another adult, was “a treat.” Parents seemed to value the opportunity to share their stories - what led up to the diagnosis of their child as well as current concerns and improvements. Initially, my concerns about and desire to minimize my intrusiveness into their lives, particularly since they were busy, made me grapple with asking or allowing them to tell their diagnosis story as it was somewhat peripheral in some cases to the study’s aims. However, I realized that it seemed beneficial to parents and I followed their lead if they went in that direction.
Second, parents also sometimes treated me as a source of information as they did with their support parents. They asked me questions that I answered about the P2P agency’s activities or online peer support networks. In other cases, parents shared with me or asked me about things that were unrelated to P2P or support for themselves as caregivers or their children. For example, parents shared with me their interests about pursuing doctoral degrees in a helping profession and asked me questions about what this entailed since they knew that I was a doctoral student. I answered and was very happy to be able to provide them with helpful information. Being asked and providing answers to the preceding types of questions paralleled the relationship between referred and support parents and in these two ways, I became an extension of the intervention.

Third, I also became an extension of some of the program staff’s roles in the P2P process. During the pre-relationship interviews, similar to the staff involved in the intake and matching, I asked referred parents’ questions to ascertain their reasons for seeking support, major concerns about their child, and demographic characteristics of themselves and their children. I also listened to referred parents’ apprehensions or concerns about what their match might be like or how the process was unfolding and answered questions that they asked as confidentiality permitted. For example, as I was ending a pre-relationship interview, a referred parent asked me if her support parent would be “somebody just random out of the blue who is the first time they doing this?” (RP6). I responded to RP6, by letting her know that the support parent was a trained volunteer parent, who would have had experience dealing with ASD. This was information that was on the agency’s website and which had been reiterated in discussions that I had with
program staff while preparing for the study. Thus, responding to such concerns was within the purview of program staff involved in intake and matching.

By conducting follow-up interviews and check-ins, I also became an extension of the program staff’s roles of conducting follow-ups and providing post-match supports to parents. Similar to program staff who conducted follow-up, in my interviews I asked parents if they had made contact and about the helpfulness of and satisfaction with their match. These follow-up interviews inadvertently allowed parents to debrief about positive and negative experiences with their match. Also, in some interviews, support parents problem-solved aloud about difficulties in their matches such as poor rapport or inability to make contact. This occurred in response to my interview questions about what they thought might have contributed to difficulties in the match and what were their next steps for the match or how they dealt with such problems in a match. This was noted, for example, by SP3, a support parent who was concerned about her match because her referred parent did not give her feedback about the usefulness of her suggestions: “You’ve helped me to brainstorm things just from me talking to you… I guess I wasn’t really thinking about it. I started thinking maybe more about the problems I was having [with the match] and ways to resolve those issues.” I did not provide parents with strategies or suggestions about how they might resolve difficulties in their matches, but the interview process led to parents’ problem-solving. Although the program staff only provided as needed post-match supports, they were available to respond to parents’ concerns about their matches and to help them problem solve. The P2P intervention did not include systematic and structured debriefing, but support parents were aware that they could seek ad hoc post-match support from the program staff.
Finally, I became more than an emotionally neutral observer as once I heard the referred parents’ stories and their needs for support not only was I moved but I also hoped that the matches would be helpful. I was sometimes privy to information that parents in the match had not shared with each other or the P2P staff or that the P2P staff had not shared with either parent that may have been helpful to encouraging parents’ engagement. For example, sometimes support parents were experiencing personal crises that prevented them from maintaining contact but had not relayed this information to referred parents and causing them to question their support parents’ sincerity. I complied with confidentiality. For concerns about not hearing from their support parent or questions about whether I had additional contact information for their support parent, I encouraged referred parents to call the P2P coordinator. I felt angst about not being able to disclose relevant information especially when it seemed program staff may not have had the information. I thought it was an unavoidable issue because as the researcher I had agreed to be confidential and as Reinharz (1998) noted, “many ‘method problems’ are not resolvable but are dilemmas that must be experienced and endured” (p. 377).
CHAPTER 4

FINDINGS: CONTEXT FOR PURSUING P2P

This study sought to answer three research questions:

a) How, if at all, do P2P matches benefit referred parents of children with ASD?

b) What factors promote or inhibit beneficial outcomes for referred parents from the perspectives of referred parents, support parents and program staff?

c) How do P2P relationships change over time?

Before I focus on findings for the research questions, I will first discuss the context within which the referred parents sought help and the type of help they pursued. This help-seeking context is important because it helps illuminate why referred parents sought help through a support parent. This context helps to situate how the support from P2P is unique compared to support from other sources such as families, professionals and parents of neurotypical children. It also influenced the type of help parents sought and their desire and ability to become and stay involved in the P2P relationship. This chapter is organized in two parts. Part I reports the findings on the referred parents’ context for help seeking and part II, the types of support they sought. In chapter five, I report the findings for the benefits of P2P, barriers and facilitators of beneficial outcomes and changes in relationships over time.

Part I: Context for Help Seeking

Referred parents sought support as a result of a felt need that arose from their perceptions that they were experiencing difficulty coping with circumstances (triggering
stressors) related to parenting a child with ASD and/or because of distressing emotional reactions to these stressors. In addition, parents perceived gaps in their coping abilities or resources to respond to these stressors, specifically inadequate knowledge and social support. Together, the stressors, emotional reactions, and evaluations of inadequate coping resources constituted the context for referred parents’ help-seeking. Stressors included acute events such as the receipt of a diagnosis of ASD or an additional diagnosis to ASD, which set in motion other events that were stressful. They also included chronic issues such as day to day demands of caregiving, concerns about worsening or unchanging ASD symptomatology or situations, and transitions (relocation or their child being in puberty).

**Evaluations of Difficulty**

Parents sought the help of a support parent amidst a sense of perceived difficulty in coping with stressors that were related to caring for a child with ASD. They experienced varied difficulties including those that stemmed from ASD symptomology (e.g., delayed speech) or from comorbid conditions such as sleeping, eating, intellectual development and attention deficit hyperactivity disorders that made responding to their children’s needs and managing their behaviors, even more, difficult:

I’m still going through a lot of daily struggles; Mike does not talk at all, so it is very hard and frustrating to find out what is wrong with him and what do I do to fix it… is he thirsty, is he hungry, is he tired, does he feel sick? (RP2, referred parent, son diagnosed eight months earlier)

Some parents had to contend with behaviors that had deleterious effects or could be life threatening such as running away, eating non-food items and smearing feces. These
behaviors required parents to be constantly vigilant which added another layer of
difficulty because of additional time burdens that this imposed and time it took away
from other activities.

For other parents, difficulties arose from transitions they or their children were
experiencing including relocations or puberty. Geographic relocations meant the need
to find new service providers, recreational resources, and linkages to the ASD and
disability communities. Puberty brought behavioral challenges that were harder to
respond because of the ASD such as those expressed by referred parent RP10:

It’s hard to deal with cause he doesn’t understand what’s happening to his body
and all that. And it’d be nice to share how the other parent handles it…cause
right now me and my husband are just – we’re doing what we think is right, but
I don’t think Will fully understands what’s happening, and I hate that. I hate for
him not to understand what’s going on.

Referred parents also found it difficult to deal with their children being
stigmatized and socially excluded as noted by RP7:

For me people look at your children so differently because they behave
differently…and they don’t fit in with typical children… they tend to stare or to
call the kids weird. Kids themselves can be cruel and shy away from your
children [and] don’t want to be around them and that is difficult [for me] as a
parent to see that.

Some parents also spoke of their difficulty in accepting that their children were different
from neurotypical children. This was also the case for RP7, although her children had
been diagnosed for approximately eight years:
It comes down to that accepting them the way they are and so the fear of going out and saying well okay my kids are really special needs like all these other kids that I’m going to see and that they really are different—that’s a hard thing for me.

For some parents, the sense of difficulty was an ongoing and daily experience and was pervasive throughout their day and in multiple areas of their children’s functioning. In these cases, the parents described the ASD as severe. In other cases, such as for RP1, the diagnosis was so new that the referred parent felt unsure of what to do or how to proceed. This led her to want from a support parent someone to walk her through responding to the diagnosis and in making decisions about what services to use. As she noted, "when you’re first going through this diagnosis it’s a lot that is thrown at you, there’s so many websites to go over, [and ] so many opinions of IEPs versus 504s”.

For other parents who described their child as high functioning, their concerns typically pertained to one to three acute or chronic issues for which they needed some advice. This was the case for RP5, whose daughter was diagnosed with high functioning autism and sought a support parent for the occasional bad day noting that “It’s not often that we have a so called bad day, it’s just from time to time.” For some parents, the trigger was an acute event – a fairly recent diagnosis of ASD or a geographic relocation. While for other referred parents, the sense of difficulty arose not from an acute event but because they had been trying for a while on their own with the realization that their ways of attempting to address the concerns were ineffective or no longer effective. They realized that they needed external help, leading them to seek a support parent or to accept one when offered by the P2P agency. This was the case of
RP7 who had been using avoidance and denial as strategies to deal with the diagnosis of ASD for her son and daughter that she had received several years earlier:

> When kids are young, you can kind of camouflage things, you can tell yourself okay maybe it’s going to change but as they get older the more you can see the disability … And so the older he’s getting, I’m forced to deal with the reality…I need to face it and try to connect with others; that’s where I am [now].

Similarly, RP3 and her husband had been trying unsuccessfully for several months to encourage their son to be sociable:

> He’s not progressing with social skills with us. I mean, I can tell him ten times a day, “Bob, if a man puts his hand out you need to shake his hand!” …I’ve got to have some help because just me and my husband aren’t accomplishing this.

**Emotional Reactions**

Referred parents expressed various negative emotions in relation to the receipt of the ASD diagnosis and/or to being a parent of and caring for a child with ASD. They used descriptors such as “heart-breaking,” “it eats me up inside,” and “emotional trauma” that reflected intense emotional reactions. For example, one parent spoke of the daily emotional toll of autism: “They have not done enough studies on the emotional trauma with autism children on parents, and they need to. It’s mighty time somebody takes into consideration the emotional distress that we go through daily” (RP2, referred parent). Many parents reported feeling alone, overwhelmed and anxious. Feeling alone denoted the perception that they were the only person going through their experiences and could understand it as illustrated by RP2:

> I just feel like sometimes that God’s not there, is he listening, you know? How
much more can I take God before I have a nervous breakdown? I feel that it’s just me, and I just want somebody else to tell me you’re not alone, I understand. “Feeling overwhelmed” was a common issue, particularly for parents with a fairly new diagnosis as they had to contend with a multitude of opinions, information, and sources about what treatments and services they should utilize for their children. Even parents who had received the diagnosis, at least, a year earlier reported feeling overwhelmed by having to search and apply for and attend multiple service appointments, as in the case of SP11, a support parent who reflected on her early post diagnosis experiences that led to her seek P2P:

So I drove 2 hours whenever we had therapy … Maybe two times a week I was driving to that city... The day that the support parent called me I was at my wits end, and I told her, “I am so glad that you called” because tears were running down my face because I had become so overwhelmed with my son’s diagnosis. Parents' reported feeling anxious and having ongoing worries about current and future outcomes for their children including how they will be treated by their peers, whether they will be able to live independently as adults and how they will care for themselves or who will care for them if they died:

I worry like every day… Like every day if they go out for recess, all the other kids are playing, he stands alone [begins crying], that bothers me, it eats me up inside… I worry that if he doesn’t learn to be a little bit social that as he gets older that he’s really gonna stand out. (RP3, referred parent)
In addition to the foregoing emotional reactions, parents also expressed feeling frustrated to as they attempted to respond unsuccessfully to their children’s needs and experiencing shock (for parents who recently received an ASD diagnosis).

**Gaps in Personal Resources/Ability and Support Systems**

In light of the demands or stressors, difficulty in coping and adjustment seemed to arise from parents’ perceived gaps in coping resources. Some parents mentioned gaps in knowledge for managing or changing their children’s behaviors, services, procedures in seeking help, and navigating the service system. For some parents, the perceived lack of knowledge was global, for example, RP1 parent, whose son had been diagnosed for about 1.5 weeks at the time of our first interview, shared, “I don’t know what to do, you know it’s like what is the next step?” Other mothers felt they lacked knowledge and skills to address specific behaviors of their children such as poor social interactional skills and were seeking the assistance of a support parent to fill these gaps. Parents felt that they did not know what to do because the ASD diagnosis was fairly recent, or they had no previous experience with it, or they had been persistently unsuccessful in their attempts to help their child for some time.

Other parents felt that they had inadequate social support from their family and community. This included companionship or social interaction but more often emotional support in the form of empathetic listening and understanding:

We get no support from our church; we get no support from family, no support from anybody, but just me and my husband. And I don’t get much support from him because he’s not here in the home and he’s at work (RP2, referred parent).
For some persons, their support systems had been disrupted because they had relocated. While for others stigma and discrimination because of the ASD diagnosis and accompanying “weird” behaviors of their children led to previously supportive persons distancing themselves and socially excluding their children:

You know, family members – at first, they didn’t want to deal with him, but they were scared, and so, I would see my other sisters would invite my other nieces and nephews to a party, but they wouldn’t invite my son. (SP4, support parent and former referred parent)

This had a ripple effect leading parents to withdraw from social contact with families of neurotypical children to avoid anticipated stigmatizing reactions.

Even if they had emotional support from family, friends and mental health professionals referred parents felt that these sources were limited because they could not understand what they were going through without having lived experience of parenting a child with autism. Parents conveyed that understanding what they were going through could only come from a parent of a child with autism who had similar experiences and felt that they lacked this source of support. For example, RP10 noted: “I need the support greatly. Like I said, nobody knows what you’re going through unless they are a parent of a special needs child…and they can connect with you in that way and understand it.” Also, other parents felt that the most useful advice would come from somebody with actual day to day experience raising a child with ASD. They reported that even family and professionals were limited in the practical advice that they could give because they lacked the daily lived experience of managing a child with autism.

For example, RP8 mentioned the limited helpfulness of conversations with family
members when she was feeling stressed or having a bad day. She noted that “[I find it] a little helpful but not a whole lot because they don’t understand some of the things about autism. They give me basic advice but some things they can’t really help me with.” Similarly, RP9, a referred parent noted that while professionals were a valuable resource in helping her cope, they were of limited help with addressing issues in day to day home life. She explained how this perceived gap drove her P2P help-seeking:

On the professional side [they] kind of let me know what to expect...but nothing like at home...How do I continue to do what they do for him at daycare and keep it easy going and smooth? How do I talk to the older siblings and let them understand?.. So how do I incorporate what I’m learning to help them I guess, for the family as a whole I guess is what I’m looking for …And that’s kinda what I’m looking for in a support parent.

**Summary: Context for Help Seeking**

Referred parents experienced difficulty in coping with acute and ASD related stressors. Their perceived difficulty arose from a sense of inadequate coping resources to tackle problems related to caring for a child with ASD. Some of these problems were pragmatic issues such as children’s behaviors and finding services. Other problems included dealing with others’ reactions to them and their children, and their distressing emotional reactions to these problems. Two prominent and consistent themes arose from the interviews. First, referred parents felt that they lacked support from someone who had lived experience with ASD. Second, they came to the P2P relationship believing that only another parent of a child with ASD could truly understand what they were going through without judging them, provide information that including tips for
everyday living that was most likely to be helpful, and social interaction for themselves and their children that was normalizing and non-stigmatizing.

**Part II: Type of Support Sought**

Referred parents primarily sought emotional and informational support, though a few sought social companionship support for themselves or their children.

**Emotional Support**

Parents sought help to deal with emotional reactions to the diagnosis and caring for a child with ASD including anxiety, fear, feelings of being alone, and shock. They also sought hope that their children’s situations would improve, an outlet to vent, and empathetic understanding. Given that almost all parents mentioned that they lacked persons who could truly understand what they were going through and feeling alone, it was not surprising that many referred parents sought an empathic listener to whom they could vent and who could truly identify with their experiences.

**Informational Support**

Parents sought two different types of information. First, they sought information for problem solving, including tips and suggestions for general coping, handling specific problematic behaviors of their children, dealing with service systems, and identifying services and resources.

I had so many questions on how to help him overcome some of his battles, or if they can be overcome and how to kinda deal with the schools…I would like a parent sponsor just to kinda of guide me and show me the ropes. (RP2, referred parent)
Parents also sought advice about dealing with immediate and extended family’s reactions to ASD, particularly family members who were unwilling to accept the diagnosis and often did not support the referred parents’ efforts to get help and/or make accommodations for the child. Second, parents sought information to help them know what to expect as their children developed and as they were begin receiving services.

Social Companionship Support

A few referred parents sought social companionship support in the form of face to face social interaction with similar parents and children with the hope of companionship for themselves and children and recreation for their children through play dates, although the P2P program was not intended to provide this type of support.

In response to my query about her reason for asking for a support parent, RP4 reported:

[I’m ] basically [seeking], some interaction with other people with other kids with autism… [with] other parents who go through the same thing I go through. I have all of my family, and I love them dearly…[but] they all have kids …and they are all very normal and athletic and computer geeks and my son doesn’t do all that (laughing)… it’s kinda hard to swallow sometimes. So it’s been nice to talk to people whose kids are like mine.

Referred parents looked forward to social interaction with similar parents and children as it provided an atmosphere where they were not being looked down on or blamed because of their children's unusual or acting out behavior. It also provided an opportunity to feel normal rather than being abnormal. Interestingly, some parents sought social interaction as an intervention to improve their children’s behavior rather than for recreation or companionship. They hoped that the interaction would be an
opportunity for their children to practice or improve social skills and even functional speech by modeling the support parent’s child.

Other parents sought help with getting linked to and integrated into the ASD and wider disability community. They hoped the support parent would be a bridge to help them form social ties for themselves and their children with similar families. This was the case for RP7, who had for several years dealt with ASD by staying outside of the ASD and the disability community.

Summary: Type of Support Sought

Parents sought emotional, informational and social companionship support to address perceived gaps in these areas. As will be discussed in chapter five, parents’ reasons for seeking help affected their expectations about P2P and would be important in their assessments of the helpfulness of P2P as they valued the help received relative to their expectations being met. Also, needs arising from perceived gaps in coping resources partly drove the duration of the P2P relationship because as needs were met whether in the P2P relationship or outside of it, there was a tendency to end the relationship unless matched pairs developed a friendship.
CHAPTER 5

FINDINGS: BENEFITS, FACTORS, AFFECTING HELPFULNESS OF P2P AND CHANGES IN RELATIONSHIPS OVER TIME

This study sought to answer three research questions:

a) How, if at all, do P2P matches benefit referred parents of children with ASD?

b) What factors promote or inhibit beneficial outcomes for referred parents from the perspectives of referred parents, support parents and program staff?

c) How do P2P relationships change over time?

This chapter is organized into three parts:

Part I: Benefits of P2P

Part II: Barriers and facilitators of beneficial outcomes

Part III: Changes in relationships over time.

Part I: Benefits of P2P

Referred parents who had, at least, one contact with their support parent reported some benefit from P2P. Although for a few some benefits were negligible or they did not get some of their needs met. Participants primarily reported emotional and practical/informational benefits consistent with these being the largely the types of help that they sought during their match. A few parents reported social benefits.
**Emotional Benefits**

Emotional benefits included feeling heard, understood, validated, and catharsis. Other benefits included increased hope, security in knowing help is available, and decreased emotional distress and a reduced sense of isolation. For some parents, the benefit was the normalizing of intense emotional reactions that are typical of grief reactions. When referred parents compared their reactions to those of their support parents, they came to realize that the reactions were normal such as was mentioned by RP1, whose son had been diagnosed for about two weeks before our first interview:

But just getting a diagnosis was kind of shocking for me and then for her to kind of come in and tell me that it’s okay to feel this way, it’s okay to be angry, it’s okay to be upset… that helps because you don’t know what to do, you don’t know how to react.

Similarly SP4, a current support parent, talked about how her own support parent helped her deal with feelings of guilt that she had by normalizing her feelings and also through reframing:

It [talking to the support parent] helps you realize [and] know you’re not the only one and sometimes if you are feeling guilty and stuff [that] there’s nothing wrong with you feeling guilty or, just, you know, you don’t dislike your child, you just dislike the situation and things you have to deal with.

Referred parents also found the opportunity to vent their emotions freely without judgment to be cathartic:

When I first talked to my support parent, like I said when she called me I was so overwhelmed, I was just crying, and crying, and crying, and before I realized it I
had just gotten everything that had been bottled up that I had been carrying, she just let me regurgitate all my feelings to her (SP11, current support parent and former referred parent)

**Security knowing help is available.** A benefit of P2P was the assurance of dependable support, that is, the referred parents’ sense of security that their support parents would be available if they needed to call on them. As RP7, a referred parent noted, “just knowing that she’s there, that alone is enough support to know that, you know if it gets tough that I can call her or text her”.

**Reduced sense of isolation.** As a result of their interaction with the support parents, referred parents felt comforted knowing that they were no longer alone in their experiences. As support parents shared their own ASD related experiences and about their connections, referred parents came to know that there was a community of similar others, leading them to feel a sense of connectedness and social belonging:

I think it’s good to know that I’m not alone, you know, that there’s other parents with children who have similarities to mine, you know, not every kid plays all the sports and has five thousand friends (RP3, referred parent).

**Hope.** Referred parents gained hope that short-term and long-term outcomes for their children, themselves and their family could be much better than they had envisioned. This came through hearing their support parents’ stories of improvement in their children’s functioning with similar problems that they were now struggling with:

She was talking to me about how her son Harry…when he first entered school and how he was…but he’s putting together sentences and words… and that’s all
I could ever ask for, for my son, for him to be able to functionally speak and so her good fortune to me is something to hope for. (RP9, referred parent)

Parents spoke about how hearing stories about other children changed their perceptions of their situation from being intractable to one that they could cope with or address. Their interactions with their support parents not only led to a change in their evaluation of stressful situations but in some cases averted particular actions that they were considering. For example, RP5, a referred parent, considered removing her daughter from public school but after speaking with her support parent changed her mind because she learned of services in the public school that could address her concerns. This new knowledge of available resources led to a change in how RP5 evaluated the situation, that is, from something in which her daughter would be unable to thrive academically to one where she could improve once she had appropriate services:

Well, the reason I say it [talking to the support parent] was helpful is because I was considering taking my daughter out of public school … Talking with her [the support parent] just kind of encouraged me to just try to fight it out a little longer … [I felt encouraged by] just her telling me that there were things that I could ask for from the school system, and I didn’t know that. I wasn’t aware of that.

Other referred parents saw future visions for their children that they had not previously thought were possible. These new visions came through comparing their children to their support parents’ children or to other children whom they came to know of through their support parent. For example, RP7, whose support parent encouraged her to visit
ASD related websites, read stories of children with ASD who were living on their own, in college and intimate relationships which expanded her ideas of what she thought would be possible for children:

It helped me to see that even though this girl had this disability … she is on her own … she is actually engaged to this guy… but I saw that they actually do have a life when they grow up! And that is something that worries me a lot… what kind of life will my children have?… And then when I saw that with her it gave me hope ….that maybe their future is not so dim… I am always saying that my kids will be with me for the rest of their lives but they may actually want to have a life outside of their mother (laughter).

From the websites that her support parent shared with her, RP7 also saw where similar parents were actively involved in advocacy to help provide supports for their children as adults and independent living. This expanded vision led her to transform her parenting philosophy from one of sheltering her children and avoiding the disability community to actually publicly identifying her children as having ASD and herself as a parent of children with ASD. It also led her actually to have her children interact with similar children and to become involved in the disability community by attending and taking her children to ASD and disability related events, and through advocacy as she illustrated below:

I sent him [the organizer of an online ASD parent page] pictures, and he used those pictures and put [them up] and made banners with my children. That to me, you know, [is] something I would not have been able to do had I not had the opportunity to talk to her [the support parent]. I would not have thought that
“hey, it’s okay...yes, I am the mother of a child with autism and it is okay”…She just kind of gave me the push, the nudge, the okay, to be okay with it.

**Informational Benefits**

Informational benefits included tips/suggestions for general coping, handling children’s problematic behaviors, dealing with service systems, and information on services and resources and what to expect. It also included having parental expertise as a second opinion.

**Information on resources and practical tips.** Referred parents reporting receiving helpful information on resources and insider tips on addressing children’s needs and navigating service systems. Particularly valuable were information and insider insight on accessing resources- tricks of the trade-, for example, RP10, a referred parent noted how she gained valuable information on “hidden” services for which her son was eligible:

Well, she [the support parent] said, “…have you went to the social security office? Do you know about guardianship, when he’s 18?” And she said you need to start preparing for that now… he can get benefits now… I just didn’t realize there was so much out there that was offered to him…She said a lot of parents don’t know until someone tells them.

Referred parents learned useful tips to balance caregiving, treatment demands and their other commitments as noted by RP11, a single parent who worked full time and had three other young children:

She just told me about her day to day routine and things that she has found helpful…Well most days she gets up thirty minutes or hour before her kids get
up so she can have a little bit of time to herself to plan her day and then she
mentioned about spending individual time with as much as possible but with
each of the kids

Some of the tips also included how to be assertive and/or advocate for themselves when
dealing with service providers or other family members. As a result referred parents
were able to better balance competing demands as noted by referred parents RP9 and
RP12:

   Whatever the therapist said, I did, even though sometimes it wasn’t convenient
for me, and so she kind of told me just have a voice, if you feel like that’s not a
good time, or you can’t do it or for whatever reason, just let them know, and so
I’ve been speaking more with my therapist…and they’ve been working
wonderful with us (RP9).

She asked what you do if you’re studying and the kids are around you. I told her
that I just put my books up. She said you are gonna have to learn how to
sacrifice …My grade at that point was 88%. So I took what she said into
consideration, learning to sacrifice…I would close my door and lock it and make
them cry and bang as long as no one is hurt, bleeding or hungry. I’m learning to
tolerate the noise and since that my grade is at 92.82%. (RP12)

Referred parents also learned tips to help them improve their spouses’ and other
children’s understanding of and acceptance that their child or sibling had ASD:

   She shared with me some things that she told her older kids about her son like to
get them involved. Like “he doesn’t quite understand when it’s appropriate or
not appropriate …we know what he wants and try to help him be independent
but at the same time just understand that he is different and he sees things a lot different from we see them” [and] she said it has worked well. (RP11)

Parents also received tips to change or manage children’s problematic behaviors. These tips were strategies that the support parent had used to change or manage their children’s behavior. Referred parents considered the tips to be helpful information because it came from someone who had experienced success with a child who had similar behaviors to their own children. These included tips to manage problematic behaviors such as, hyperactivity, running away and temper tantrums:

We did talk about the temper tantrums and she said she does a lot of taking things away like if he misbehaves or doesn’t do what he’s supposed to do she will actually take toys from him so that was something, and also time out which I have not done with my son so that was very helpful. (RP11)

Referred parents also received tips to encourage positive behaviors such as speaking, potty training, and being sociable. For example, RP3 reported that she learned tips to improve her son’s social interaction: “She gave me some helpful advice on some things to try with him, like role-playing and stuff like that, so it’s been helpful.”

**P2P as a second opinion.** Referred parents found and used their support parent as a valuable resource to test and evaluate the opinions, recommendations, and practices of professional service providers. This was particularly useful when they had apprehensions and nagging discomfort about experts’ recommendations or how services were being delivered to children. Referred parents made comparisons between what professionals said, their own feelings and their support parents’ feedback, using it as a way to evaluate if their reactions to what professionals were doing were valid. For
example, RP9, a referred parent was uncomfortable with and questioned her ABA therapist’s advice not to make toilet training a current priority for her three year old son who had not yet been toilet trained. This advice seemed inappropriate and unwise to her as a mother since her other children had been trained by that age and she solicited her support parent feedback. She was able to accept that the therapist’s suggestion was valid and appropriate because it concurred with her support parents’ lived experience:

I shared with her my struggle with potty training my son, and then she was explaining that her son was five before he was completely potty trained…so I guess it’s kind of confirmation for me because the ABA therapist was telling me don’t think about that right now, that’s not something he’s going to be able to do right now and as a mother of 4 and all of my other kids being potty trained before age 3, I’m thinking well he should be able to do it too and when she told me how old her son was then[when he became potty trained] it kind of was just confirmation that hey, that’s not the biggest battle right now.

Social Benefits

Referred parents derived social benefits, specifically friendship, non-stigmatizing social interaction for themselves and their children, and linkages to other supportive networks and particularly to ASD and disability community. SP4, a support parent, mentioned companionship for herself and non-stigmatizing play dates for her son as a benefit of the relationship with her own support parent:

Sometimes you can become friends, and, you know, if you meet a support parent that has a child the same age…you could go out together. Both your kids could become friends and have somebody to play with without worrying about other
people staring, or thinking something’s wrong with your child, or you’re not a good parent. (SP4, support parent and former referred parent)

Through support parents, the referred parent became connected to the ASD and the disability community, forming relationships with other parents in person or virtually through being introduced to online support forums and parent advocacy groups. As M3, a P2P staff member, noted about her support parent, “My match was really good. She was able to connect me with actually some other parents and get me started in attending like a mom’s group.” Similarly, through adopting support parents’ suggestions referred parents’ children became connected to other children in the ASD and disability community as was the case for RP7:

Darlene also mentioned to me about the Monkey Joes on the fourth Wednesday night of every month that they have for special needs children there, and so I said that was another thing that I said OK, I’m gonna start with my son…I’m gonna let him go so he can feel comfortable with who he’s with. And he went, and he had a ball! So I think the little bits and pieces that she had to offer and the information she had to give and I took it, and I tried it and it’s just working for me.

Summary: P2P Benefits

Referred parents derived informational, emotional and social benefits from their match to a support parent. Swapping stories with and receiving information from an experienced parent enhanced their coping with ASD-related stressors in several ways. First, parents were able to release pent up emotions freely and to share their struggles while feeling understood without being judged. Second, parents gained information,
links to resources, and practical tips to directly address problems. In the context of the wide variation of ASD symptomology, multiple solutions, and opinions about how to intervene, referred parents valued and considered the suggestions of support parents helpful and credible since they had experienced success with their own children. By conducting social comparisons with their support parents’ situations and children, referred parents often reappraised ASD related stressors as less threatening either by seeing them as normative, amenable to improvement, or less severe. These reappraisals helped parents deal with emotional reactions such as anxiety and isolation. Finally, opportunities for face-to-face interactions with support parents and their children provided social companionship that was non-stigmatizing and a sense of normalcy.

**Part II: Facilitators and Barriers of Beneficial Outcomes**

Although referred parents who had, at least, had contact largely reported benefiting from P2P, some parents had unmet needs or found the match to be largely unhelpful. Respondents identified six interrelated factors associated with the referred parent, the support parent, the interaction between both, and program processes that affected various aspects of the helping process and subsequently the helpfulness of the match. These factors included: a) relationship program level; b) program level; c) support parents’ experiences with P2P and in the disability community; d) practical/logistical issues; e) psycho-emotional issues; and f) congruence in referred parents’ needs and support parents’ and the P2P agency’s expectations for the type (s) of assistance the support parent should provide. These factors did not have isolated effects on the helpfulness of the relationship, but instead, they interacted with and reinforced the other factors over time and in the continuing phases of the relationship to
affect helpfulness. Among these six factors, relationship appeared to be the most important influence on the helpfulness of the match. Further, parents perceiving a sense of similarity (a subcategory of relationship) appeared to be the central process leading to a beneficial outcome. I used the term perceiving similarity because although parents could be objectively similar in many ways, it was the similarity related to referred parents’ need that both parents felt would make the match helpful. Also, although in every case these were actual or objective similarities, parents could only judge them as such based on their mutual disclosures.

The other factors affected helpfulness by facilitating or inhibiting the creation of a P2P relationship in which parents perceived similarity and/or conditions that enabled parents to use similarity to meet referred parents’ needs. These conditions included making contact, identifying referred parents’ needs, offering help that addressed or fit needs, and acceptance of help. In the following sections, I discuss how these six factors affected beneficial outcomes beginning with the relationship.

**Relationship**

Several relationship factors affected the helpfulness of P2P. These included: a) parents perceiving similarity and emotional connection between each other; b) support parents’ relational qualities, and c) referred parents’ relational qualities. The relationship factors were the most reported factors affecting helpfulness. They impacted helpfulness indirectly and directly. Of these factors, perceiving similarity was the central relationship factor affecting helpfulness. Parents feeling an emotional connection to each other was primarily a consequence of perceiving similarity. This encouraged parents to open up to each other during conversations and to maintain
contact. Even before making contact, matched pairs approached the match believing that a similar parent would be helpful. However, these beliefs would be confirmed or disconfirmed based on how parents interacted with each other and the content of the information they exchanged. Thus, the relational qualities were important to matched pairs perceiving similarity and using it to meet referred parents’ needs.

**Perceiving similarity and emotional connection.** Parents and program staff identified perceiving similarity as one of the most important factors that affected helpfulness of matches. Being similar was the most frequently mentioned facilitator of helpfulness. Perceiving similarity contributed to helpfulness by facilitating an emotional connection between parents and the credibility of the support parent both of which in turn encouraged referred parents’ openness. Most importantly, having similar characteristics and lived experience to the referred parent and her child gave the support parent the knowledge and characteristics to meet their match’s need. In fact, the support parent being knowledgeable was a frequently co-occurring code with perceiving similarity and was also reported by parents and staff as one of the most important facilitators of helpfulness. As will be discussed below, participants identified various kinds of similarities that were important to meeting specific types of needs.

Similarity could be at two levels: between children and between parents. Common to both parents in every match was that they had a child with ASD. Beyond that, the types of similarity at the child level affecting helpfulness that were most often mentioned were in symptomatology including those for comorbid conditions, behaviors, experiences, and functioning, age, and gender. While at the parent level, the types of similarity mentioned included social background (number of children, marital status,
and employment status), personality, interests, faith, parenting style, and attitude to and outlook on the disability.

Similarities affecting helpfulness. The areas of similarity that contributed to helpfulness depended on the type of support that the referred parent sought. For parents who were looking for general information such as the steps to apply for Medicaid and get on waiver lists, a similar diagnosis was sufficient to make the match helpful as certain experiences were common to all parents of children with ASD. For example, SP10 reported that she found her match with her support parent helpful “because they [the P2P staff] connected me with someone that had a child with either autism or high functioning [autism].” Although her support parent was of a different race and their children were different ages, she noted that these differences did not affect the helpfulness of the match, as she was seeking information on the diagnosis:

I wanted to get more information about my child’s diagnosis …The doctor pretty much gave me the diagnosis and just put you out there and say oh well this is what your child has, this is what you can do, and that’s all I knew. He told me to read a book, and the book wasn’t enough, I needed a personal touch. I needed to be in touch with somebody instead of reading a book.

When probed more she emphasized that anyone with a similar diagnosis would have been sufficient for her needs at that time.

Participants identified similarity in demographic characteristics of children and parents as facilitators of beneficial outcomes of P2P. The same or very close age was very important for those referred parents who were hoping to have play dates for their children. However, it was not a barrier to helpfulness when referred parents were
seeking a friendship or social interaction for themselves rather than their children as SP4B, a support parent explained about referred parents who had much younger children than her son:

The match prior to the one I just had, she had four little ones, they all were under the age of eight, so my son, he couldn’t really relate to them because he’s 15, but nevertheless, we [the parents] meet when we can and do little things, and it’s just like a stress reliever, like a hangout session with someone you can connect and we can talk about the quirks and everything that our kids have and actually understand what we’re talking about.

Age differences were also not important for parents whose children preferred friends who were much older than themselves.

Similarity in specific experiences and children’s functioning was important for referred parents looking for tips for particular problems or who wanted to know what to expect for their children’s future. For these referred parents, it was important that their support parents’ children had already gone through the pertinent experiences so that they would be able to share how they had coped, how to plan for the future, and how their children or situation had improved. For example, RP5, a referred parent spoke about how her concerns about whether a social skills program would work for her daughter was allayed because her support parent’s daughter had similar social skills issues and had positive experiences with the program:

She said her daughter went through the same program there, and she just raved about it how wonderful it was, so that was encouraging. So, the social skills issue and the issues with inattentiveness (cause my daughter also has ADD) she
said her daughter went through that also… [and] the therapy group that she’s
gonna be in, she’s gonna be the only girl…and I didn’t know how that would
work, but she said it was the same way for her daughter, her daughter was the
only girl. But, she said it worked out just fine

Although support parents of children of the same age who had been diagnosed with
ASD earlier than the referred parents’ children were helpful, as was the case for RP5,
usually similarity in lived experience and, therefore, helpfulness was facilitated by
being matched to a parent of an older child. Typically, an older child was diagnosed for
a longer period than the referred parent’s child and had therefore gone through
experiences with which the referred parent was now grappling. For example, RP3,
whose support parent’s son was three years older, identified the similarity in behaviors
and older age as the reasons she found the match helpful:

  Every time I’ve talked to her I’ve felt like I had something in common with her
  because her son has a lot of the same characteristics as my son and then since
  he’s a little older she gave me some helpful advice on some things to try with
  him, like role-playing and stuff like that, so it’s been helpful.

The similarity in lived experiences pertaining to children’s behavior and functioning
gave the support parent knowledge to be able to meet their referred parents’
informational needs. Indeed, referred parents who got their information needs met,
frequently mentioned the support parent being knowledgeable as a facilitator of
helpfulness. For example, RP10 illustrated how her support parent’s knowledge
derived from lived experience made their conversations helpful:
She knew so much information that I didn’t know! She pointed me in the right direction of what to do ...She knows what to do. She has done it. She has the experience in it, and that was a major plus from the conversation.

Similarity in lived experience also facilitated meeting referred parents’ need to have an empathic listener. As noted by support parent, SP6, similarity in experience enabled parents to identify with and disclose aspects of their own situation that communicated that they truly understood the referred parent’s concerns:

I think part of what might have been helpful is she would mention something about Nigel, and I could relate instantly. She would say, “Oh, he’s very active”, and so I would say something about Harry, and she would say, “Oh that’s him exactly!” So maybe it helped her just to have someone else who could understand.

Beyond similarity in experiences caring for their children, parents also mentioned similarities at the parent level such as marital status, financial circumstances and family structure as factors contributing to the helpfulness of the P2P relationship. These parent level similarities were important because they added a nuanced level of complexity, and sometimes additional difficulty, to referred parents’ concerns.

Participants reported that coping with ASD related stressors was somewhat qualitatively different for single parents versus those living with a partner as the former had less caregiving help. Balancing the caregiving and treatment demands with other responsibilities was also more difficult for parents with one or no additional children compared to those who had multiple children. Therefore, similarity in these demographic factors gave support parents a more holistic understanding of their
referred parents’ concerns and practical experience in addressing them within a particular context. For example, SP11 and RP11 identified similarities in their family structure and circumstances along with children’s experiences as important facilitators of helpfulness:

[I felt I was most helpful] to my second referred parent. I only say that because she was as overwhelmed as I was… So I think because we were in the same boat that’s what made us click… We were in the same boat when it came to money… She didn’t have a significant other; I didn’t have a significant other… our children were doing the same thing. (SP11, support parent)

She was very open and very helpful to me…I would definitely think she can relate because we both have a lot of children and just managing that in itself. I guess if I was talking to someone who had just one child I don’t think we could relate as much, I’m sure I could learn a lot from that person but just the balance of juggling, of having other children just makes it that much more difficult so that’s why I feel like she can relate more and have more tips for me. (RP11, referred parent)

Other referred parents spoke about how similar parental longings in addition to similarity in children’s experiences, made the stories support parents shared helpful. For example, RP9 shared how she was encouraged by one of her support parent’s stories because of the similarities in their children’s functioning and their own dreams for improvement in speech:

She was talking about how the only thing she wanted for Christmas was for her son to say, mommy…and she said the first thing when they woke up that
morning was he said mommy to her… And so I was telling her you know I had the same kind of dreams… I have that same urgency in wanting to hear those things from him…Her son’s like mine: he kind of lost language…It really made me feel good because I know that there is hope for him. (RP9, referred parent)

Another similarity at the parent level that contributed to helpfulness was geographic location. Program staff and support parents reported that when support parents lived in the same county and more so in the same school district, they were usually able to meet referred parents’ information needs for local resources.

Referred and support parents also mentioned similarities in personality, interests, faith, parenting style, and that contributed to the helpfulness of their match. Some support parents reported that when there was a similarity in religious faith and parenting style, this made it easier for them to draw upon their experiences to offer assistance that their referred parents could identify with and found acceptable. These similarities along with those in personality, interests, and outlook on the disability, also helped to develop rapport and sense of closeness, enhancing both parents’ interest and engagement in the match. Together these, in turn, encouraged mutual openness and maintaining contact, both of which were critical to help-seeking and help provision.

Differences affecting helpfulness. On the other hand, all three participant groups reported that some perceived differences were a barrier to the helpfulness of matches. These included differences in children’s symptoms, functioning, treatment, age, gender, and parents’ demographic characteristics – physical location, cultural background, race/ethnicity and socio-economic level.
Participants mentioned differences in children’s symptoms, functioning and experiences with treatment and services as a barrier to meeting referred parents’ information needs for practical tips, what to expect with treatment providers and how their child might respond to treatment. It was also a barrier to providing referred parents with emotional support in the form of feeling understood with respect to children’s experiences. These differences often left the support parent without the knowledge needed to provide support to meet these foregoing needs. Program staff who conducted follow-ups reported that differences in children’s circumstances including functioning and symptoms was one of the reasons referred parents gave at follow-up for why their match was unhelpful:

Sometimes it’s just they didn’t feel like they had a whole lot in common …They could be on opposite ends of the spectrum, and so they didn’t really have a lot in common and it wasn’t really that helpful to them to talk to that person. (F1, P2P staff)

Similarly, support parents reported that they were unable to help in these areas of difference as they lacked experiential knowledge. For example, SP4 explained: “because my son is high functioning…he’s never had to take medication, he’s never had psychological problems…I don’t know what to tell her cause I’ve never been in those situations”. For other parents, it was a difference in the use of treatment approaches rather than children’s functioning that was a barrier to helpfulness. In these cases, referred parents wanted information on experiences and efficacy of treatments as was the case of SP6 who reflected on why she did not find her support parent helpful:
She just seemed like she had not really tried anything outside of just traditional [things] like pre-school speech therapy type things...I thought that she would be more resourceful... but she just didn’t seem to be knowledgeable about any of the stuff that I was trying with Harry.

Differences in children’s ages were a barrier to meeting parents’ needs for play dates for their children. When children were not same or very close age, referred parents were often dissatisfied with the match and often requested a re-match as they felt that the gap in development would not make the support parent’s child an appropriate playmate. Similarly, program staff reported that for parents who were looking for play dates or support around puberty, that age difference was frequently a reason for requesting a re-match. Program staff also reported that younger age of the support parent’s child was a barrier to meeting referred parents’ informational needs for practical tips and what to expect as children developed and a listener who could understand their experiences as this often meant support parents did not have lived experiences to share with the referred parent.

Program staff mentioned that different gender could be a barrier to meet support needs and desires for play dates for adolescents. However, this did not come up in the interviews for the matches I followed or in relation to study participants’ previous matches.

Differences in children’s functioning and experiences were not always a barrier for meeting referred parents’ informational and emotional needs. Support parents could sometimes provide practical tips and empathy based on knowledge that came from their exposure in the ASD and wider disability community, thereby compensating for
personal lived experience. For example, M3, a P2P staff found her match helpful, although her support parent’s child was low functioning while hers was high functioning, she still found her to be knowledgeable:

Our children were definitely different…but I think she was a real outstanding support parent that knew exactly the right thing to say at the right time and sort of what to suggest next…It’s the parent that makes a difference more so than the similarities of your child …like the level of knowledge of the parent…or how good of a listener they are and those kinds of things matter more …I didn’t need necessarily her to say “oh my child does the exact same thing,” just for her to be able to say, oh my child does this, but it reminds me of this, or whatever, she was able to relate it back to my situation.

There were mixed opinions on whether particular demographic differences between parents were a barrier to helpfulness. For the matches that I followed, racial differences did not appear to be a barrier to helpfulness at least as was mentioned by referred parents:

For me personally, it doesn’t matter if she’s Black or White… I can talk to anybody. I just love meeting people and talking to people, but that doesn’t make a difference to me. Now when you’re going to some places, a support group, you would like to think that you’re not the only one [that is Black]. (RP7, referred parent)

It is not clear if this would have been different if matched pairs met. Only one racially different matched pair had met, and while the referred parent speculated whether her support parent’s seeming loss of interest could have been due to their racial difference,
she was not sure and offered other possible reasons. Also, there was not enough data to support this.

Program staff and support parents reported that racial differences did not seem to impact the helpfulness of matches. However, one support parent, SP7, explained that racial differences affected how she interpreted and judged her referred parent’s parenting style initially, but it did not affect the overall helpfulness of the match as she was able to realize that it was different rather than deficient. This realization enabled her to adjust her responses so that she could be helpful in a way that honored and accommodated her referred parent’s parenting style:

I think just some of her [parenting] approaches to things were a little bit different… that maybe was not what I would have been exposed to growing up… I think it confused me a little bit, and I think it might have caused me to in those moments to maybe erroneously misjudge her or some of her parenting skills… [But once I understood it] I think I was able just to listen differently and to try to take that parenting style into consideration when I did make suggestions, and I tried not to impose my own parenting style or beliefs on her, like I made a more conscious effort not to do that.

So at least, from SP7’s match, it appeared that how support parents responded to differences may have been more important than the differences themselves.

When it came to socioeconomic differences, program staff largely felt that these differences did not undermine the helpfulness of the match as noted by F1, who conducted follow-ups:
I haven’t seen where it makes much of a difference … It doesn’t matter what social class you’re in or what race you’re in. You’re still dealing with a lot of the same issues with your child that has that disability.

However, differences in social background, particularly economic and cultural ones, could create awkward moments though not have a detrimental effect on helpfulness or could lead the support parent to offer suggestions that the referred parent would find culturally inappropriate and unlikely to accept as M3, a matching coordinator illustrated:

I had someone call and say, you know we invited them to go to the movies with us and they couldn’t afford to go and it was an awkward situation … Or if a parent said, oh I tried such and such therapy that worked wonders for my child but the other family maybe doesn’t have insurance that covers it or can’t afford it, something like that could be a sticking point too. Or you have cultural differences where someone might say oh I tried this with my child… and the other person’s going, “what is that? That sounds freakish!”

All three participant groups mentioned that differences in parents’ physical location were a barrier to helpfulness depending on the referred parent’s needs. Program staff and support parents reported that differences in counties and school districts were a barrier to meeting needs for information on local resources. While all three groups mentioned that it was a barrier for parents who wanted play dates for their children or a face to face friendship for themselves.

*Emotional connection between parents.* All three groups of participants identified the emotional connection between parents as a factor that influenced
helpfulness of the match indirectly. Feeling connected involved an interpersonal attraction where parents felt that they enjoyed the other person’s company, found the conversation interesting and easily flowing or felt a bond or close to their match. This interpersonal attraction largely had its basis in parents perceiving similarity at the parent and/or child level. Emotional connection also developed as a result of mutual openness of both parents and then encouraged further openness especially of the referred parent. As mentioned earlier, feeling connected was an important influence on encouraging referred parents’ openness which enabled support parents to identify needs, know what type of help to offer and what aspects of their story to judiciously disclose. Without this disclosure support parents were unable to meet their matches’ needs. Emotional connection also affected helpfulness by sustaining contact between matched pairs because they felt that conversations would be interesting, easy and helpful as SP6 shared in her interview following her first conversation with her referred parent:

I think we had a connection. I think a connection means our personalities can kind of go together…[we] have a little bit of a same perspective on how we’re approaching having a child with special needs … it was just a, hey, I think that we could get together and have coffee, we’d have enough to talk about…we have enough of a similar personality that this relationship could be about more than a child with special needs.

Deeper levels of emotional connection seemed to be especially important to meeting emotional support, friendship and social companionship needs of parents. Emotional connection characterized by a sense of closeness was vital for those parents who were seeking a friendship with another parent and someone with whom to share
their struggles and vent frustrations. However, it was not as important for parents who were more focused on learning practical tips or acquiring information. It enhanced helpfulness of P2P in that a sense of closeness encouraged both parents to open up to each other. This exchange of information allowed support parents to identify the referred parents’ needs and provide information that was practically useful. However, it was not always necessary for a match to be helpful as M1, a matching coordinator, explained:

I would think that might be like an advantage [to getting your needs met]…I think that’s just the icing on the cake if that happens. Obviously it seems like the closer they feel they may open up and share more, but [Interviewer: But it’s not necessary?]. No I wouldn’t think it would have to be.

Conversely, when referred parents felt that the emotional connection was lacking or insufficient they concluded that the match would not work as noted by RP6:

So I don’t wanna to talk to someone who just talking because you ask a question …I want to see if you connect. If we don’t really connect, well that conversation definitely, you won’t be going too far…It will be like two strangers meeting again and again …The conversation has to be flowing. If it ain’t flowing, you know it’s just gonna be hard to sit down and get a conversation going. (RP6, referred parent)

Further, some referred parents asked to be re-matched to another parent because of perceiving an inadequate level of emotional connection as was the case of RP10:

It’s just like, you know how you get on the phone with a person and you just
don’t know what to say?... [And then] my hunch was to call and see if I could get [another support parent]. Not everybody’s gonna get along, not everybody’s gonna be compatible. …It’s not like I don’t like her or anything. It’s just that I feel like I need a deeper connection with another parent.

Also, program staff reported that often satisfaction with the match was a function of the level of connection that the referred felt with their support parent. This was illustrated by F1, who conducted follow-up of matches, as she responded to my question on the reasons for referred parents’ feeling satisfied with their match:

I guess it’s the level of connection they had with the person supporting them…Like an emotional connection, I guess you could say, to where the person receiving the support feels that there’s finally someone that understands what they’re going through; that they’re not out there alone.

While perceiving similarity and feeling emotionally connected were characteristics of the matched pairs’ relationship that affected helpfulness, both parent’s relational qualities contributed to building a sense of similarity and emotional connection. Also, each parent’s relational qualities tended to have reciprocal effects on each other’s responses to the other, maintaining contact and engagement in the relationship.

**Support parents’ relational qualities.** Support parents’ relational qualities that affected helpfulness included genuineness and trustworthiness, personality or disposition, active listening, and openness. The qualities also included how they verbally responded to the referred parents’ communications, namely being non-judgmental, empathic, non-directive and honest. Overall, the support parents’ relational qualities affected helpfulness indirectly through inhibiting or encouraging referred
parents’ openness and engagement in conversations and maintaining contact. Some qualities also affected helpfulness directly (e.g., active listening) by being a type of support.

**Genuineness and trustworthiness.** Genuineness involved the referred parents' perception that the support parent had a sincere desire to help them, cared about them and their children and was interested in a P2P relationship. Referred parents reported it as an important factor influencing the helpfulness of the relationship as it encouraged them to open up to and ask their support parent for help. For example, RP7, a referred parent, spoke about how her support parent being a parent of a child of ASD was not sufficient for her to engage in and find the P2P process helpful. She felt that genuineness was imperative:

> It [has to be] someone I feel that genuinely cares, and not just doing it just because you were asked to do this, but you genuinely do care and understand...

> So not just anyone. If I don’t feel I connect with you, I’ll know that the first time that I talk to you and so no, we’re not gonna get any farther.

**Gauging genuineness.** Parents gauged genuineness using various indicators including support parents’ expression and/or demonstration of concern and compassion towards themselves, their children and other families in general as illustrated below:

> She was truly concerned because she got down on the floor to play with my children, and with Tyson [child with ASD] people don’t do that....This is the very first time I met her. (SP11, support parent and former referred parent)
I think she’s just open-hearted…She’s a support parent for other parents as well, so I think she’s out to help a lot of people. But she said, "There’s help, the minute I heard you crying on my phone I knew I needed to call you first”. So, I think that she is a very caring person. (RP4B, referred parent)

Support parents’ attention to ensuring that they made the referred parent’s needs and comfort a priority during their conversations was seen as an indicator of genuineness. As illustrated by RP7, this was accomplished through listening and allowing referred parents to disclose as they felt comfortable:

She has gentleness about her in the way that she speaks. She’s one that pauses and actually lets you talk and not just over talk you and just trying to make sure they’re heard… She can tell if you get uncomfortable to back away from that and give you a minute to say what you want to say and what you don’t want to say. She does not push… She knows when to talk and when not to talk.

For other referred parents, the support parent’s expressing a desire to meet and/or have their children meet was an indicator of sincere interest in providing support via the P2P relationship. A related indicator of genuineness was the support parent offering open availability to talk as needed and about anything, as noted by referred parent, RP9:

She’s there to help…She said you can call me anytime… [and] she kind of went over her schedule…she was like, if you ever need to call, if you ever need to talk, if you ever just want to tell somebody about something great that you think was wonderful just give me a call and we’ll share it together.

Referred parents’ gauging of their support parents’ genuineness was an ongoing process. When referred parents perceived that their support parent was no longer
interested in a relationship, they asked for a rematch or gradually disengaged from the relationship.

In addition to genuineness, the support parent’s trustworthiness was important to facilitating the referred parents’ engagement in the relationship and subsequently beneficial outcomes. As illustrated by RP7, referred parents judged the support parents’ trustworthiness based on their dependability:

One of the biggest things that I do like about her is that she follows through… and that is crucial for me in developing any kind of relationship with anybody because I don’t trust well, and people have this tendency of not following through.

Disposition and personality. Referred parents mentioned several support parent characteristics including a congenial disposition (“nice”, “friendly”), being extroverted, humorous, lighthearted and positive that developed rapport and made them feel relaxed and comfortable opening up to the support parent about their experiences and asking questions. Being positive referred to the support parent sharing ways in which their children’s functioning had improved. Also, to encouraging the referred parent to open up, being positive was also directly helpful by providing hope for improvement in the referred parents’ situation.
Active Listening. All three types of participants identified active listening as a factor influencing helpfulness. Support parents reported that it facilitated P2P’s helpfulness by giving referred parents the opportunity to disclose. This in turn enabled support parents to identify referred parents’ needs and to offer or to link them to support that would match these needs. All three participants also mentioned that listening was directly helpful as a form of emotional support since referred parents often sought P2P because they felt that family, friends and others in their social circle who did not have a child with ASD did not understand their concerns. As a result, they felt that they did not have a non-judgmental and validating outlet to express and release their feelings. For example, SP11 shared how her own support parent’s listening provided her with emotional release of feelings she had suppressed:

Before I realized it I had just gotten everything that had been bottled up… She just let me regurgitate all my feelings to her and she never said, “I have to go” or “let me talk to you about something else” … She just listened.

Similarly, in response to my question about what parents of children with ASD mentioned as benefits of P2P, program staff reported that referred parents being able to share concerns with someone who understood their experiences was a positive outcome:

I think a lot of times parents they don’t feel like they can talk to their friends that have the typical children …being there to be that active listener is what I think has been so helpful for so many. (M1)

On the other hand, helpfulness was undermined when referred parents did not perceive that their support parents were listening to them. Program staff reported that
this was one of the reasons referred parents gave at follow-up for dissatisfaction with their match and wanting to be re-matched to a new support parent:

   I have had that where they felt like they’d like to be matched with someone else because their person [support parent], they didn’t feel like they listened to them at all, they just wanted to talk the whole time. (M1, P2P Staff).

**Support parents’ openness.** Both parents in the match identified support parents’ openness as an important factor affecting helpfulness of P2P. Being open meant talking about one’s life, children and experiences especially those related to ASD and affected the relationship and its subsequent impact on helpfulness in several ways. First, when support parents were open it encouraged referred parents also to be open by modeling that they could share intimate details of their lives with a stranger as illustrated below by matched pairs SP4B and RP4:

   I didn’t feel like she [my referred parent] had any qualms telling me about her son because I learned enough about him to feel like I know him personally already…. I felt like she felt comfortable enough after I told her enough about myself to feel comfortable enough to tell me what she felt was necessary for me to know. (SP4B, support parent)

Her referred parent, RP4, concurred that she felt “very comfortable” talking to SP4B. She attributed her comfort to her support parent’s openness, noting that it was easy to disclose because “[SP4] just talked about her son, she talked about schools problems, so we have a lot of things in common.” Thus, the support parent being open was the means through which they were able to communicate and create a sense of similarity. Other referred parents, such as RP9, were nervous about how the first conversation
would unfold and/or were initially uncomfortable but became relaxed and found communication easier as their support parents opened up about their experiences:

   It was a little awkward at first, but then once we started talking about her kids it was a lot easier…and she shared a lot of stories with me…. I was a little concerned about what type of person she would be or how she would I guess kind of share her stories…and she seemed to be very open about her experiences and you know I feel like she and I can communicate well with one another.

   Second, the support parent’s openness enabled the referred parent to assess their support parent’s credibility as a helper by showing if they had relevant experiences, sufficient similarity and willingness to share their knowledge to meet their needs. Referred parents assessed credibility using the disclosed information to make comparisons between themselves and their support parent and their children to see if there was a similarity in their experiences and background. When referred parents felt that the support parent was a credible helper, it encouraged them to open up to their support parent, be receptive to offers of assistance including implementing suggestions, and to continue the relationship. Third, the support parents’ disclosures themselves were often a direct benefit to their referred parents. Hearing the experiences of similar parents, gave referred parents hope for improved outcomes, normalized their struggles and distressing emotional reactions, and provided practical information on what might work and not work when addressing specific problems. It also reduced their sense of social isolation as they came to realize that there were other parents who had similar experiences.
Not every kind of openness facilitated helpfulness as discussed above. Only openness characterized by a judicious use of disclosure led to helpfulness. Judicious use of disclosure included sharing details that showed similarities between parents and children especially difficult experiences. These details were balanced with accounts of improvement, approaches that support parents used that were efficacious, and what is beautiful about the child with ASD. Support parents identified this type of disclosure as a factor contributing to them being helpful to their matches as illustrated by SP3 as she responded to my question about what has helped her to be an effective support parent:

I think first telling your story, coming from a commonality there and, first explaining who I am and where my child came from and where he is [now] … The first thing is to let them hear your story and where you are now so they can see that even though you might have struggled they hear your successes. And I think that that’s always encouraging.

Her referred parent, RP3, illustrated how this disclosure that highlighted points of similarity in struggles and successes led her to believe that SP3 would have useful knowledge to address her concerns about her son:

Her son’s story sounds pretty similar [to mine]… she’s been dealing with it since he was three years old and so I know that she’ll have a wealth of knowledge for me…She told me some things that have worked with her son as far as socially… She said that she had the same issue with her son, and she kept working with him and she would kind of role play with him … and that’s what she says has helped him.
Judicious disclosure also included balancing the amount of time the support parent spoke compared to the referred parent with the latter being given more conversational time and their concerns the primary focus:

I want to make sure with the parents I connect with that I give them lots of room to talk about their life…and just be someone who listens and can encourage them, instead of pouring out my problems. (SP6, support parent)

On the other hand, when support parents did not use disclosure judiciously it became a barrier to helpfulness. One unhelpful use of disclosure occurred when support parents primarily shared the negative aspects of their past and current story as this left referred parents feeling discouraged. Another unhelpful type of openness was when support parents’ disclosures constituted the majority of the conversational time, and they rather than the referred parent became the focus of the helping relationship. This led to the referred parents’ needs being unmet. Program staff reported that this was a complaint referred parents who were dissatisfied with their matches reported during follow-up: “Sometimes the support parent is putting her situation first, like talking too much about their own child and not listening enough about what the parent is saying” (MF2, P2P staff). Once the support parent was or became the focus of the conversation, referred parents did not find the interaction helpful. For example, SP7, a support parent spoke about how this undermined helpfulness in the relationship with her own support parent:

She helped me and she didn’t help me… The first few calls went pretty well, she just kinda wanted to check in to see if I needed any help and then it kinda almost turned round where I was giving as much or more support than she was giving
me. I appreciated it but thought after a while it was not working very well… I think she needed support as much as I did so it ended up kinda being more reciprocal… Initially, I was [receiving support] and then after a while I felt like I was providing more support than I was receiving.

Helpfulness was also undermined when support parents were not open or no longer being open. For example, RP10’s accounts showed how her match moved from being emotionally helpful when her support parent was open to being unhelpful when her support parent was no longer open. In the interview after her first conversation with her support parent she illustrated how her support parents’ disclosure about her daughter’s ASD enabled her to release pent up emotions about her son’s diagnosis:

I got emotional and usually I don’t do that with strangers…[but] I knew she understood me that’s why I relaxed enough to let myself go there for a while…

Interviewer: How did you know that she understood you? How did you know sense that?

RP10: She told me about her child being high functioning autism and all that.

However, in a later follow-up interview RP10 reported that by their second conversation, she began to feel that she could not confide in her support parent and, therefore, get her emotional needs met because her support parent had stopped being open:

She would answer my questions, but we weren’t like having a conversation. I mean it was more like, “yes,” “no,” “well call this number,” [but as] far as the personal touch – it wasn’t there… It was like we didn’t talk about our kids,
hardly or anything. I guess I’m the type of person that likes to talk to someone that’s a little bit more open.

**Nature of support parents’ verbal responses.** How support parents verbally responded to referred parents affected the helpfulness of P2P. Being non-judgmental, empathic, non-directive and honest were qualities that facilitated referred parents’ openness and engagement in the relationship.

**Being honest.** Honesty involved the support parent letting parents know when they did not know the answers to their questions. It also involved not giving referred parents false hopes for a cure or their children’s future. For example, SP11, a support parent, mentioned that an honest vision of what the future would be like for her and her son as one of the reasons that she found her support parent helpful:

She didn’t lie to me and tell me things were going to get better overnight. …

And because she told me to take one day at a time I think that’s what made her a good support parent… She didn’t give me hopeful dreams of something that might not of ever come to pass but no, “we have our good days, and we have our bad days and we just got to roll with the good and take the good with the bad”.

**Directiveness.** How support parent provided information or practical tips affected the helpfulness of P2P. When support parents were directive or “pushy” (i.e., telling referred parents what they should do) rather than presenting their ideas and choices they made as options, referred parents were likely to be unreceptive to their suggestions and more generally this led to poor rapport. Both support parents and program staff in their interviews emphasized being non-directive as an imperative. SP12, a support parent in reflecting on what affected how matched pairs got along over
phone described how being directive could negatively affect the relationship as it could make the referred parent feel that they were not being listened to or their agency, needs, and concerns have not been taken into consideration:

If you become too aggressive or a know it all parent then sometimes it lets the other person know that you could be a pusher, that you may force your ideas and beliefs on to them and that’s not what they need. They are trying to get someone to listen to them vent what they’re going through.

Similarly, RP4, a referred parent who requested a re-match shared in her follow-up interview that she preferred a more laid back style as she had been turned off by her first support parent’s directiveness:

I’m happy with the information [she gave me about another service provider] but don’t tell me to switch because you think one’s better than the other…She definitely had her opinions and was definitely not bashful at all [in expressing them], and I didn’t like that at all.

Empathy. Referred parents considered support parents’ responses that expressed concern, sympathy, or acknowledged difficulty as empathic. Identifying with referred parents’ feelings and situation by sharing a similar experience was also seen by referred parents as empathic. When support parents were perceived as empathic, this met the referred parents’ need to feel understood and have their emotional reactions validated. It also led to the continued disclosure of needs and venting. On the other hand, when referred parents did not perceive support parents as empathic they felt unsupported and became disengaged. Referred parents perceived responses that minimized their concerns and/or failed to reflect their feelings as not being empathic.
Summary of support parents’ relational skills. The support parents’ relational qualities impacted helpfulness of P2P indirectly by encouraging referred parents’ openness, continued engagement and acceptance of the help provided by their match. They also directly met referred parents’ needs through providing practical tips, hope, reducing social isolation, validation and normalization, and a non-judgmental and empathic outlet for venting. Referred parents were continually assessing the relational qualities of their support parents. The foregoing indirect and direct positive impacts on helpfulness tended to ensue when referred parents made judgments that these relational qualities were present. Conversely, when referred parents judged these qualities as being absent in their support parent, this undermined helpfulness as they rejected the help the support parent offered or ended contact.

Referred parents’ relational qualities. Support parents and program staff identified two relational qualities of the referred parent that affected the helpfulness of P2P: receptiveness and openness.

Referred Parents’ Receptiveness. When support parents felt that referred parents were receptive to their overtures and other types of support that they offered during the match, this spurred them to initiate additional contacts with their match, as support parent SP6 noted about her match: “She’s very receptive, and that makes it easy to continue the relationship.” Conversely, when they perceived the referred parent as unreceptive, they tended to stop calling and/or offering help to avoid being pushy and an imposition. Felt need for support made the timing right for referred parents to be receptive to their support parents overtures. RP9, a referred parent, for example, in response to my question about what made her match to her support parent helpful,
identified the timing when it was offered as an important factor to her receptiveness.

For RP9, because the diagnosis was new, she was grappling with new emotional reactions and decisions to make and so had felt she needed support:

> I think it was just the timing…if it wasn’t as soon as it was, I don’t know if I would have been as accepting, as susceptible to it because it was a new diagnosis for me… If it [P2P] would have come a year later, it would have been, “okay, I’ve already been there, done that, I get it.”

In addition to felt need, support parents being non-directive, genuine and trustworthy encouraged referred parents’ receptiveness.

Support parents frequently mentioned that they understood the busy lives of parents caring for a child with ASD and continually gauged receptiveness as a cue to help them manage their overtures to their referred parents.

*Gauging receptiveness.* Support parents’ gauged receptiveness using several indicators. One indicator that they mentioned frequently was referred parents’ giving feedback or asking follow-up questions about the support parents’ suggestions while one-sided conversations were an indicator of being un receptive as noted by SP12, a support parent:

> If I’m just doing all the talking and giving and giving and giving and they’re just listening and not really giving any feedback then that lets me know one: that they’re really not interested; and two: they’re not interested; and maybe the third option is I’m just way too busy for this but I will entertain it for a little while.

Support parents and program staff also saw the referred parents’ endorsing, expressing intent to, or acting upon their suggestions as indicators of their receptiveness,
particularly information that was critical to obtaining services for a child with

disabilities. Conversely, when referred parents did not seem to indicate interest in

learning about and acting upon information about essential services, support parents

saw this as being unreceptive:

Sometimes when you talk to them, they don’t seem to want the information that

you’re offering and/or they don’t ask for any other information… And so you’re

like “oh do you have a service coordinator?” and they say “no, what’s

that?”…and you’re like, “the service coordinator you need their help to get on

waiting lists”…and they’re like “oh well I don’t really feel like I need that” and

it’s like kind of hard to move on from there because a lot of the things otherwise

you might recommend, they really need that connection in order to make that.

(M3, P2P staff, supported 20 parents and a parent of a child with ASD).

Another indicator support parents used to assess receptiveness was whether the referred

parent persisted in trying to make contact by initiating and/or returning calls. This also

included referred parents staying engaged in conversations even when there were

distractions or competing demands for their attention as noted by SP6 about her match:

She kept calling me back; so that was a sign to me that she really wanted to

make the connection…She was very open, she didn’t sound rushed to get off the

phone, she seemed like the conversation was important enough to her that she

stayed on even when her kids were acting crazy in the background, and so, those

were the signs to me that she was looking for [a] relationship.

Some support parents felt their match was being receptive when they verbalized interest

in the support parents’ invitation to meet or participated in making plans to meet.
Finally, support parents also interpreted referred parents’ expressing excitement, appreciation, and gratitude for their overtures as indicators of their receptiveness.

**Referred parents’ openness.** Program staff and support parents identified referred parents’ openness as one of the most important factors affecting helpfulness of the match once parents made contact. “Being open” meant talking about one’s life, children, and concerns. It was crucial to getting the helping process started because it enabled support parents to offer help based on their understanding of the referred parents’ needs or provide information on how to access assistance. It also was important for referred parents who were seeking help in the form of venting to an understanding and empathic listener. As F1, a follow-up staff member noted when I asked about what makes some matches helpful while others are not, “I feel like the more that the person that wants to receive the support opens up, the more the support parent can help them.” Similarly, support parents concurred that referred parents’ opening up was one of the most important facilitators of helpfulness. For example, SP7, a support parent reflecting on why she felt she was able to help her referred parent, explained that her being open about her problems enabled the match to be helpful:

She was pretty willing to talk about her children …She was able to open up about what her experiences with them had been… about some of the challenges…so I think that helped too in that she was willing to talk.

In addition to allowing for the identification of needs, the referred parents’ disclosures also facilitated the helping process by enabling the support parent to foster conditions for continued disclosure. As support parents learned more about the referred parents’ experiences and their children, they were able to selectively disclose those parts of their
own story and background that were points of similarity which helped them
demonstrate that they understood, could be helpful in practical ways since they had
already travelled that path, or could share stories of what other parents had done that
were pertinent. Conversely, when referred parents were not forthcoming, support
parents were unable to identify their match’s needs as noted by SP4, a support parent:
“She really didn’t want to talk…She just gave the impression like you have to pull stuff
outta her. So, I really don’t know what she really wants.” In these instances, they also
had difficulty offering help to the referred parent, for example, M1, a P2P staff, and
former support parent stated “some people, even though they say they want support,
they don’t open up and talk, you know, and it’s really hard to get through.” Although
program staff largely mentioned openness in relation to disclosing to support parents,
one matching coordinator, M4, reported that it also affected the matching process. She
noted that it was difficult to ascertain the needs of some referred parents during intake
as they were not very open.

Several factors influenced the referred parents’ openness including their
perceptions of similarity and emotional connection, support parent’s relational qualities
and their readiness for a helping relationship as discussed earlier. Also, their degree of
comfort talking with strangers was an influential factor.

*Comfort talking with strangers.* P2P staff and support parents identified
referred parents’ comfort level in trusting and talking to strangers as a factor influencing
referred parent’s openness. Referred parents had to feel comfortable talking about
personal and private matters with a stranger for them to open up to the support parent
or, at least, develop comfort as the match progressed as noted by F1, a follow-up staff member, and former support parent:

Sometimes when we are matched with a parent that calls in to say they want support we’ll call them but they’re just not very open, it seems like they’re very reserved and closed up and don’t really feel comfortable talking, because I’m guessing of course, I’m a stranger to them and it’s their child they’re talking about which is very personal. So sometimes it can take a while for them to open up and sometimes they don’t ever feel comfortable opening up. They were comfortable with the idea, but once it actually happens then they find themselves not being so comfortable at talking about things.

P2P staff also felt that referred parents’ personality traits of shyness and being nervous when talking to strangers inhibited them from opening on the phone to another parent. While this was not a pertinent barrier for the matches that I followed during the study, P2P staff mentioned that it was a barrier to being open for some referred parents whom they had matched, followed up or had supported. Still, talking about personal emotional reactions and children’s difficulties are considerably intimate topics. Therefore, given that the P2P agency asks that the support parent makes three to four phone calls to the referred parent, these relationships are not planned to be long-term and so this level of intimate sharing with a stranger and so quickly may have been difficult for some parents who were shy and reserved. As SP6, a support parent mentioned, P2P required that in the first conversation parents discuss intimate details of their lives that one typically would not share until after multiple conversations among friends and acquaintances.
She noted how her referred parent feeling comfortable talking to a stranger about intimate details seemed to influence her subsequent openness:

You can’t ask for a support parent and then be a very private person. I mean they’re basically talking to a stranger about your life …It’s like the kind of conversation you have after maybe you’ve met someone for the 4th or 5th time but you’re hitting subjects in the first conversation that are deeper. And so she seems really open to talking and sharing about her life. She responded to the questions. There wasn’t like “can I trust this person?” “this is really awkward!”

Program Level Factors

Participants identified two program level factors affecting the helpfulness of matches. These included the support parent training and the staff’s matching approach.

Training. Support parents mentioned that the training enabled them to meet their referred parents’ needs. They reported several aspects of the training that they found especially helpful: resource guides for children with special needs, information and a video simulation on how to (and not to) initiate and manage conversations with referred parents to build rapport and provide support to their match. For example, SP4B, a support parent explained how the training gave her the skills needed to build a helping relationship with parents:

It [the training] was very useful, it was necessary because I wouldn’t know how to talk to a parent up front...The training allowed me to understand that it would be a lot of listening involved… The training made sure that we understood that we weren’t going in as okay here we are and we’re the ones that got all the answers.
Another element of the training that they mentioned as useful was hearing the stories of the other parents who were being trained. Support parents reported that hearing what trainees found unhelpful in their matches with their support parents was useful in helping them learn how to approach their referred parents especially in avoiding a focus primarily on their difficulties and talking about their concerns excessively as SP6 noted:

One of the big things I took away from it [listening to parents’ negative experiences with P2P] was [that] it’s good to share a little bit of your story so they know, hey, this person really knows where I’m coming from, but to just keep it very positive and encouraging cause that’s what the person needs at that point.

Support parents also mentioned that hearing other parent’s journeys with their children’s disability helped them “to be more understanding of other people’s perspectives and other parenting needs” (SP7) because their fellow trainees included parents of children with diverse needs and not just autism. Listening to other parents’ journeys also increased their empathy and compassion for other parents.

Matching. All three groups of participants mentioned the matching as an important factor affecting helpfulness. The matching process, including the criteria program that staff used, influenced whether support parents would be a good fit to meet referred parents’ needs. Program staff reported that the matching process involved several steps. First, they asked the referred parents’ what their needs and/or concerns were, as well as their child’s age and functioning. Next, they searched the support parent database for a support parent who might be a good match and asked that parent
whether they could provide support at that time and in relation to referred parents’ areas of greatest concern. A number of matching criteria appeared to be important to realizing beneficial outcomes, although there were exceptions. Program staff reported that they generally tried to match referred parents first based on their most important concerns (that is, to a support parent who indicated they could provide help with these concerns) and then based on similarity in children’s level of functioning and gender, slightly older age of support parents’ child, and similar locale. The matching coordinator searched their support parent database to find a parent who fits these criteria. Program staff reported that these criteria tended to facilitate helpful matches by making the support parent more likely to have knowledge and practical experience that was pertinent to referred parents’ concerns:

We try to match them with a support parent with child a little older, a year, two or three than the referred parent’s child because they [the support parents] have been through a little bit more and can help them…I think when you can find a parent that’s right in the specific same area because they are familiar with their resources out there in their area; I think that helps if you can have the same county. And same sex child too. (M1, P2P Staff)

Similarly, parents directly attributed matching as a contributor to the helpfulness of their matches. They often referred to being “matched well” or that it was a “good match” in terms of children’s similar functioning and behaviors as the reason for the helpfulness of their match:

I think it was a great match...Our kids are really similar as far as some types of behavior. I believe her son is older now, but they had similar traits when he was
Spencer’s age…I felt like they did a really good job as far as when I told the P2P agency about Spencer’s traits that they took the time to match me up with someone who could relate. (RP1, referred parent)

Other referred parents such as RP11, also mentioned additional criteria that were central to their concerns, such as family structure, which contributed to making their match helpful. For RP11, having multiple children and being employed full-time made it even harder to cope with the demands of caring for her son with ASD, and so being matched to a parent with these characteristics provided her with a peer who could holistically understand her situation:

I’m actually glad she was chosen. I’m glad they didn’t put me in contact with someone that just has one child or doesn’t maybe work. I think they picked someone that was a good match for me…because that’s my biggest challenge, all my children. So that’s huge for me. Because we have a lot of kids…. and because we have a child with autism, we can kind of relate.

Support parents also highlighted the matching criteria of similar functioning as affecting their ability to meet their referred parents’ needs for information on practical tips and resources. For example, SP7 recommended matching on functional similarity as a way to improve P2P because it made a difference to her helpfulness in her matches:

If they can base matches on the functional level of autism also… I think where I’ve had children at a similar functional level I can be more helpful as opposed to a child with low functioning autism…[be]cause there really are different types of resources for different levels…They may have benefited by getting a
parent who had more experience with programs or resources for that particular functional level.

In matches where referred parents felt that the support parent could not meet a major need, they questioned and/or attributed this to the agency’s matching. This was the case for both RP4 and RP10 who asked to be re-matched. In RP4’s case, she was dissatisfied with her match because she wanted play dates for her son but her son at 14 years was six years younger than the son of her first support parent. Because of this wide difference in age and therefore development, she questioned the P2P’s agency matching:

I was hoping she would have someone more of Alan's age. So I was disappointed that they connected me with someone who was so much older than Alan…I didn't know why they made that connection, unless, I didn't know if they had anyone with Alan's age available or not.

Similarly, RP3 attributed the agency’s matching (specifically matching her to a support parent in another city an hour away) as a barrier to meeting her need for her son to have play dates with a similar child. She noted: “I did get some useful information, but our distance from each other was probably the biggest barrier, but the P2P Agency is actually the one that does that, right? That sets you up with the support parent”. Thus, there were times when the matching criteria used did not result in a support parent that referred parents saw as a fit to meet all their specific needs.

Two factors appeared to contribute to the P2P agency arranging matches that were not a good fit for meeting all the needs of the referred parent. First, it was sometimes difficult for the matching coordinators to find a support parent that lived in
the same locale and had experience with the referred parent’s concerns. This was the case for RP3, who although getting her needs met for practical tips was not able to arrange play dates because her support parent lived in another city:

Joy at the P2P Agency offered to try to get me someone closer, but there was no one closer with a kid my age. There was a girl maybe around the same age, but girls and boys are different, so that wasn’t gonna help me… There was somebody[else] nearby, but their child was nine years old, so that wasn’t gonna help me because obviously I’d be telling her more than she’d be telling me, you know, because Bob’s almost 13 year old.

In the case of both RP3 and RP10 who did not get a major concern met they both lived outside the metropolitan area for their region and RP10 in a very rural and isolated area. The second factor that contributed to the P2P agency arranging matches that were not a good fit for meeting a major concern of referred parents was that the matching coordinator was not aware of the need as parents may not have expressed it during intake. Therefore, the matching coordinator would not have taken the need into consideration when matching. In some cases, this was due to the dynamic nature of parents’ needs – new issues came up that they would not have at the time they were being matched, and the agency learned of the new need when they were conducting follow-ups.

**Practical Issues**

At the most fundamental level, the parents in the match had to make contact for interaction to take place. It was through the interaction that matched pairs exchanged information that they use to form ongoing judgments about the similarity to each other.
Also, it was through their interaction that both parents made use of that similarity to meet referred parents’ needs. As a result, making and maintaining contact was an important factor influencing helpfulness. Practical issues primarily undermined helpfulness by preventing initial or follow-up contact or leading to shorter than desired conversations. Barriers to making contact included conflicting schedules, disconnected phones, lost contact information, geographical distance, parents’ busy lives, and unreturned phone calls, text messages, and e-mails. Generally geographical distance was a barrier for contact for those matches where referred parents’ needs were for an in-person social interaction with the support parent and/or between their children. Other barriers came from unanticipated and acute events that added to other demands in their busy day to day life. Among all the foregoing factors, participants most frequently reported busy lives as a barrier to contact and therefore to helpfulness.

**Busy lives.** An unfortunate irony was that although referred parents reported the unique value and need to talk with someone who had experiential understanding, their busy lives sometimes inhibited making contact with the support parent or having extended conversations. Even after, either parent had perceived that they were similar enough that they wanted to continue to seek or offer help, their busy lives were a frequently mentioned barrier for not interacting. Busy lives came from the everyday routine associated with caring for a child with ASD. This included attendance at multiple appointments for varied therapies. For others, an added layer came from having recently received a diagnosis and/or recently relocated. These meant parents were in the middle of searching or signing up for new services and finding a new equilibrium as they struggled to incorporate these activities with their other family and
personal demands. For example, RP10, a referred parent explained how her attempts to secure services for her son, Will who had just been diagnosed with another developmental disability, kept her from contacting her support parent:

She just told me to call her when I needed to, and I just haven’t had a chance yet. I feel bad about that, but I’ve been going through, and I’ve been on the phone every day with people, you know, for Will. So it’s very hectic.

Referred parents often found it difficult to make time for self-care including the need for social interaction and emotional support. They felt that the day to day care and attending to the needs of their child trumped getting support for their own needs as noted by F1, a P2P staff member, who conducted follow-up calls:

Sometimes [the parents] stay in touch quite frequently and other times there is just so much going on with their child, because the child is on the severe end [of the spectrum] that they have so many different therapies, emotional outbursts, meltdowns, tantrums, and things of that sort that it doesn’t allow them to be on the phone as much as they’d like to be.

In other matches, it was the support parent who never called or failed to make follow-up phone calls and referred parents felt they had difficulty reaching the support parent by phone as was the case for this referred parent:

She [the support parent] was supposed to call me back later that evening. And I’ve never gotten a call back as of today… [I] did call her twice [and never got her]. (RP1)
Program staff reported that support parents’ failure to make the initial or follow-up call was a frequent reason for referred parents’ dissatisfaction with a match as M1, a matching coordinator explained, “usually they want a rematch because the support parent has not called or only called once.” Despite support parents’ commitment to providing support, their busy lives in addition to that of the referred parents created obstacles to following through on their plans to call or meet with their match. This was seen, for example, in the match between SP4B, a support parent and her match RP4, who was looking for in-person social interaction. SP4B offered this explanation for why their repeated plans to meet fell through:

Between school work, my traveling, and my brother passing…And with her, it’s just still her trying to get acclimated and with her husband being away she’s kind of like a single parent…I was really, really banking on us being able to get together…but things happen at the last minute. Sometimes you just can’t control the circumstances.

Two other factors added time demands to the already typically busy day to day routine of these parents. The first was holidays. It was harder for parents to maintain contact when children were out of school as they had less time to talk on the phone. As a result, some matches lost momentum and tapered off following holiday breaks. The second factor was unanticipated events including illness and hospitalization of parents, their children or other family members, and death of relatives. These created additional time constraints for parents that prevented them from maintaining contact with each other.
Although time constraints were often a barrier to maintaining contact, this did not necessarily mean that referred parents who had fewer interactions found P2P unhelpful. Some parents’ needs were met with only one conversation, and they also felt helped through knowing that if they had a need, they could call upon their support parent. For example, RP5, a referred parent, who had sought a support parent to get information on academic and social services and emotional support for the “occasional bad day” had gotten her needs met in a short conversation. She reported that “By the time we got off the phone, I didn’t have any questions for her. I wasn’t left with like ‘oh, shoot, I forgot to ask her that’. No, we covered everything.” In follow-up check-in calls she would report that she had not needed to call her support parent:

**Geographical distance.** Although the P2P agency strove to match parents that lived in the same area, this was not always possible and two of the matches involved pairs who lived in different counties and cities. The geographical distance became a barrier to contact and to helpfulness for those referred parents whose need was for in-person social interaction for themselves and/or children. For example, in the case of RP3, a referred parent, who lived in a different city from her support parent, her need for information on the normalcy of her son’s behavior and practical tips were met but the distance was a barrier to meeting her social interaction needs:

She was very helpful. Like anytime I had a question she would answer it…It would have been more helpful if we were very close where we could have some outings with the kids… but like I said, she’s over an hour away.

Although not an issue for the matches that I followed, support parents and staff reported that geographical distance was also a barrier in some matches where the support parent
was not in the same county and/or school district as the referred parent. This led to the support parent being unaware of local resources and, therefore, unable to meet this type of informational need of the referred parent.

**Psycho-emotional Issues**

Participants identified emotional well-being of either or both parents in the match and referred parents’ readiness as psycho-emotional issues that affected helpfulness of P2P. These psycho-emotional issues impacted helpfulness by affecting parents’ initial or follow-up contact or engagement in the relationship that in turn prevented help-seeking and help provision.

**Emotional well-being.** In some matches, referred parents’ poor emotional well-being inhibited contact as it led to them not answering the phone, returning calls or turning down opportunities for interaction with the support parent. SP6, a support parent, spoke about how this resulted in unsuccessful attempts to have phone and then later face- to- face interactions with her referred parent:

“So you want to try to do breakfast?” I said, “or you guys are welcome to come out here” …and she kind of went quiet, and when I mentioned it before she seemed really excited about it, and so I thought I’d bring it up again, and that’s when she started talking about her aunt moving [out] and how she felt she was really missing her husband, and didn’t really feel like being around people.

Support parents also experienced emotional difficulties where they felt unable to support another parent. Although they were trained and accepted the assignment to provide support, their children still had ASD and so they had their struggles that sometimes were very emotionally taxing as SP6, a support parent explained:
One thing to kind of remember about support parents [is] they haven’t arrived… they still have children with special needs …we’re parents…[There’s] a lot of really great things about it but there’s also a lot of hard things, and it fluctuates from day to day, so I may not always be in the mood to call the parent that I’m supposed to be supporting because I actually need a little support myself.

**Referred parents’ readiness.** Readiness referred to being at a point where one was willing to address concerns and accept help through talking with another parent of a child with ASD. P2P staff and support parents identified referred parents’ readiness as one of the crucial factors affecting helpfulness of the match. For example MF2, a staff member in response to my question about what made some matches more helpful than others, reported that level of readiness affected the helpfulness of matches:

Sometimes the family’s not ready for a match, but that is okay, like I don’t force the family… it’s just because maybe it’s not the right moment and I learned that this is okay, that is not something that is bad.

Similarly, SP7, a support parent, in reflecting on why her match with her current referred parent was helpful compared to some of the previous ones, identified referred parents’ readiness as making a difference in the outcomes.

[Sometimes] a parent thinks they are ready, but they are not quite ready. So it sounds like this parent is really kind of ready or actually does want to really want to start opening up, and start working on whatever the issue that she needs to work on…Whereas, in some other cases, the parents weren’t really able to do that.
As SP7 illustrated, being ready affected helpfulness by encouraging referred parents’ disclosing their needs and using information from the support parent for problem-solving. Both staff and support parents noted that disclosure was critical to the helping process because without it support parents found it difficult to know what type of help to offer. M3, a P2P staff member and parent of a child with ASD identified how readiness enabled her to open to her own support parent:

You need to be at a point in your journey where you’re ready to open up to someone and trust someone else… If the parent being supported is not ready to open up and accept help or advice or something from someone else, then the match is not going to be successful no matter how good the supporting parent is.

Readiness also affected helpfulness by influencing referred parents’ making contact with their support parent. P2P staff reported that it appeared that when referred parents did not feel ready for a P2P relationship, they would not answer or return the support parents’ follow-up phone calls and, therefore, negated the opportunity for the support parent to offer help.

Referred parents’ level of readiness was affected by their felt need for external help as illustrated by RP3, a referred parent, as she talked about how her desire to find answers was related to her readiness to talk with her support parent:

I wasn’t nervous…I was very much looking forward to it [talking with the support parent] because like I said, I want to find out what they have done, what may have worked, what may not have worked… I was actually ready to talk to her.
On the other hand, when parents did not have a felt need for P2P, they tended to have little or no interest and engagement in the relationship. Support parents mentioned that referred parents sometimes became involved in P2P although they had no sense of a specific need for it because it seemed like one more service for which they needed to sign up to help their children. For example, SP6, a support parent, identified lack of felt need as the reason for her poor engagement with her support parent. She had already had an existing support system of friends that included parents of children with ASD and professionals who provided treatment to these children:

When my special needs coordinator said, “hey have you heard of P2P Agency? Would you be interested in a parent mentor?” I was like, yes, cause I was saying yes to everything…but when it was actually time for me to talk to a parent mentor, I really just wasn’t interested…I had too much going on. I already had a support network.

In a later interview, she reflected on how she would have been more engaged with her support parent if she had not already had relationships with other parents of children with ASD:

I think it would have made a total difference if I didn’t already have people in my life that understood what I was going through… If I did not have that in place, I probably would have clung to her [or] anyone who understood what I was going through.

In addition to the felt need for support, referred parents’ acceptance of the ASD diagnosis also appeared to be an important influence on their readiness. Without that acceptance, parents were unwilling to discuss what was happening to their children or to
hear from parents of children with ASD because they did not yet (or want to) identify their children and themselves as being a part of the ASD community. Therefore, acceptance was critical to creating a sense of felt need for peer support as indicated by M3, a P2P staff member, in response to my question about what gets parents to a state of readiness:

It’s kind of like the stages in grief, you go through like denial and anger, and until you get to that acceptance phase, you think “I don’t need to talk to somebody else!” “What do I need to talk to somebody else about, you know how bad my life is, or how bad my kid’s life is gonna be?”…I think once you get to the acceptance phases then you’re ready to hear stories of hope.

**Support Parent Experience with P2P and in the Disability Community**

Support parents and P2P staff members reported that experience from their previous matches and other interactions with other parents in the ASD and disability community enabled them to be helpful to their referred parents. Support parents mentioned that their support parenting experience contributed to their effectiveness by helping them to be skilled and comfortable disclosing their experiences and managing the conversation with their referred parent so that they were able to encourage the referred parent to share their needs and concerns. For example, SP4B noted,

I’ve had enough referred parents that I’ve talked to that I’m comfortable with what I do now… I’ve kind of got a knack on what I say and how much I allow them to say and let them peacefully and comfortably tell me what they want me to know…[I] tell them everything about myself because now I’m at a
comfortable state of mind where I don’t have a problem with relaying things that I go through or what my child is dealing with.

Their support parenting experience also taught them how to pace what, when and how much information to share with parents through careful listening as SP7 noted in response to my question about what had enabled her to be helpful to her referred parents:

I think part of it is my past experience and knowing how much is too much…just kind of paying attention to what the parent is saying and when they are starting to feel overwhelmed, or it’s too much information or just really listening to what they need… You want to be careful as you give information - try and give a little bit at a time and then kind of ask them or kind of gauge if that’s what they need.

Program staff reported that other experiences working with and interacting with families in the disability community built support parents’ knowledge in areas where they or their child did not have personal experience so that they were able to offer helpful tips and information in matches where their children were different as noted by M4, a P2P staff member involved in matching parents:

Sometimes although the support parent’s child does not have those same issues they can help because they’ve been in touch with so many other parents who do, especially those support parents who attend the support groups that they learn about a lot of other issues from other parents.

Similarly, F1 who followed up matches but was also a support parent spoke about how her lack of personal experience with the issues of the referred parents’ child had limited
her helpfulness in earlier matches but this was no longer a barrier when through exposure to other parents she developed vicarious experience. This enabled her to meet informational needs and be an empathic listener in matches where she did not have similar lived experience:

Since I started working for the P2P Agency I feel like I have contact with so many different people and families, that a lot of times I am able to make suggestions or to say “Oh I have a friend who’s been through that” or whatever, that kind of thing that I still am able to support.

**Congruence in Expectations for P2P**

Support parents and program staff identified the congruence between the type of support referred parents sought and expected, and the support parent’s and the program’s goals for the P2P relationship as a factor affecting helpfulness. The program offered short-term emotional and informational support through three to four telephone contacts from a volunteer support parent who has experiences with the referred parents’ concerns. The support parent could opt to meet the referred parent, become friends, have play dates with their child and have more than the minimum contacts, but this was beyond what the service offered. Referred parents who sought support within the program’s parameters for type and length of support tended to get their needs met. However, those who had expectations beyond these parameters particularly for tangible assistance (e.g., rides to appointments), play dates, friendship and long-term support were less likely to get their needs met. For example, SP7, a support parent explained how congruent expectations with program goals enabled her to help her current match. This was in contrast to a previous match where she was unable to help because the
referred parent’s needs were for material assistance which was outside of the type of support that P2P program provided:

I was able to help her [current match] with a lot of the concerns or needs that she had. I think with some other of the matches that I’ve had some of the requests or needs were kind of, been unreasonable, but based on her needs, and her requests were very reasonable and there was definitely resources that I could let her know about…[But there] was one parent, who really wanted things like rides and just needed help that would have been more sort of DSS level help, getting rides or helping pay for bills or food or that type of thing.

Program staff reported how referred parents’ expectations that were beyond the program’s goal led to them being dissatisfied with the helpfulness of matches and reporting this at follow-ups. They noted these referred parents’ expectations, especially for play dates, extended contact and parent friendships, were frequent causes of dissatisfaction and barriers to helpfulness. It is important to note that these expectations only became barriers when support parents were unwilling and/or unable to work outside the programs parameters but they sometimes did as explained by F2, a staff member who conducted follow ups:

A lot of times our parents expect a lot more out of our support program than the program is really designed for…They want a friend themselves …More often than not the support parent and the parent do become friends … but like I said, we can’t make somebody be their friend.

Similarly, RP10, a referred parent had some unmet support needs partly because the type of support she sought was outside the program’s scope and was not congruent with
what her support parent expected to provide. In particular, she was looking for a bi-directional relationship in which she and her support parent would solicit and provide support and become friends but the program was designed to be unidirectional. This unidirectional focus was strongly emphasized by program staff and support parents in their interviews when describing the role of the support parent in P2P. In her third follow-up interview, she expressed disappointment in her match as she was unable to develop a friendship with her support parent. Also, she reported that she had requested a new support parent and hoped that she would meet her need for a bi-directional relationship:

See, that’s sort of what I want, you know, to form a friendship. I don’t know if I’ll be able to do that or not, but I want to be able to talk to someone, and I haven’t had that yet. I don’t want this to be a one-sided thing, you know I wanna talk to them and see how they’re doing, and I wanna be there for them too.

In contrast, her support parent’s understanding of the type of help RP10 wanted did not include bi-directional support and friendship: “she basically just wanted support, needed help with resources and that was pretty much it” (SP10). When I probed her about her next steps with RP10 she also did not indicate that she was hoping it would turn into a friendship or to receive support from RP10:

It would be just basically on a professional level…It’s not much else that you can really do with referred parents because you don’t want to cross the line…All I can do is be a support…. I try not to be too personal, so all I can do is help her from a professional (phone static) – can’t go no further than that.
How parents came to have expectations and to seek support beyond the program’s goals was not always clear. However, for some it seemed the context in which they sought help—particularly perceived gaps in their coping resources and feeling socially isolated and stigmatized—may have led to initial and persistent expectations that were incongruent to program goals. For example, MF2, who conducted matching and follow-ups for the Hispanic program, noted that support parents often complained that their referred parents expected rides to their appointments and attributed this expectation to the lack of transportation experienced by the referred parents:

When I talk to the support parent, they tell me, “yeah the mom wanted me to go everywhere with her, and I told her that I can’t and even if I tell them they usually they ask again” because the biggest problem with Hispanic families is transportation. So if they become kind of friendly they gonna ask, “can you take me to this place?”

Similarly, the expectation for play dates that was outside of the scope of the P2P program seemed to have stemmed from the stigmatization and social exclusion that referred parents’ children experienced. This was noted for example by F1, who conducted follow-ups: “They want playmates for their children because a lot of times regular children they don’t play with your child.” Other referred parents had transitioned from the family partner program in which their family partner was paid and provided long-term and intensive support and had expectations that the support parent would do the same as F2, a staff member who conducted follow-ups, explained:

A lot of times they think the support parent is gonna take over from this family partner...[so they’ll say] “well I had a family partner and she did X, Y, & Z” and
then we explain to them: ...Your support parent comes in and they’re a volunteer … Then they understand the program better and the P2P coordinator explains that to them when she talks to them but they don’t always hear you.

Another apparent source of these incongruent expectations may have come from the program’s staff failing to state clearly the parameters of the support parent role as M3, a matching coordinator, noted:

Sometimes it can be like unrealistic expectation on the part of the supported parents… which again I feel like it’s the matching coordinators responsibility to set out what exactly the relationship is for. So maybe they either didn’t understand what the matching coordinator was saying, or the matching coordinator didn’t set up that level of expectation that it’s just gonna be emotional support.

Similarly, for example, M4, a matching coordinator reported that she did not explain the number of contacts at intake or during the matching process:

I tell them that the support parent is a parent who can relate to them because they also have a child with special needs; that the support parent will call them a couple times. Sometimes parents expect that they and the support parent will meet and have play dates. I don’t say it’s just three to four calls at the beginning. I’m not sure that it’s in the letter that we send to the referred parent.

Other program staff mentioned that the expectation for number of contacts was in the letter sent to referred parents but it was not in the copy that they sent me. Also, when I queried referred parents who expected more contacts or friendships about what they were told to expect some could not recall. One parent mentioned that the support parent
was to call them at least once per week that was more frequent than the three to four calls over a two month period that the program recommended to support parents.

**Summary of Barriers and Facilitators to Beneficial Outcomes**

Factors at the referred and support parent levels, within the match, and at the program level affected the helpfulness of P2P in meeting referred parents’ needs. Some factors such as perceived emotional connection, perceived similarity, and practical issues were identified by all three participant groups. Others, such as referred parents’ readiness, expectations, and receptiveness, were identified only by support parents and the program staff. While, some of the relational qualities were identified by both parents only (e.g., support parents’ openness) or by the referred parent only (e.g., genuineness, congenial disposition). The impact and relevance of some factors were dependent on the type of support sought, particularly for perceiving similarity and matching criteria as these largely determined the fit of the support parent for the referred parents’ needs. Other factors such as practical and emotional issues of parents and referred parents’ readiness were fundamental to making and maintaining contact without which the helping process could not be initiated and sustained as needed.

Once contact was made, how parents interacted with each other and what information they shared affected the creation of a climate in which referred parents disclosed their needs and support parents could offer help that matched their needs. Parents engaged in ongoing assessments of each other based on these interactions. Some of the more important interactional factors included both parents’ level of openness. They also included perceptions of the support parents’ genuineness and trustworthiness and
referred parents’ receptiveness as these two factors were crucial indicators that the matched pair was interested in the relationship.

Overall, matches were most likely to be helpful when the referred and support parents perceived each other to have similar experiences relative to the needs for which the referred parent sought help. Also, P2P was beneficial when parents had congruent expectations, the support parent was perceived as genuine and trustworthy, and the referred parent was ready for a helping relationship and receptive to their support parents overtures. Training, similar lived experience as a parent of a child with ASD, experiences from previous matches and from participation in the ASD and the disability community, equipped the support parent with the knowledge and skills to be helpful to referred parents. This especially included skills in building reflective listening, conveying similarity, using disclosure judiciously, and being non-directive,

**Part III: Changes in Relationship over Time**

Before I discuss how relationships changed over time, I will give an overview of the evolution of the 12 matches that I followed during the data collection. One match (RP8/SP8) never began a relationship. Of the 11 remaining matches, five of these matched pairs had, at least, three phone conversations meeting the minimum requirement for three to four contacts. Among the other six matches, one pair had two conversations with the relationship lasting about three weeks. The other five pairs had one telephone conversation. In the next sections, I first discuss factors that influenced pairs to go beyond the minimum requirements and then how relationships changed over time.
Factors Affecting the Duration of Relationship

Pairs who went beyond the minimum requirement did so because the referred parents still had needs that the matched pair felt that the support could meet, both parties had availability and continued interest in a helping relationship, and felt that they had developed an emotional connection. In addition, both parties, especially the support parent, felt that the match could still meet the referred parent’s needs, for example, SP6, a support parent, explained how her referred parent’s continued need and sense that she was being and could still be helpful motivated her to keep in touch with her match:

I feel like she’s genuinely helped by our conversation. If I was telling her a bunch of things she already knew, I’d say well okay, we’re both really wasting our time. …But Whitney is right on the forefront, like everything is new, she has a lot of questions… She doesn’t really have other mom friends who have kids with autism, so I think that makes a difference, that’s why our conversations are continuing because there’s a legitimate reason for those calls to happen.

Continued desire for the P2P relationship was also a function of whether or not the referred parent found more proximal supports to meet their needs. Support parents and program staff reported that when referred parents no longer needed or pursued the P2P relationship when they found other proximal supports for their needs. Once parents formed relationships with other parents at their children’s schools, waiting rooms for therapies, or support groups at the P2P agency, they no longer felt the need to depend on their support parent.

When support parents felt that their match did not have a need, interest, or time for their support, they stopped making contact with them. Support parents made this
judgment based on the referred parents’ actions or inactions. If, in response to follow-up calls or communications, their referred parents indicated that they were “doing good” or “everything is fine” and did not initiate any further contact, then support parents interpreted these responses as an indication of the referred parent not needing their support. If calls were unanswered and not returned, or referred parents responded but said they were busy, support parents surmised that referred parents did not have time to devote to or were no longer interested in the P2P relationship. Support parents also gauged their match’s receptiveness to the help they offered throughout the match and used this to determine whether they would continue beyond the required three to four phone calls. As illustrated by SP11, if parents did not seem receptive as indicated by their failure to act on information, then support parents would cease contacting them:

I usually ask how the IEP is going. Have you contacted anyone that helped you go through the process of the IEP?..[If] I gave you this information in the first phone call and this is like the 4th phone call and you haven’t done anything, how serious are you about educating your child?... I normally try not to bother the parents anymore if they’re saying “no I haven’t made contact yet.” That lets me know they’re not really interested in it.

However, if parents seemed to be receptive to the information as indicated by acting on it (e.g., making a call to service providers, signing up for a service), then support parents would sometimes check back after the fourth call to see what progress was made and whether there were any additional questions.

Support parents and program staff reflecting on their previous matches also reported that matches sometimes went beyond minimum requirements if they had had become friends. Friendships were usually driven by a strong sense of emotional
connection and similarity between match pairs in children but also in personality and interests, along with the availability of the parents. Friendships were more likely to develop when pairs found other ways to stay in touch or meet outside of the phone conversations. So then, pairs who saw each other in other proximal settings such as support groups, activities at the P2P agency, or in waiting rooms where their children received therapy or on Facebook were more likely to develop friendships. For example, SP7, a support parent, identified proximity and communication outside of P2P as reasons why she stayed in touch for a long time with one of her previous matches compared to the others:

I think mainly because she’s in the area ...and she’s literally right down the street and we keep in touch through Facebook, so that’s what’s kind of kept us in touch. I think [the other parents] they were all in other school districts, and we didn’t like do Facebook or anything like that, it was maybe some emails, but we didn’t make that other kind of connection, so, it was all other, pretty much phone-based sessions.

Friendships were also more likely to develop if parents met each other, partly because deeper levels of emotional connection tended to occur in person.

**Changes over Time**

There were two major dimensions on which matches evolved or not over time for the six matched pairs who had, at least, two contacts. These included the nature of contact and the nature of the relationship.

**Nature of Contact.** Over time relationships changed in the nature of contact with respect to who initiated contact and its the mode, length, and frequency. The support
parent initiated the first contact by telephone. After the first conversation, referred parents typically initiated the second contact or some of the later contacts that were usually phone calls and in a few instances text messages. This happened largely as a result of several simultaneous developments in the relationship. First, the referred parent felt a continued need for support. Second, referred parents continued to believe that their support parent could still be helpful based on their perceived similarities in experience and emotional connection. Also, they perceived their support parents as genuine and trustworthy. Further, they believed that the support parent could still be helpful since they had benefitted from previous conversations, and the support parents’ disclosure contained accounts of successful coping and improvement from which they could learn. Usually, one to two interactions contacts were sufficient for most referred parents to make these judgments. One matched pair was an exception to this, with the support parent initiating all contacts. The referred parent reported that she had problems with trusting persons and would not call but instead would wait for the support parent to contact her to test her trustworthiness:

I will wait a couple of weeks, and this would be my personality in play here and see if I hear back from her. I would not be the one to pick up the phone and call back. Even though she said it [that I could call her anytime] I just, I am that personality that feels that people need to follow through. (RP7, referred parent)

As mentioned earlier, matched pairs made the initial contact by telephone call but over time also used text messaging to communicate. Parents found these other forms of communication more convenient. Also, support parents, in particular, used them in an attempt to stay in touch unobtrusively as they were minding boundaries between being
pushy versus being supportive. Support parents also used email to provide information to referred parents. These media remained the forms of communication over time for matches in the study except for one matched pair that met once. Of the remaining five pairs, four had talked about or made plans to meet or have their children met but these fell through due to practical issues (e.g. time constraints, distance) in most matches and depressed mood and social withdrawal of the referred parent in one match. Interviews with support parents and P2P staff about matches in which they provided support indicated that meeting in person was generally the exception. Some program staff and support parents reported that they used Facebook to keep in touch with past referred parents, but none of the matched pairs in the study indicated that they used this form of media to communicate.

The length of contacts over time varied somewhat across pairs. For most pairs the first conversation was the longest, lasting from at least 30 minutes to about an hour. Second conversations were much briefer for half of the six pairs and about the same length or longer for other pairs. Eventually subsequent conversations became brief. The frequency of the conversations also became less over time with the majority or all of the conversations taking place in the first month of beginning the relationship. Three matches lasted a month or less and in the other three matches, calls, emails or texting occurred over a span of three to six months. Only in one of the latter matches was there somewhat of an even spread of contacts across months. In this match, parents stayed in touch for three months. In the other two matches that were spread out over six months, there was a gap in communication after the first month, with the final conversation taking place in the fifth to sixth month. In one of these matches, it appeared that the final
conversation occurred because I had called the support parent to plan for a close out interview as neither parent had made any attempts to contact each other after the first month.

Program staff and support parents, in reflecting on their experiences providing support or as follow-up matches, reported a fairly similar pattern in the length and frequency of contact over time. For example, MF2, a P2P staff member indicated that by the three-month follow-up parents were not talking as frequently with their support parents and typically only called if they have a question unless they have become friends then they may call more frequently. By the six month follow-up it was the same pattern as noted by F2, who conducted follow-ups and was also a support parent:

They may not talk as often, but they will say oh I have her number, I’ll give her a call if something comes up or I see her at the support group once a month or they’ll [the referred parents will] say [to the support parent], “tell me what’s going on in the area this week... I’ll tell them what’s going on like … and they’ll say “okay well we’ll see you there” and I’ll say okay and that’s kind of the end of it.

**Nature of the Relationship.** The nature of the matched pairs’ relationships could change in four ways: a) direction of support provision and receipt between parents; b) topics discussed in terms of whether they were specific to providing supports to parents related to ASD or not; c) the types of ASD related supports that were requested and offered; and d) whether the relationship remained as a helping relationship or became a friendship.

Most of the matches in the study remained unidirectional, that is, the support parent provided support to the referred parent. In two matches, support became bi-
directional. In one of these matches, the support parent reported that by their third conversation she was using the match as an opportunity to be listened to and to receive support when she disclosed about concerns about her children:

SP7: I shared with her some of the issues I was having even the kids being fidgety with school and what not, so I think we’ve reached that level where it’s more of a sharing rather than of me kind of feeding her information.

Interviewer: OK, and do you feel that’s benefiting you as well?

SP7: Yes, absolutely.

In one other match, both parents had “offered to baby sit each other’s children to allow parents to have date nights.

The nature of the matched pairs’ relationships remained largely unchanged on the other three preceding dimensions. None of the matches evolved into a friendship. Only one match changed on the other dimensions (SP6/RP9). In this match, parents expanded the focus to include activities unrelated to P2P or autism, namely they discussed the possibility of SP6 becoming a paid child care provider for another of the referred parent’s children. Parents in this match also expanded the types of supports involved in the relationship to include tangible forms of assistance such as being back-up baby sitters for each other as SP6, the support parent, illustrated:

She offered to watch my kids too so my husband, and I could go on a date…I cooked a meal for her family while she was having surgery, which was more just like you know a family support situation, it wasn’t necessarily Stuart specific, and then when I did drop off the meal I asked her husband if he needed help with the kids while she was in the hospital and he said that he didn’t.
As SP6 explained above, some of these supports were not related to helping the referred parent cope with autism related stressors but was more about supporting the family as a whole.

Program staff and support parents indicated that previous matches in which they were involved or followed up either became friendships or remained as helping relationships. When parents became friends, the content of conversations expanded beyond ASD. For example, SP8, a support parent, talked about her relationship with a parent she had supported that had turned into a friendship noting that “sometimes when we talk, we don’t even talk about our children. We talk how our day was, and that’s really good to do sometimes too”. It appeared that during the helping relationship phase the focus remained largely on informational, emotional and to a lesser extent social companionship support. As relationships progressed into friendships, more attention was on parents and/or children spending time together, and support became bi-directional. They, however, mentioned that some referred parents sought tangible assistance in the form of rides to appointments.

**Summary: Changes over Time**

Consistent with the aims of the P2P program, the matches that I followed in this study were short-term helping relationships. Most or all conversations were concentrated in the first month of the relationship. Over time, generally the frequency and length of conversations decreased. Communication largely took place by phone with pairs adding emails and text messaging as the relationship progressed. There was very little change in the nature of the relationship across matches over time. Support giving and receipt remained primarily unidirectional. In, addition pairs’ interactions continued in the
context of a helping relationship rather than becoming a friendship and with only minor exceptions, and the supports referred parents requested remained focused on ASD-related concerns.
CHAPTER 6

DISCUSSION, STRENGTHS, LIMITATIONS, AND IMPLICATIONS

The purpose of this study was to examine how parents of children with ASD benefit from P2P, the factors generating beneficial outcomes and how these relationships change over time. In this chapter, I first summarize the findings presented in Chapters four and five and synthesize the primary factors that explained the success of P2P in meeting the needs of referred parents and influencing changes in the P2P relationships. Next, I discuss how this study’s findings correspond to existing literature on P2P as a peer-based social support intervention. I then discuss the strengths and limitations of the study. Finally, I present implications of these findings for practice, policy, and social work education and make recommendations for further research.

Discussion

Synthesizing Themes: The P2P Process

Findings indicate that referred parents sought P2P in response to perceived difficulty coping with pragmatic issues and/or emotional reactions to ASD-related stressors. Also, parents perceived gaps in their coping resources, especially support from parents who had experience caring for children with ASD. Referred parents approached the match believing that support from a similar parent would be beneficial. Although most referred parents derived some benefits—whether
Informational/practical, emotional or social--some did not or found their match largely unhelpful. Six interrelated factors influenced the success of the match. These included: (a) program level, (b) practical, (c) psycho-emotional, (d) relationship, (e) support parents’ experience, and (f) expectations for the match. Of these six factors, the relationship was the most important factor affecting success. Further, both parents perceiving similarity (a sub-category of relationship) was the central psychosocial process that led to a successful match.

Perceiving similarity affected helpfulness by leading both parents to believe that the support parent could be helpful. It gave the support parent experiential knowledge to understand referred parents’ situation, offer useful information, and be a normalizing and non-stigmatizing source of social companionship. It also gave credibility to the information, practical suggestions, feedback, and empathy that the support parent offered, making referred parents more receptive to them and enabling them to ask for assistance and to disclose concerns. Finally, it helped to build a feeling of emotional connection between parents, which entailed a sense of closeness, bonding, and interpersonal attraction. This was especially important for the referred parent to open up about themselves, their children, and their concerns and acted as a motivator for both parents to stay engaged in the match.

Swapping stories with and receiving information from an experienced and similar other enhanced referred parents’ ability to cope with ASD-related stressors in several ways. First, it enabled them to freely release pent-up emotions and to share their struggles while feeling understood without being judged. Second, parents gained information, links to resources, and practical tips to directly address problems. By
conducting social comparisons with their support parents’ situations and children, 
referred parents often reappraised ASD-related stressors as less threatening by seeing 
them as normative, amenable to improvement, or less severe. These reappraisals helped 
parents deal with emotional reactions such as anxiety and isolation.

As mentioned earlier, there were six sets of factors that impacted the success of 
the match. Below, I summarize how these six factors--that included actions, reactions 
and/or perceptions of program staff, referred and support parents--operated together to 
create perceived similarity and enable referred parents to benefit from it. I begin with the 
program-level factors of matching and training.

Staff matching parents well was essential to parents perceiving similarity and, 
consequently, to the success of the match. In this study, matching referred parents to 
someone with similar but longer experience with their need and children’s functioning 
level was critical to both parents perceiving similarity. This meant matching referred 
parents to someone with a child who was a few years older or similar age with a longer 
time since diagnosis. Because the needs for which parents sought help were dynamic, 
matching around the foregoing criteria fostered continued helpfulness and perceptions of 
similarity as referred parents introduced new concerns. Matching on same or very close 
age was critical for referred parents seeking play dates for their children. Matching on 
children’s gender enhanced satisfaction with P2P for play dates. It was especially critical 
to perceiving similarity and finding P2P helpful for concerns directly related to puberty. 
Finally, when program staff also matched parents on parental or family characteristics, 
such as marital status and family size, this enhanced mutual perceptions of similarity, and 
subsequently rapport. Also, it optimized the helpfulness of the match as similarity in
these characteristics afforded support parents a more holistic understanding of referred parents’ concerns and practical experience in addressing them within their particular context.

Conversely, when parents felt that they were not matched well, a sense of the difference in relation to the need for which parents sought support dominated their perception of the relationship. This led referred parents not to perceive the support parent as a credible helper. It also often left support parents without the lived experience to meet referred parents’ needs. In these situations, the referred parent tended to discontinue contact, and the relationship yielded little or no benefit. Being matched well was crucial, but not sufficient, for parents to perceive similarity in each other and then benefit from their common lived experience. Training support parents in relationship skills was necessary for support parents to convey and use similarity to meet referred parents’ needs.

The training equipped support parents with the relationship skills to effectively convey similarity and use it to encourage referred parents’ disclosure or openness about their needs and circumstances and receptiveness to the help offered. Program staff also taught support parents how to share similar experiences to meet referred parents’ needs for empathic understanding, belonging, and social connectedness, normalcy, hope, and feedback and information for problem-solving. The relationships skills included reflective listening and being nondirective. The training also provided information on resources, which added to the knowledge they had from lived experience to meet the informational needs of support parent.
As with the training, support parents’ experience with P2P matches gave them knowledge and relationship skills, specifically in communicating similarity and using lived experiences to offer successfully various types of support to referred parents. Their experiences providing support also built their confidence and comfort in establishing rapport, and especially in using self-disclosure judiciously. Support parents’ experiences with P2P and in the ASD and disability communities gave them vicarious lived experience that they disclosed to meet referred parent’s needs for emotional and informational support.

Although matching, training, and support parents’ experience provided the critical foundation for perceiving and using similarity, the quality of the relationship was the most important factor to the success of the match. This was because the benefits of P2P accrued from the interaction of the matched pair as they exchanged information and swapped stories. It was only through these exchanges that the mutual perceptions of similarity continually developed, referred parents disclosed needs and sought assistance, and support parents offered help. Therefore, the choices both parents made about what and how they disclosed and responded to each other ultimately led to referred parents getting their needs met.

Ongoing mutual openness about self, children, and experiences was the key relationship factor to parents perceiving similarity and to the match resulting in beneficial outcomes. These outcomes only occurred if support parents’ openness was characterized by judicious disclosure that involved balancing accounts of similar difficulties with how they had improved or experienced success, and allowing most of the conversational time to be given to referred parents. When this occurred, it established a sense of similarity,
and the comparisons that referred parents made to their support parents inspired hope, normalized their experiences, validated their emotional reactions, and yielded practical information for problem-solving. The comparisons also reduced their sense of social isolation as they realized that they had shared experiences with their support parent.

Referred parents’ choice to be open was partly influenced by their support parents being open as the information established their credibility, willingness to help, and a sense of emotional connection. Also, they also chose to disclose and were receptive to the assistance offered when they perceived their support parents as genuine and trustworthy, and their responses to be nonjudgmental and empathic. But they also chose to disclose if they were ready for external help. Conversely, they chose not to open up when they were not ready for a helping relationship, were experiencing poor emotional well-being or were very wary, shy or uncomfortable sharing intimate details with strangers. These characteristics often prevented referred parents from making contact with their support parent, thereby negating the opportunity to receive help. Support parents also chose to disclose and offer assistance if they perceived referred parents as being receptive to their overtures. They assessed receptiveness based on how the referred parents responded to their disclosures, suggestions, and general overtures. They perceived referred parents as receptive if they gave feedback, asked follow-up questions, expressed intent to act or acted upon their suggestions, and initiated or returned calls.

Even when there were mutual perceptions of similarities and relational qualities, such as support parents’ genuineness and referred parents’ readiness and receptiveness, practical and logistical factors undermined helpfulness by preventing contact. These stemmed primarily from the busy day-to-day lives associated with caring for a child with
ASD, and unexpected events, which created severe time constraints. In addition, factors such as geographical distance and conflicting schedules made it logistically difficult to make contact, which was necessary for support parents to provide help. Finally, referred parents harboring expectations for types of support that were incongruent to those held by the support parents led to needs not being met. In every case when referred parents’ expectations were incongruent with that of their support parent, they were also outside the parameter of the program goals. As a result, support parents did not offer assistance to meet such needs, as they typically would not have been matched with those considerations in mind. Also, they were unwilling and sometimes unable to work outside the program’s parameters.

Overall, consistent with the goals of the P2P program, relationships were short-term with all or most contact occurring in the first month of the relationship. There were very few changes in these relationships over time. They remained as helping relationships rather than evolving into friendships. Support giving and receipt remained primarily unidirectional with support parents providing support. In the few matches where it became bi-directional, relationships had extended beyond one month. The only consistent change was in the nature of contact with decreasing frequency and length of contact and referred parents increasingly initiating contact. The decreasing frequency and length of contact were driven by referred parents getting their needs met by their support parent or finding other, typically more proximal, sources of support. With the time constraints stemming from very busy lives, it was difficult to make time for P2P if parents did not meet in proximal settings that were part of their routines. The increasing initiation of contact by referred parents was driven by their continued need for help and
perceiving the support parent as genuine and trustworthy. It was also driven by their belief that their support could still be helpful based on perceived similarities as well as already benefiting from their assistance.

**Summary of the P2P Process.** The study’s findings point to the P2P as a dynamic process with success being primarily contingent on parents perceiving similarity. This process of perceiving similarity (or not) was ongoing and depended on the choices made by program staff and matched pairs. Parents evidenced considerable agency regarding the relationship. They continually chose how and what they would share, whether they would accept and maintain contact and ask for, offer, and accept help. These choices were informed by their own personal psycho-emotional issues, time demands associated with their busy lives, and also their ongoing assessments of perceived similarity and each other’s relational qualities. In the next two sections, I discuss how the study’s findings contribute to the P2P scholarship.

**Contributions to P2P Research**

**Benefits of P2P.** As with previous studies on P2P, parents in the current study reported similar emotional, practical/informational and social benefits that came from interacting with their support parents and swapping stories and information. As reported in other P2P studies (Iscoe & Bordelon, 1985; Rearick et al., 2011), emotional benefits for parents in this sample included reduced social isolation, feeling understood, being able to share feelings without being judged, increased hope and an expanded vision for their children’s future, validation of their emotional reactions, and a sense of normalcy. They also reported additional emotional benefits including being more comfortable in public spaces and identifying themselves and their children as a part of the ASD and
disability community. This is an important benefit since parents of children with ASD have reported stigmatization of themselves and their children especially in public places (Ryan, 2010).

In congruence with existing studies, participants in the current study reported social benefits included non-stigmatizing and non-judgmental social interaction for themselves and their children and linkages to other supportive networks (Shilling et al., 2015a). These benefits of P2P are significant given that parents of children with ASD tend to experience social exclusion from friends and family members (Altiere & Von Kluge, 2009; Nealy et al., 2012; Ryan, 2010). Also, parents have reported the need to enjoy activities with other parents and their children, since they have felt that parents of neurotypical children often judged them as “bad” parents and their children as undisciplined and weird (DePape & Lindsay, 2014; Lutz et al., 2012).

Like previous P2P studies, parents in the current study reported informational or practical benefits that included information on resources, insider tips to manage problematic behaviors and encourage desired behaviors, navigate service systems and work with professionals (Abinder et al., 1999; Ardal et al., 2011; Rearick et al., 2011; Sullivan-Bolyai et al., 2004). Given the varied presentation of ASD, the plethora of treatment approaches and often conflicting opinions about what works, practical tips from a similar parent on what might or might not be successful is a valuable starting point for parents (Mackintosh et al., 2005; Matson, Adams, Williams & Rieske, 2013).

Parents in the current study mentioned four additional informational benefits that previous studies did not report. First, parents in this study reported practical tips on how to balance relationships with their other children, along with various treatment and
caregiving demands for their child with ASD and other commitments. This is an important benefit since parents tend to express guilt about the greater attention that their child with ASD often required compared to other siblings (Ludlow, Skelly, & Rohleder; 2012; Lutz, Patterson, & Klein, 2012). In addition, parents are typically involved in coordinating multiple treatments that are delivered to their children in the home and community settings with an average of seven to nine treatments depending on the type of ASD concerns (Goin-Kochel et al., 2007) which creates considerable time burdens. A second additional benefit reported in this study was information on “hidden services and benefits,” that is, for services that were not typically publicized. This is important because data from national surveys of US parents of children with autism have generally reported higher rates of unmet needs in specific health care services for their children (Kogan et al., 2008; Chiri & Warfield, 2012). A fourth benefit identified by this current study was tips to help other children and spouses understand and accept the ASD diagnosis. These tips are valuable given that there are no outward or physical features that are distinctive to ASD and so this makes it difficult for others including family members to accept that development is atypical especially when the child is fairly high functioning (Ryan, 2010).

Factors affecting the Helpfulness of P2P. Similar to these existing studies, the current investigation found that practical issues (e.g. busy lives, geographical distance, scheduling conflicts and lost contact information) undermined helpfulness of the matches for this sample of parents by preventing initial or follow-up contact (Abinder et al., 1999; Preyde et al., 2001; Nicholas & Keilty, 2007). However, the present study provided some more nuanced understanding of how geographical distance affected helpfulness.
First, it was a barrier for parents who sought social companionship support for themselves and/or their children by making it costly to meet in terms of travel time and transportations costs. Second, it was a barrier for referred parents who were seeking information on local resources in their area and inhibited helpfulness because support parents who lived in different counties and cities often did not have this type of knowledge. However, the geographical distance was not a barrier to meet needs for emotional support (e.g., an empathic listener, hope) or other types of informational needs such as practical tips to manage children’s behaviors that in this study was delivered by telephone and other media.

The current study adds to current understanding of how psycho-emotional issues of the parents involved in the match can affect the helpfulness of P2P. Like Shilling et al. (2015a; 2015b), the current study found that referred parents’ lack of readiness inhibited contact and subsequently helpfulness. However, Shilling and colleagues concluded that it was difficult to tell what factors shaped a referred parent’s readiness for P2P. This present study responds to this gap, by showing that for this sample of parents of children with ASD, acceptance of the diagnosis and felt need for external help led to readiness. The findings indicated that some parents may agree to a match because they were referred by a service provider and felt that it was just one of the many services that they should sign up for without having felt a need for support from a similar parent. Another unique contribution of this current study is that it identified poor emotional well-being of either parent in the match as another psycho-emotional factor that inhibited contact and, therefore, undermined helpfulness of the match.
In alignment with existing studies, this study found that perceiving similarity between matched pairs at the parent (personality, parenting style, family structure, and outlook on the disability) and especially at the child level (functioning, symptoms, and diagnosis) was one of the most important facilitators of helpfulness of P2P while differences inhibited it (Abinder et al., 1999; Ardal et al., 2011; Nicholas & Keilty, 2007; Preyde et al., 2001; Shilling et al., 2015a; 2015b; Shilling, Morris et al., 2015). This study expands our understanding of the role of perceiving similarity through identifying that the type of similarity that is important is based on the type of support that the referred parent seeks. First, similarity in children’s diagnosis, functioning, symptoms and experiences with services were important for parents who are seeking practical tips to make decisions about treatment or to address a specific behavioral issue. For the sample in this study, similarities in the first three areas were important to helpfulness for parents seeking emotional support to deal with specific stressors. However, a similar diagnosis was sufficient to find P2P useful when the referred parent sought general information on the diagnosis, how and where to sign for services like Medicaid, and general resources.

A unique contribution of this study was in delineating when similarity in age may matter. For the parents in this sample, same or very close age was generally a facilitator of helpfulness for parents who wanted play dates for their children. On the other hand, older age seemed to be typically important for those who wanted a support parent who could provide practical tips and empathic understanding because their child had already gone through what referred parents were now experiencing.

While previous studies found that similar lived experience afforded support parents the knowledge needed to provide informational support and emotional support
(e.g., Nicholas & Keilty, 2007), the current study also found that having vicarious experience could in some instances enable supporters to be helpful. Specifically, support parents’ experiences from their previous matches and interactions with other parents in ASD and disability communities in settings such as support groups provided them with knowledge that sometimes compensated for specific lived experiences. They could draw on the similar experiences of other parents to provide support to their referred parent. Also, information on resources that they received during their support parent training was an additional source of knowledge.

Findings from the current study contribute to existing research on the role of differences in children as a barrier to the helpfulness of P2P. The current study also found that differences in children’s functioning, symptoms and age were barriers to helpfulness when they led to the support parent not having the experiences to provide practical tips and to be able to understand the referred parents’ concerns (Abinder et al., 1999; Nicholas & Keilty, 2007; Preyde et al., 2011). In these cases, referred parents found the comparisons to the support parent unhelpful. The current study however diverged from two of the studies (Abinder et al., 1999; Nicholas & Keilty, 2007) when it came to differences and upward comparisons (i.e., comparing one’s child to a support parent’s child that was doing better). I found that upward comparisons led to beneficial outcomes such as hope for improvement. However, in the other studies, upward comparisons did not lead to beneficial outcomes as it led parents to avoid the other parent because it was a reminder of how poorly their own child was doing.

Two factors might explain the different outcomes between the current and these two studies. In the current study, parents were matched to support parents of older
children who had similar problems in the past as the referred parent’s child now had and had shared strategies that led to improvement. As a result, it was reasonable for the referred parent to expect that improvement was possible. However, in Nicholas and Keilty’s (2007) sample of parents of children requiring assistive lung technology, parents were matched on similar age of their children. Therefore, with similar age, parents whose children who were doing worse, may have felt less hopeful about the possibility of future improvement. Abinder et al.’s (1999) sample included parents of children with different disabilities and chronic illnesses who were not necessarily matched on diagnosis and it is possible that the areas of concerns were not issues that were amenable to improvement.

Few studies have examined how program level factors shape helpfulness of P2P and the current study contributes to expanding knowledge in this area. Similar to Shilling et al., (2015a, 2015), findings from this study indicated that support parent training and matching facilitated helpfulness of matches to mothers in this sample. However, the present study identified the structures that appeared to effectively deliver these training benefits. These included a resource guide, a simulation of how to initiate and manage conversations using active listening and other skills. It also included being cross trained with parents of children with other disabilities and listening to other trainees’ stories of their journey with their children’s disability and of any negative experiences they may have had with their support parent.

In one existing study (Shilling at al., 2015b), participants reported that matching was important to ensuring that support parents were a good fit for referred parents’ needs, but did not agree about what criteria ensured the level of similarity needed to make it a
good fit. This study identified potential criteria by showing for this sample of parents that the following matching criteria was generally likely to lead a helpful outcome: first, matching parents to another parent of child with a similar diagnosis who indicated that they could provide help with parents’ concerns and then based on similarity in children’s functioning and gender, slightly older age of support parents’ child and similar locale.

This study contributes to existing research on the role of referred and support parents’ relational qualities as facilitators of helpfulness of P2P. These included support parent factors of genuineness and trustworthiness, active listening, congenial and positive disposition, empathic and nonjudgmental responses, and openness (Shilling et al., 2015a, Shilling, Morris et al., 2015). Similar to the foregoing studies the present study also identified referred parents’ openness as a facilitator of helpfulness. The current study contributes to expanding knowledge in this area in several ways. First, it identified support parents’ non-directive and honest responses and referred parents’ receptiveness as additional facilitators of beneficial outcomes. Second, it showed the type of openness (i.e., judicious disclosure) that appears to contribute to the helpfulness of P2P. Third, this study showed referred parents and support parents are constantly gauging genuineness and receptiveness respectively and identified the indicators that they use to make these assessments. Furthermore, the findings indicated that referred parents and support parents continually made decisions about engagement, openness and maintaining contact based on their judgments of genuineness and receptiveness, respectively.

Existing P2P research does not explain what contributes to referred parents having expectations for P2P that are incongruent with the support parents’ role (Shilling et al., 2014b; Shilling, Morris et al., 2015). This incongruence is a barrier to the
helpfulness of P2P. This study indicated that referred parents’ perceived gaps in support, their previous experiences with peer support and inadequate program staff explanations of the support parent role potentially contributed to these expectations.

**Changes in Relationship over Time.** Similar to previous studies, the frequency of contacts decreased over time (Rearick et al., 2011). Similar to another sample of parents of children with disabilities involved in a similar volunteer-based P2P program, most parent pairs in the current study had one to two contacts (Abinder et al., 1999). None of the existing studies identified factors driving changes in the relationships over time. This study sheds some light on this question by showing that relationships may be likely to extend if pairs had become friends or based on the continued need of the referred parent, emotional connection and perceived similarity between parents and/or their children, and mutual interest and availability of both parents.

**Contributions to Theoretical Frameworks**

The current study contributes to existing theoretical frameworks that inform social support as a resource to help persons cope with stressors. The transactional model of stress and coping (Lazarus & Folkman, 1984; Park and Folkman, 1997; Thoits, 1986) provides an overall framework for the study’s findings. Support parents’ assistance provided coping resources (e.g., information, a non-judgmental listener, and a recreational partner for themselves and/or children) that referred parents used for problem solving or to reappraise their ASD related stressors as less threatening.

Referred parents’ comparisons to the support parents’ past and present struggles and successes was the mechanism through which referred parents gained hope for improvement in their children and family’s lives, validation of their emotional reactions
validated, and normalization of their experiences. These findings align with social comparison theory (Suls et al., 2002). The study’s findings give some additional insight into the conditions under which positive inferences of upward comparisons (i.e., gaining inspiration or hope by comparing oneself to another person who is better off) might be encouraged and realized, specifically, through choices program staff make in the matching process and how support parents disclose their experiences. As suggested by Suls et al. (2002), if the possibility for improvement in the particular stressful circumstance is high, then a person’s capacity to gain comfort and useful knowledge from upward comparisons might be enhanced. For this sample, support parents’ openness characterized by judicious disclosure appeared to be one way in which support parents can encourage referred parents to make positive inferences from upward comparisons. Specifically, when support parents disclosed experiences in which they show that they had similar problems with similar contexts as the referred parent but experienced improvement, they were able to inspire hope that improvement was possible. Also, this study suggests that when program staff match referred parents to a support parent with an older child who has already experienced some improvement with the area of concern, referred parents tended to derive hope from upward comparisons.

At the heart of every beneficial match was help from a similar parent. Consistent with social identity theory, social support was more likely to be provided and accepted within the matches when parent pairs perceived that they shared a sense of social identity (Haslam, Jetten, Postmes, & Haslam, 2009). Also, social learning theory suggests that peers with lived experience are credible models (Salzer, 2002). Further, consistent with
Social learning theory concepts P2P helped referred parents cope with ASD related stressors through providing the support parents as a successful model of coping.

Referred and support parents’ being open was among the most important interpersonal facilitators of helpfulness and swapping stories was a central activity in helpful matches. This relates to the concept of narrative exchange (Green, 2003). As noted by Orbuch (1997), swapping stories benefits storytellers as it “allow[s] individuals to cope with emotionally charged and stressful events…provide[s] a greater sense of hope and will for the future [and] establish order in daily relational experiences” (p. 459).

The identification of support parents’ relational qualities, namely, being empathic, non-directive, being non-judgmental and listening as facilitators of helpfulness, is congruent with ideas from supportive communication scholarship as important conditions for recipients to perceive enacted support as helpful (Bodie, Vickery & Gearhart, 2013; Burleson & Bodie, 2008).

Noticeably absent from existing theoretical frameworks are program level influences on the helpfulness of P2P as a social support intervention. The current study expands this by adding the program’s matching criteria, training, and explanation of support parents’ role in the creation of expectations for the support parent that are congruent with P2P goals, as important factors affecting helpfulness.
Strengths and Limitations of the Study

Strengths

A major strength of the study was its short-term longitudinal qualitative methodology—that followed the entire course of most parent matches from beginning to end—using scheduled phone interviews and check-ins by phone or e-mail. The in-depth interviews produced rich details of perceived benefits and processes that facilitated and impeded helpfulness that a quantitative study would not have delineated. Following matched pairs prospectively and, in particular, conducting pre-relationship interviews and follow-up interviews within a few days after they conversed along with check-ins before interviews allowed me to track developments more closely than if I had done retrospective interviews for the matched pairs in the study. This made it easier for parents to remember details of the conversations and other contacts they had with each other. This was instrumental in capturing various micro processes or sequences; for example, how the support parents’ disclosures that contained personal details and emphasized similar struggles influenced referred parents to open up about their concerns and accept help. Repeated interviews and check-ins also helped to identify how parents continually used indicators based on their communications and actions during and between their conversations to assess similarity, emotional connection, genuineness, and receptiveness. They also helped identify how parents subsequently used these assessments to decide what their level of engagement in the match would be, which subsequently affected the helpfulness of P2P. Further, it enabled me to identify the dynamism in parents’ contexts (e.g., time demands and gaps in coping resources) that influenced ongoing perceptions of felt need and decisions about whether they would
make time for P2P. Another advantage of a longitudinal data collection with matched parents was that it allowed me to test and elaborate emerging concepts by going back to participants during follow-up interviews.

Because my relationships with matched pairs mirrored in some respects their relationships with each other and also with program staff, my personal experience conducting the research provided insight into the P2P process. In my role as an interviewer, I asked questions and practiced reflective listening to solicit and elaborate on referred parents’ stories. This helped me to understand the P2P benefit of a nonjudgmental listener as an outlet for venting. It also helped me understand what parents meant about not feeling understood by persons who lack experience caring for a child with ASD. As one referred parent said to me, although I could listen compassionately, she felt that I could not “truly understand” her experiences on a “deeper level” because I did not have a child with ASD.

Having to follow parents longitudinally and schedule and conduct interviews and check-ins also mirrored the relationship between parents and between parents and staff. I had to reschedule often and sometimes made multiple attempts before I made contact with some parents. This gave me insight on how challenging it can for parents to make and maintain contact with each other and the staff and how much flexibility and persistence it required. Like staff and support parents, I grappled with the tension of balancing not wanting to be intrusive with needing to make contact. I debated and experienced apprehension about calling parents after I had already had multiple unsuccessful attempts to make contact or schedule an interview. Like support parents, I made judgments about what nonresponse meant, particularly using it as an indicator of
lack of continued interest in the study and the P2P relationship or just being extremely busy. My judgments, especially about lack of continued interest, were sometimes incorrect, which showed how me how parents could misinterpret each other’s actions or inactions.

Finally, although I am not a parent of a child with ASD, I was able to establish a rapport based on other identities and interests that I had in common with parents. This provided practical insight on how matched pairs developed emotional connection partly based on other commonalities outside of their children, and how this made conversations easier. Overall, my experiences as a researcher, because of my inextricable involvement in the intervention process, provided another source of data that confirmed findings based on participants’ data about how P2P worked.

A second strength of the study was the triangulation of sources, that is, collecting data from matched pairs and program staff as most P2P studies have only solicited referred parents’ perspectives. Triangulation of sources provided a more comprehensive understanding of factors affecting helpfulness as there was a tendency for support parents and more so referred parents to reflect primarily on the other’s party contribution to the helpfulness of the match compared to their own. For example, while no referred parents identified their openness and receptiveness as factors affecting the helpfulness of their match, the program staff and support parents did so. Staff added to a richer understanding of what makes P2P work well by their contribution of program level factors such as matching and explaining expectations to referred parents. Also, following pairs allowed me to see the dynamic and reciprocal reinforcing impacts of both parents’ life context, actions and characteristics on the relationship and its helpfulness. It also
specifically allowed me to identify (in)congruence in support and referred parents’ expectations and desires for the match and how this affected the helpfulness of the match. This was, therefore, advantageous over previous studies that either only included one party in the match or included referred and support parents who were not matched to each other.

A third strength of the study was the sample. Previous P2P studies involving parents of children with disabilities excluded parents who program staff or researchers felt were in crisis and parents who felt that their needs were so urgent that they declined to be put on a waiting list (Abinder et al., 1999; Shilling et al., 2014a; 2014b). However, this study did not exclude such parents, making the findings more transferable to parents who request P2P. Also, the parents in my sample were somewhat diverse with respect to race including a fairly even mix of White and African American parents. Referred parents’ children were diverse with respect to age, time since diagnosis, and functioning making the findings transferable to a somewhat wide cross-section of parents of children with ASD.

**Limitations**

One limitation of the study was that my role as a researcher was confounded with the role of staff. My involvement likely modified the P2P process by introducing additional and more frequent follow-ups, especially for support parents who only received one follow-up from staff. It also added structured debriefing for support parents. Together, these seemed to have led to some reactivity for some participants. Specifically, the incentives, scheduling follow-up times in advance, and check-ins likely encouraged some parents to call each other. Also, some referred parents likely persisted
with the relationship because they did not want to disappoint me and because this dissertation study was a course requirement for me. Together these sources of reactivity may have disrupted a more natural evolution of the match where parties may have kept in touch less frequently or ended the relationship sooner. Also, for some support parents, knowing that I was conducting follow-up interviews seemed to have affected how they judged the receptiveness of their referred parent. Support parents typically interpreted the referred parents’ initiation of contact as a sign of receptiveness. However, with my involvement in the matches, some support parents wondered if the referred parents’ initiation of contact was because they knew I would be following up with them rather than because of their continued interested in the P2P relationship.

My follow-up interviews also inadvertently provided an opportunity for debriefing and, in some cases, problem-solving when support parents encountered difficulties in their matches such as poor rapport or inability to make contact. The debriefing and problem-solving that arose out of the follow-up interview questions may have especially encouraged support parents to persist with their matches, particularly those in which there were difficulties making contact or providing help.

A second limitation of the study was that I did not collect data from the program’s staff about their specific involvement in the matches that I followed in the study. This meant I did not query program staff about what referred parents in the study shared at intake about the major concerns for which they were seeking support. Neither did I question staff about feedback referred parents gave them at the follow-ups about their satisfaction with their match and, if applicable, reasons for requesting a re-match. While I had asked parents what were their reasons for seeking support, I did not ask what
reasons they gave to the program staff at intake. This would have improved understanding of how matching criteria and referred parents’ expectations affected helpfulness.

A third limitation was that I was unable to conduct additional follow-ups for some of the matches as parents numbers were out of service or they did not return calls.

A fourth limitation was the sample itself. Although the small sample size was appropriate for a qualitative study, it only represented a small proportion of referred and support parents of children with ASD and P2P program staff that limits generalizability to the wider population. However, I believe the findings have transferability to parents in similar volunteer-based programs. The sample only included only females, English-speaking parents, and parents from primarily urban areas. Parents were White or African American except for one support parent who was a White Hispanic. Therefore, the study’s findings may have limited transferability to fathers, parents of other races and those living in rural areas.

**Implications**

**Implications for Practice**

This study’s findings have direct implications for optimizing the helpfulness of P2P programs serving parents of children with ASD and other special health care needs. More broadly, findings may also be important to optimize one to one peer support programs for parents generally and also for other populations that use or might use one to one matches as a social support intervention, for example, those for persons who have chronic illnesses such as kidney disease (Hughes, Wood, & Smith, 2009).
The first implication pertains to intake and matching procedures. During intake it is important for program staff to confirm referred parents’ need and desire for P2P as these may affect their readiness for and subsequent engagement in the relationship. It is also important that staff clearly explain to referred parents the types of support that support parents are asked to provide and what they should expect in the number of contacts. This is especially important for P2P programs that intend to provide short-term support and phone-based support. Having expectations that are modest and in keeping with the scope of the program may lead to increased satisfaction with matches. Program staff can help link referred parents to other options to pursue long-term support and other opportunities to meet other parents and/or children.

A second implication is that staff during the intake, and matching process may be able to reduce phone tag and scheduling conflict barriers by asking referred parents and support parents the best times to receive calls or meet. Also, programs may better facilitate beneficial P2P outcomes if they match parents based on the referred parents’ major concerns and children’s symptoms and functioning levels. This is expected to enhance the likelihood of parents perceiving similarity, therefore enhancing support parents’ credibility and actual ability to meet referred parents’ needs.

The second implication pertains to support parent training in terms of length, content and delivery. The training used for the P2P model in this study was three to four-hour training, but support parents unanimously reported it as being very useful. This therefore suggests that short trainings can be effective in equipping parents with required skills and basic knowledge on resources to provide short-term and primarily phone-based support. The findings also highlighted that training in the skills of active listening, non-
directive sharing of suggestions, empathic responses, and judicious disclosure of their experiences may optimize support parents’ abilities to be helpful to their matches. Also, the trainer’s delivery of the content on skills should include demonstrations of how to and how not to have conversations as both ways appear to help parents learn relationship skills.

The study’s findings suggest that training support parents on how to communicate genuineness and trustworthiness may optimize the success of the match since perceiving these characteristics were important for referred parents’ receptiveness. Specifically, trainers can encourage behaviors such as offering availability through informing referred parents of the specific times that support parents can talk, and of other ways to access them (e.g., text messaging, Facebook).

Since support parents are aware of the need to pace their overtures based on the referred parents’ availability and needs, it is important for trainers to encourage support parents to use less obtrusive ways to stay in touch such as via text messaging, emails and Facebook. In this way, they can show and offer their continued availability that referred parents in this study used as a marker of their genuine interest to help them.

The third implication concerns follow-up procedures. Program staff involved in the follow-up of matches should also routinely follow-up with support parents to let them know whether referred parents are finding their assistance useful. This is important since support parents continue with follow-up contact based partly on their perception that referred parents are receptive to their overtures and are finding it helpful. Also, support parents use these assessments to help avoid being intrusive given their awareness of referred parents’ busy lives.
For programs similar to the one studied, where all or most contact occurred within the first month of the relationship, program staff should, whenever possible, follow up two times within the first month to ascertain whether support parents are making or attempting follow-up contact. Some referred parents partly judge support parents’ genuineness by their following through with contact. Given this, a follow-up call or the expectation of one may encourage or remind support parents to maintain contact with their match.

A fourth implication is that support parents may benefit from structured, or planned opportunities to debrief and problem solve about their matches. The follow-up interviews provided the support parent with opportunities to reflect on their match and interactions, brainstorm how they might encourage openness, and follow up with any difficulties in their matches. Support parents mentioned that although they knew they could call the P2P agency when there were difficulties, they often did not do so because they were so busy. This suggests that program staff should take a proactive approach by checking in early (e.g., within a week, to see how the match is going) and offering support for matches that are working well.

**Implications for Policy**

A policy recommendation is that social workers and those who work in the ASD community should advocate for government attention including funding for support programs for the parents and families of these children. The study’s findings indicate that these families need opportunities to meet with similar parents and have play dates with their children. Although meeting this need may be outside the scope of P2P
programs as it was in this study, organizations that offer P2P should include opportunities for such interactions or refer parents to other networks that do the same.

It is important that social workers advocate for policies to reduce stigma, discrimination and social exclusion of children with ASD and their families. This includes calls for public education on ASD to help the public understand various ways in which ASD might be expressed. I suggest that policy focus on educating the public on how to respond to children with ASD and their families in non-stigmatizing and accommodating ways in public spaces (e.g., places of worship and recreation). This may be an effective strategy to reduce stigma and increase social inclusion for children with ASD and their families.

**Implications for Social Work Education**

Preyde (2007) noted that “a common social work strategy for helping individuals deal with uncommon events is peer support” (p. 67). It is, therefore, important that students and practitioners working with parents of children with ASD and other special health care needs learn about one to one matches as an option for peer support. More attention in the literature is typically given to support groups including best practices to operate them and factors affecting their usefulness to participants. Courses with content on children’s disabilities and other special health care needs and parenting should include information on how best to structure P2P programs and on the theory underlying the intervention that optimizes their helpfulness to recipients. This should include information on matching criteria to optimize the level of similarity for particular types of support needs, both parents’ openness and other relational qualities.
Recommendations for Future Research

I recommend several research directions to continue to further advance knowledge. There is a need to investigate the helpfulness and evolution of P2P relationships among fathers, non-English speaking parents, recipients of other races/ethnicities other than Caucasians and African Americans, and those living in rural areas. This will improve transferability of findings as well as specifically improve understanding of the impact if any of these demographic factors on beneficial outcomes. Indeed, research from the supportive communication field indicates that persons of different genders and races respond differently to messages intended to provide support (Bodie & Burleson, 2008). Persons who live in rural areas may have fewer opportunities to meet and interact with other parents of children with ASD, and this might lead to a stronger felt need and desire for extended contact.

Future studies should examine the current study’s outcomes and how relationships evolve with different models of P2P: those that use paid supports, in-home or other face to face visits and different training models. Since support parents’ genuineness is an important contributor to referred parents’ openness and engagement in the relationship the role of genuineness and how it is assessed may be different in face to face interactions and with paid support parents. Also, paid support parents may be more likely to be persistent with follow-ups, and this may have implications for helpfulness and duration of the relationships.

Future investigators should also ascertain if possible the reasons parents give at intake for seeking P2P versus what they tell support parents and researchers. This may
improve understanding of the impact of expectations and matching on getting their needs met.

Future studies examining the use of and impact of P2P on parents’ and children’s outcomes should consider the role of other types of support, including online support, that parents may be simultaneously using. As with this sample, parents of children with ASD involved in P2P may already use or begin to use online sources of peer support (Reichow et al., 2012; Twombly et al., 2011). The availability and convenience of these online supports may alter the need for and engagement in P2P. It may also affect the duration of P2P relationships. Simultaneous involvement in P2P and online supports suggest the need to explore the functions that P2P plays in parents’ coping efforts and their relative advantages in comparison to online support. In their survey of 135 parents of children with ASD, Twombly et al. (2011) found that parents primarily used the internet to seek information about ASD, with only 34% and 30% respectively reporting interest in using it for emotional support and to meet other similar caregivers.

Finally, it is important that the research questions be explored with larger samples to generate findings that can be generalizable to parents of children with ASD who use P2P. The findings of this study suggest categories and subcategories of benefits that warrant further exploration as outcome measures. Previous studies have not consistently found statistically significant findings regarding a positive P2P impact on more global measures such as parenting stress and coping efficacy. This study suggests that the P2P might have more specific impacts as indicated in the categories and subcategories of benefits that need to be captured in the outcome measures.
Conclusion

Findings from this study suggest that providing primarily phone based support through P2P may be a viable and effective way to support parents of children with ASD. In this sample, because of their similar lived experiences support parents filled gaps in referred parents’ support system that parents felt could not be met by professionals and family who did not have that lived experience. These similar peers understood their experiences holistically, provided practical tips that were grounded in their everyday life and were a source of non-stigmatizing social companionship for these referred parents of children with ASD. The beneficial outcomes reported by parents of children with ASD in this sample are especially important given this population’s high levels of caregiver burden, parenting stress and documented need for parental support (Karst & Van Hecke, 2012; Twombly, Holtz, Daub-Sychra, 2011). The study’s finding are also important because there have been few programs developed to address caregiver and overall family well-being for these parents. Likewise, there are few studies that examine their efficacy. Instead, much of the policy and research focus has been on early diagnosis, treatment and the needs of the child (Tint & Weiss, 2015; Twombly et al., 2011).

As the first known study with this population of parents this study provides insight into P2P’s benefits to recipients, factors affecting its helpfulness and how these relationships change over time. It also responds to the gap in the P2P scholarship on program staff’s role in and perspectives on barriers and facilitators of beneficial outcomes. In particular, the findings suggests the importance of the role of program staff, particularly in training support parents, matching, explaining expectations, conducting follow-ups and debriefing in optimizing the success of P2P. The results of this study can
be used to inform research to further understanding of the conditions that may promote
effective practice of arranging and supporting P2P relationships.
REFERENCES


use of treatments and therapies for children with autism spectrum disorders.


doi:10.1016/j.rasd.2006.08.006


Green, S. E. (2003). They are beautiful and they are ours: Swapping tales of mothering children with disabilities through interactive interviews. *Journal of Loss and Trauma, 8*, 1-13. doi:10.1080/15325020305875

Green, S. E. (2007). “We’re tired, not sad”: Benefits and burdens of mothering a child with a disability. *Social Science Medicine, 64*, 150–163.

doi:10.1016/j.socscimed.2006.08.025


doi:10.1037/a0019847


Social Sciences, 27(2), 99-117.


Maxwell, A. J. (2005). Qualitative research design: An interactive approach (2nd ed.).

-------------------

206


Nealy, C.E., O’Hare, L., Powers, J.D., & Swick, D.C. (2012). The impact of autism


212


APPENDIX A – RECRUITMENT SCRIPT FOR REFERRED/SUPPORT PARENTS

I will be sending you a flyer about an exciting study of how parent to parent support works for parents of children with autism spectrum disorders. This study is being conducted by Ms. Nina Nelson from the University of South Carolina. We are inviting you to participate in this study as you can help us know how we can improve parent to parent support. This study will involve short 15 to 30 minute interviews with Ms. Nelson on the phone or in-person: one interview before you start your match and at least one follow-up interview after you begin your relationship with your support/referred parent. You will receive a $10 Walmart gift card for each interview you complete. May I have your permission to give your contact information to Ms. Nelson so that she can give you more details about the study and let her know if you like to participate?
Informational Flyer/Announcement to Request Research Participants
Nina Nelson, University of South Carolina

SHARE YOUR Parent to Parent Support Story

If you are a parent/caregiver age 18 or older, who asked Family Connections to match you with a support parent in relation to a child with autism spectrum disorder, you are invited to participate in a confidential study.

The purpose of this study is to examine how parent to parent support works for parents/caregivers of children with an autism spectrum disorder.

I am conducting this research as part of completing a Ph.D. in social work through the University of South Carolina.

I am inviting you to help build up knowledge in this area by participating in short 15 to 30 minute interviews about your parent to parent support experience. Our hope is to enhance P2P especially for parents of children with ASD.

All information will be strictly confidential.

If you are interested in participating in this study or have questions that I may answer, please feel free to contact me, Nina Nelson at nelsonnn@mailbox.sc.edu or (803)-463-9568
SUPPORT PARENT FLYER

Informational Flyer/Announcement to Request Research Participants
Nina Nelson, University of South Carolina

SHARE YOUR Parent to Parent Support Story

If you are a parent/caregiver age 18 or older, who accepted Family Connection’s request to be a support parent for a parent of a child with autism spectrum disorder, you are invited to participate in a confidential study.

The purpose of this study is to examine how parent to parent support works for parents/caregivers of children with an autism spectrum disorder.

I am conducting this research as part of completing a Ph.D. in social work through the University of South Carolina.

I am inviting you to help build up knowledge in this area by participating in short 15 to 30 minute interviews about your parent to parent support experience. Our hope is to enhance P2P especially for parents of children with ASD.

All information will be strictly confidential.

If you are interested in participating in this study or have questions that I may answer, please feel free to contact me, Nina Nelson at nelsonnn@mailbox.sc.edu or (803)-463-9568.
APPENDIX C- INFORMED CONSENT

PARENT INTERVIEW

Parent Support for Parents of Children with Autism Spectrum Disorder:
Perspectives of Parents and Program Staff
Principal Investigator: Nina Nelson

Introduction and Purpose
You are invited to participate in a research study to help us better understand how parent to parent support (P2P) works for parents of children with an Autism Spectrum Disorder (ASD). I am Nina Nelson, a doctoral candidate in the College of Social Work at the University of South Carolina and I am conducting this study as part of the requirements for my doctoral degree. This form explains what you will be asked to do if you agree to participate in this study. Please read it carefully and feel free to ask me or my supervisor Dr. Arlene Andrews any questions before you make a decision about participating. Our contact information is at the bottom of this form.

Study Procedures
This study will involve a few brief 15-30 minute interviews which I will conduct by telephone or in person, depending upon your preference. I will contact you by phone or e-mail to schedule the interviews. The first interview will take place before you make your first contact with your [support/referred] parent. After you make contact with your [support/referred] parent, we will have up to 7 follow-up interviews (for up to six months) depending on how frequently you contact each other and how long your P2P relationship lasts. The first follow-up will take place within one week after you begin your relationship with your [support/referred] parent. After this, we will schedule follow-up phone or in person interviews at mutually convenient times. Each interview will be audio-recorded so that I can accurately reflect on what you share with me. I will ask you questions about your child’s disability, and what led you to become involved in the P2P program. I will ask you about your experiences with the P2P program such as how you got to know your [support/referred] parent and how your relationship with your [support/referred] parent is developing. I will also be inviting your [support/referred] parent to participate in their own interviews. However, I will not share what you tell me with your [support/referred] parent.

Benefits of Participation
This study will give you an opportunity to share your own experience, express your feelings and opinions and share information that may help us understand how to make P2P more helpful for parents, especially those whose children have an ASD.

Possible Risks of Participation
Any risk to participating in this study is very low. You may find that answering questions about your child’s disability such as how does autism affect your child, and what led you to become involved with the P2P program is somewhat upsetting to you, although many parents report feeling good as a result of talking about how they manage as a parent. If needed, referral information to a counseling resource will be provided.
Costs
There will be no costs to you for participating in this study other than any transportation costs if we meet face-to-face.

Payment
In appreciation for your participation in this study, at the end of each month you will receive a $10 Wal-Mart gift card for each interview that you complete.

Confidentiality of Records
What you share with me will be kept confidential. The audio recordings will only be reviewed by me and transcriptionists who will sign a Transcribers Confidentiality Agreement. The results of this research will be published in my dissertation, subsequent journals or books, or may be presented to a professional audience and used for scholarly purposes. However, no names and information that can identify you and others will be in the typed interviews, or released in write-ups or when presented. All study materials and communications will be kept in password-protected computer files and in a locked file cabinet.

The only exception to confidentiality is that if I have reason to believe a child may be at risk of child abuse or neglect or that you may at risk of immediate harm to yourself or others, I am required by law to make a report to the state child welfare or law enforcement agency.

Voluntary Participation
Participating in this study is voluntary. You can stop participating at any time without any consequences. There is no right or wrong answers to any of the questions and you can choose not to answer any question for any reason. Whether or not you choose to participate or answer the questions will not affect your receiving services from Family Connection.

Contact Persons
If you have questions or concerns you may contact me (Nina Nelson) at 803-463-9568 or nelsonnn@mailbox.sc.edu. You may also contact my dissertation chair, Dr. Arlene Andrews at 803-777-1126 or AANDREWS@mailbox.sc.edu. If you have any questions about your rights as a research participant, you may contact Thomas Coggins, Director of the Office of Research Compliance, University of South Carolina, Phone - (803) 777-7095, Fax - (803) 576-5589, or E-mail, tcoggins@mailbox.sc.edu.
Dear P2P Staff,

My name is Nina Nelson, a doctoral student in the College of Social Work at the University of South Carolina (USC). You are being invited to participate in my research study about parent to parent support (P2P) for parents of children with autism spectrum disorder (ASD). I am conducting this research as a part of completing a Ph.D. in social work through USC. There is very little research on P2P and so your input can help us build up knowledge in this area. Our hope is to enhance P2P especially for parents of children with ASD. You are eligible to participate if you are at least 18 years old and have arranged, followed-up matches or provided consultation to support parents.

This study will involve 40-60 minute interview which I will conduct by telephone or in person, depending upon your preference. I will contact you by phone or e-mail to schedule the interview at a time that is mutually convenient. The interview will be audio-recorded so that I can accurately reflect on what you share with me. I will ask you questions about your experiences with the P2P program. The interview will be audio-recorded and transcribed so that I can accurately reflect on what is discussed.

What you share with me will be kept confidential. The audio recording will only be reviewed by me and a transcriptionist who will sign a Transcribers Confidentiality Agreement. The results of this research will be published in my dissertation, subsequent journals or books, or may be presented to a professional audience and used for scholarly purposes. However, no names and information that can identify you and others will be in the typed interviews, or released in write-ups or when presented. All study materials and communications will be kept in password-protected computer files and in a locked file cabinet.

Taking part in the study is your decision. You can stop participating at any time without any consequences. There is no right or wrong answers to any of the questions and you can choose not to answer any question for any reason.

I will be happy to answer any questions you have about the study. You may contact me at 803-463-9568 or nelsonnn@mailbox.sc.edu or my dissertation chair, Dr. Arlene Andrews at 803-777-1126 or AANDREWS@mailbox.sc.edu. If you have any questions about your rights as a research participant, you may contact Thomas Coggins, Director of the Office of Research Compliance, University of South Carolina, Phone - (803) 777-7095, Fax - (803) 576-5589, or E-mail, tcoggins@mailbox.sc.edu.

Thank you for your consideration of this important research. If you would like to participate, please contact me as outlined above.

Sincerely,

Nina Nelson, MSW, PhD. Candidate
College of Social Work, DeSaussure College
University of South Carolina
Columbia, SC, 29208
APPENDIX D - INTERVIEW GUIDES

Interview Guide: Pre-match- Referred Parents

1. Please tell me what led you to become matched to a support parent?
   
   **Probes:** What do you want most from your support parent?
   
   What do you plan to share, talk about, ask about?
   
   What events led up to this? Why at this point?

2. How have/were you and your family coping? What has helped you cope?
   
   **Probes:** Other sources of support-peer support, family, faith community- how have these helped?
   
   What are you hoping a SP will add to your life?

3. Have you ever been matched to a support parent before, if yes tell me about it?
   
   [For this child? When? ]
   
   **Probes:** What were you hoping to get from that experience?
   
   Did you get what you were hoping for? How did it help with the concerns that led you to ask for a support parent?
   
   What was most helpful? What other ways did it help?
   
   What ways if any was it not as helpful as you had hoped?
   
   What made the match helpful and/or not as helpful?
   
   What if anything would have made it more helpful? You would have changed/hoped was different?
   
   [About how long you kept in touch, how many conversations].
   
   What happened after that? How would describe the relationship now- friends, etc.?
   
   What led you to (not) keep in touch?

Information Form- Referred Parent (if not previously mentioned)

1. When was your child diagnosed with ASD?
2. How does autism affect him/her
3. Any other special health care needs/diagnoses?
4. Birth month and year of your child with ASD
5. Number of other children, age? Special health care needs/Disabilities?
6. Employed/Self-employed: No Yes Part-time Full-time
7. If yes, what type of work?
8. Do you work outside the home? No Yes
9. Other time commitments (e.g., school, volunteer work)?
10. Age
11. Marital Status married/partnered single divorced
12. Apart from you/ & spouse/partner who helps you take care of your child?
13. Highest level of education completed?
14. How would you describe your ethnicity/race?
Interview Guide: Support Parents- Pre-match

1. Please tell me what led you to become a support parent?
2. What led you accept the FC request to be a support parent for ______ at this time?
3. [How do you plan to approach this match?]
4. What information were you given about the referred parent?
   **Probes:** reasons for seeking P2P? About his/her child? About the parent himself/herself?
5. Have you ever had a support parent? If yes, When? For what child?
   a. What were you hoping to get from this match?
   b. Did you get what you were hoping for? How did it helped with concerns that led you to ask for a SP?
   c. What if anything was most positive/helpful about that experience? What other ways did it help?
   d. What ways if any was it not as helpful as you had hoped?
   e. What made the match helpful and/not as helpful?
   f. What if anything would have made it more helpful? You would have changed/hoped was different?
      **PROBES:** About how the P2P agency set up the match? How the SP interacted with you? How you interacted with the SP?
   g. How long did you keep in touch, how often? How would describe your relationship now- friends, etc?
6. Have you been a support parent prior to this match, If yes [When/1st time? How many times?
   a. Let’s talk about the match where you felt you were able to be most helpful to a parent? What ways were you most helpful? How else?
   b. What made the match helpful?
   c. Were there times when you felt this match or another was not as helpful as you had hoped? –tell me about an instance that stands out to you
   d. What made the match helpful and/not as helpful?
   e. What if anything would have made it more helpful? You would have changed/hoped was different?
   f. What type of relationship do you have with the referred parent now?
   g. What led you to stop keeping in touch or not as often?
7. What has helped you so far to be an effective support parent?
   **Probes:** Training? Other resources/information from FC? Having a support parent? Other experiences?

**Background Information**

1. When was child diagnosed with ASD? (other diagnosis if not ASD; other comorbidities)
2. How ASD affects child’- past at diagnoses, and how those have changed and now.
3. Birth month and year of your child with ASD
4. Number of children? Their ages? Disabilities if any?
5. Are you now receiving P2P from a SP?
6. When did you receive your SP training?
7. When was your first experience as a SP?
8. Number of matches to a RP of a child with ASD:
9. Number of RPs are you matched to now/at the time of match?
11. Marital status
12. Age
13. Apart from you/& spouse/partner who else helps you take care of ____?
14. Highest level of education completed?
15. How would describe your race/ethnicity
Interview Guide - P2P Staff Interview Guide

Let’s begin by telling about your role in the P2P program & how long you worked with it?

1. How long have you been working with the P2P program?

2. Tell me the ways in which you have been involved with the program?  
   **Probes:** intake (initial call with RPs), matching, follow-up, training support parents

3. Are you/were you a parent/caregiver of a child with a special care health need/disability?  What disability?

4. Have you received support from a Support Parent?

5. If you had a SP and RP, how long ago? Your child’s diagnosis

6. What led you ask/accept a SP?

7. What were you hoping for? Did it meet those expectations? Did it help in other ways as well?  
   What made it helpful? Not as helpful as you would have liked?

8. How long did you stay in touch? What made you end before the minimum of 3-4 calls or continue after that?

9. Have you been a support parent? How long? How many matches? Times Matched for ASD?  
   Are you still an active support parent now?

**Transition statement: Now I would like you to explain how the matching process works:** What happens when the referred parent calls?  
**PROBES**
  a. What information do you ask for? do you ask parents specifically what they wanting help with at first match or is this only at rematch  
  b. What matching criteria do you use to match  
  c. What information do you give them?  
  d. What do you share about what they should expect from their support parent?

10. SPs talk about having matches where they feel have been able to help RP and others not so much. What has been your experience as a SP have you had that?  In your experience as a SP what makes matches most likely to be helpful?  
    **PROBES:**  
    Commonality: what ways? (Children’s, parents- social background: race, social class, religion, locality, gender, feeling connected (is it necessary?)  
    How do these make matches helpful?-age, gender, locality, social background?
11. In your experience as a SP what limits the helpfulness of matches? felt you weren’t as helpful-example

**PROBES**
What RPs says - Matching characteristics-age, gender of child, locality where SP lives, SP behaviors, personality, SP openness
a. What SPs says- RP openness, receptiveness, expectations, similarity

12. In your experience as someone who does matching/re-matching or hears about the f/ups what makes matches most likely to be helpful?

**PROBE**
a. What RPs says - Matching characteristics-age, gender of child, locality where SP lives, SP behaviors, personality, SP openness
b. What SPs says- RP openness, receptiveness, expectations, similarity

13. **PROBE**
14. What RPs says - Matching characteristics-age, gender of child, locality where SP lives, SP behaviors, personality, SP openness
15. What SPs says- RP openness, receptiveness, expectations, similarity
16. What in your experience seems to be the most important thing that make matches work?

**PROBES:**
Commonality? What ways? (Children’s, parents- social background: race, social class, religion)

17. In your experience as someone who does [matching/follow-up/matching and follow-up] what limits the helpfulness of the match? What reasons do parents give for wanting a rematch? Are these issues any different for referred parents of children with ASD?

18. How long have you stayed in touch with your matches? What made you end before the 3-4 calls or continue after that?

19. What are your recommendations for improving P2P to make it more helpful to parents of children with ASD?

20. Is there anything else that you would like to share concerning your experience with P2P?
Follow-up Interview Guide - Referred Parents

1. When and how did you (first) make contact?

2. Tell me about your first conversation:
   a. What did you talk about/share/questions asked? What did your support parent share?
   b. How did you feel about her responses to___? Was it helpful? What if anything was most positive about the conversation, what else?
   c. [If not brought up- In our first (last) interview you mentioned __________ as the concerns/areas that you wish to benefit from having a support parent. So far have you talked about this? How helpful was this?
   d. How long was your conversation?
   e. How did you get along? How comfortable did you feel talking to each other? What contributed to this?

3. Have you spoken/been in contact since then? If yes, how and how many times? Tell me about those contacts/conversations? REPEAT QUESTIONS 2a-e

4. You have mentioned that your conversation(s) has been helpful and/or not very helpful-what has made it (them) helpful? Not very helpful?

5. So far how good of fit do you think this match is for you?
   a. What makes this match such a good/poor/ok match for you?

6. What, if anything, would have made/would make this relationship more helpful? Would you have changed about the conversation/ or the agency set up this match?

7. If you have had another support parent before, how does this relationship compare with each other?
   a. How you got along?
   b. How helpful?
   c. How good of a fit is this match for you?

8. What your next steps for this match?

9. Is there anything else that you would like to share about your experience with P2P?

10. Since our last interview tell me about any changes in your working situation/ school situation/other time commitments-volunteer work

    scheduling f/up interviews: If it’s okay with you I’d like to call1-2 days before our scheduled follow-up to see if you have made contact/ talked with your match since our last interview, if you have not then we can reschedule the interview?

    Gift cards: At the end of the month I will send you a$10 Walmart gift card for each interview you have completed.
Follow-up Interview Guide - Support Parents

1. When and how did you first make contact and talk?

2. Tell me about your first conversation:
   a. What did you talk about/share? What did your referred parent share? What do understand to be her concerns? Questions asked?
   b. How did she seem to respond to what you shared/suggestions/response to _______? Was it helpful? What if anything was most positive about the conversation, what else?
   c. How long was your conversation?
   d. How did you get along? How comfortable did you feel talking to each other?
   e. What contributed to this?

3. If you have contacted each other since then let’s talk about that:
   a. How many other times have you spoken/contacted each since then? By what methods(text, phone-call, e-mail, in-person)
   b. Repeat 2a-e

4. You have mentioned that you were (not) able to helpful with …. What do you think has contributed to you (not) being able to help?

5. What are your thoughts so far about how good of match are you for each other?

6. What, if anything, would have made/would make this relationship more helpful? Would you have changed about the conversation? More contact/longer conversations? About how the agency set up this match?

7. If you have/had other parents you are supporting, how does this match compare with the others?
   **PROBES**
   a. How you got along? What contributed to this
   b. How helpful? What contributed to this?
   c. How long you stayed in touch? What contributed to this?
   d. How good of a fit you were for each other? What contributed to this?

8. Is there anything else that you would like to share concerning your experience with P2P?

9. What your next steps for this match?

10. Since our last interview tell me about any changes in your working situation/ school situation/other time commitments-volunteer work.
APPENDIX E- TRANSCRIPTIONIST CONFIDENTIALITY AGREEMENT

Transcriptionist Confidentiality Agreement

Purpose of Agreement:

This serves as an agreement between ________________________________

Transcriptionist Name

and Nina Nelson, student researcher and doctoral student at the University of South Carolina, College of Social Work. Nina Nelson has obtained University of South Carolina Institutional Review Board Approval to conduct this study and adheres to all policies related to confidentiality and human subject protection. Nina Nelson is conducting research in order to fulfill degree requirements on a study tentatively entitled, "Parent to Parent Support for Parents of Children with Autism Spectrum Disorder: Perspectives of Parents and Program Staff"

Confidential Information:

All digital audio taped information provided to ________________________________

Transcriptionist Name

is considered highly confidential pertaining to this research project. Any information pertaining to this research project can only be shared with Nina Nelson.

Agreement:

______________________________ agrees not to disclose, publish or reveal

Transcriptionist Name

information received from Nina Nelson and maintains all information in a safe, locked secure location. Electronic information will be password protected. No information can be duplicated.

Work Completed:

______________________________ agrees to return work, along with original

Transcriptionist Name

materials provided, within ten days upon request of Nina Nelson. Any copies of files made remaining in transcriptionist’s possession must be destroyed within ten days upon completion of the work. I will return a signed form to Nina Nelson, indicating that all information has been destroyed to maintain confidentiality.
By signing below, I agree to the above expectations and guidelines:

______________________________  ______________________________
Transcriptionist Signature      Date

I ______________________________have destroyed all information provided to me by
                             
Transcriptionist Name

Nina Nelson, student researcher and doctoral student pertaining to the study tentatively
titled, “Parent to Parent Support for Parents of Children with Autism Spectrum Disorder: 
Perspectives of Parents and Program Staff”.

______________________________  ______________________________
Transcriptionist Signature      Date