UNIVERSITY OF CALIFORNIA

Santa Barbara

The Development of a Measure of Readiness to Volunteer as a Peer Support Provider for an Organization Serving Parents of Children with Special Needs

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

by

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University of California Santa Barbara –Santa Barbara, CA 2011-2015
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California State University at Dominguez Hills –Carson, CA 2002-2004
California Teaching Credential
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Emerson College –Boston, MA 1997-1999
Master of Fine Arts in Writing, Literature and Publishing
Master's Thesis: "Common Cues"- 30 Short Poems with Seasonal Influences
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Binghamton University –Binghamton, NY 1993-1997
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The Early Childhood Education Center –Albany, NY 2008-2011
Master Special Education Teacher
Preschool Self-Contained Classroom
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The Center for Disability Services –Albany, NY 2006-2007
Special Education Teacher
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United Cerebral Palsy of Nassau County –Roosevelt, NY 2004-2006
Early Intervention Special Educator
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Clinical Research Project Coordinator
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The Early Childhood Education Center-Albany, NY 2011
Parent Workshop/ Make and Take
Utilizing picture exchange in the home to facilitate the communication of basic wants and needs

The Early Childhood Education Center –Albany, NY 2010
Parent Training
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The Early Childhood Education Center –Albany, NY 2009
Site Training
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The Center for Disability Services –Albany, NY 2007
MOVE Curriculum Trainer
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Los Angeles Unified School District 2004
Parent Training
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PUBLICATIONS AND PRESENTATIONS

- **Speaker Session** 2015
Parent to Parent USA Directors Institute, Scottsdale, AZ
Parent to Parent Support for the 21st Century: Online Training and Support

- **Panel Presentation** 2015
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Providing Parent To Parent Support To Traditionally Underserved Families

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What Does it Mean to be Ready? A Qualitative Interview Study with Parent to Parent Leaders

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CalTASH, San Francisco, CA — 2013
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Disability Studies in Education Conference, Hunter College, NY, NY — 2012
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Dodds, R. (2011). iPad Usage in the Special Needs Classroom. *Autism Spectrum Quarterly*, Spring 2011, 11-12. — 2011

Dodds, R. (1999). I See My Mother. *The Beacon Street Review*. 12(2). 2. — 1999

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ABSTRACT

The Development of a Measure of Readiness to Volunteer as a Peer Support Provider for an Organization Serving Parents of Children with Special Needs

by

Robin Lynn Dodds

The question of who is ready to serve as a help-giver reflects an unresolved question in the research on parents of children with disabilities. There is little consensus as to whether or not there are regular, predictable phases of adaptation to a child's disability. The purpose of this research was to develop a measure of readiness to be trained as a supporting parent volunteer for the Parent to Parent USA Network (P2P). The measure is based on a theory of change developed from a qualitative interview study with P2P leaders and a review of the literature. The measure was hypothesized to be comprised of multiple dimensions corresponding to the categories of giving back, successes, building capacities, building relationships, communication/ listening, positive thinking, future orientation and red flags. Following exploratory factor analyses, a three-factor solution was attained. The 17-item measure of readiness was comprised of factors named Into Action, Wellbeing and Skills and Navigation. The measure demonstrated good internal consistency, and evidence for convergent validity was demonstrated by showing that the readiness scale displayed significant correlations with measures of empathy and depressive symptoms as hypothesized. A significant relationship was not established with posttraumatic growth, possibly due to a lack of power. Additionally, significant group differences on the readiness measure existed between parents who had and those who had not been trained to be peer supports and parents who had and had not received support from P2P. Implications, limitations and areas of future research are presented.

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I. Introduction

Parent to Parent is a program by which parents of children with disabilities or other health needs receive informational and emotional support via a one-ton-one match with a more experienced support parent. A parent seeking help is matched with a trained veteran parent along a variety of child and family specific factors such as child age, disability, specific systems navigation, culture, language, geographic area and socio-economic or marital status (Santelli, Turnbull, Sergeant, Lerner, & Marquis, 1996). The criteria used to make a match are determined by the needs and concerns of the referred parent, and the first contact is generally made between the support parent and the referred parent within 48 hours. Matches between parents of children with rare disorders or very specific needs may require additional time to put together, as coordinators may need to contact coordinators from other areas in order to locate a suitable match.

Parent to Parent support programs are available in most US states and programs are currently being developed internationally. Matched dyads communicate mostly by telephone, and in successful matches bonding between the two parents is often attributed to the similarities in their experiences of raising a child with a disability. Although Parent to Parent USA is available across the country, it is not generally a stand-alone organization in that a parent would be introduced to the organization by way of the intake interview at a regional center in their geographic area. Parent to Parent coordinators in charge of the recruitment and training of support parent volunteers are generally individuals who work at the regional center or community resource center and wear multiple hats in their service to the disability community. They are also, for the most part, the parent of a child with a disability.

Statement of the Problem

The question of who is ready to serve as a help-giver reflects an unresolved question in the research on parents of children with disabilities. There is little consensus as to whether or not there are regular, predictable phases of adaptation to a child's disability. Parent to Parent training documents often include information related to one or more phase theory, but do not state in these materials whether these theories are applied in the selection or evaluation of support volunteers.

The Parent to Parent board posed their question of volunteer readiness, as the hypothetical question: "What if a parent is still crying a lot?" This phrasing reflects the persistent belief parents initially experience considerable sorrow about their children's disabilities, and implies an implicit belief in stage theory. In the early 1980s, one view was parents went through particular stages of grief leading to ultimate psychological adaptation. One such map of stages was borrowed from Kubler-Ross's theory of grieving in which bereaved people were said to progress through five stages of grief beginning with denial, anger, bargaining with God, depression and culminating in acceptance (1969). Under the influence of grief theories, interventions were designed to help parents move beyond sorrow.

Parent to Parent resource materials may include references to Kubler-Ross as well as a later stage theory, specific to parents of children with special needs, as proposed by Nancy Miller in her book, *Nobody's Perfect: Living and Growing with Children who have Special Needs* (1994). Miller's four stages of adaptation derived from four years of observation and transcription of a support group for mothers of children with disabilities: Surviving, searching, settling in and separating. Each phase posits a variety of physical and psychological manifestations that may vary in their presentation in an individual. For example, the surviving stage may include fatigue, headaches, depression, guilt, fear, shame, anger and denial amongst other markers. When a parent has "regained a sense of control" over their emotions (p. 31), they are thought to have "survived." At this point, Miller asserts, a shift in life-purpose occurs for a parent of a child with a disability, and they begin the work of searching for answers regarding their child and how disability will affect the family. As parents feel more confident in their abilities to help their child and enter a more balanced way of life, they are said to be settling in. The final stage proposed in *Nobody's Perfect* is separating. Separating is noted as a parent makes long-term plans and goals for their child toward increased autonomy.

Although not explicitly outlined in training manuals, coordinators have shared they seek volunteers who appear to be in the "settling in stage." This stage theory focus however, may preclude the use of certain volunteers such as those of children with significant persistent medical issues or those living in poverty, as these are noted in Miller's book as barriers to settling in. These experiences may be valuable to those experiencing similar struggles, and opportunities for rich matches with otherwise exceptional supporters may be missed due to these life circumstances.

Stage theories, however, were called into question by research showing parents did not progress along an orderly series of stages on the way to adaptation (Blacher, 1984). A more recent longitudinal study by Bonanno and associates examined patterns of spousal bereavement from the pre-loss period to 18 months post-loss in 205 individuals, and found evidence of at least five distinct patterns of grieving. These include, in order of prevalence; resilience, chronic grief, common grief, depressed-improved, and chronic depression. Of these five, common grief is the sole category associated with stage theory, accounting for only about ten percent of respondents. Interestingly, resilience was noted in more than forty-five percent of participants and marked by low levels of depressive symptoms at pre-loss and even lower levels at six and eighteen-months post loss. Resilient individuals were more likely to exhibit emotional stability and indicate higher levels of support. This finding runs counter to grief stage theories that contend an individual must have a release of emotions to adjust to a stressful event. Individuals showing no signs of depression are considered to be in denial, and experience a delayed grief response. Bonanno and his colleagues found this untrue, as less than four percent of respondents demonstrated this pattern of delayed grief. This longitudinal bereavement study highlights a new depiction of resilient individuals who do not appear to display signs of external grief, rather choosing to emotionally move past the event (Bonanno, Wortman, Lehman, Tweed, Haring, Sonnega, & Nesse, 2002). Therefore, a new approach to the assessment of the readiness of recruits may provide a better idea of volunteer fitness for parents of children with disabilities and special healthcare needs to provide peer support in this community.

A measure highlighting the positive attributes and attitudes of volunteers rather than relying on specified stage theories may prove to be more inclusive of a greater number and variety of recruits. Additionally, such a measure may provide Parent to Parent Coordinators information regarding particular strengths and needs of individual volunteers by examining scores on individual factors. Interventions can be put in place to support those families whose experience is valuable to others, but may have a particular pressing need. A volunteer who scores poorly on several or all factors however, may never become an appropriate fit for the role of support provider. A parent who scores poorly across factors is likely not moving through stages, stuck in a state of negativity. As they do not display many positive attributes, they would offer little help to another and could possibly harm a parent in need.

Peer-support organizations like P2P USA have moved into unchartered territory by employing such online training modules and online support groups or listservs, following the need to reach young families and meet parents "where they are at." A concern expressed by some P2P coordinators though, was "training has to have a face-to-face component." Because you "don't even know who [a] parent is" without in-person interaction (Dodds, 2014). Bypassing this initial relationship through technology and volunteering via an internet portal, a coordinator may miss an opportunity to assess the readiness of the recruit through conversation, and fail to spot potential "red flags" detrimental to a fragile referred parent matched with them. Alternatively, some Coordinators use online training and recruitment processes as an opportunity to "work backwards," finding reasons to connect with the trainee over the phone or in-office during the training process to more familiarize themselves with the parent.

The inability of parents to travel to trainings and support groups due to inflexible work/parenting schedules lack of transportation and geographic spread are also stimulating this change. Access to web-based trainings and online assessments completed at a parent's convenience, without the need to travel, may improve a Coordinator's ability to recruit a greater diversity of parent volunteers thereby meeting the needs of more referred parents. A measure of readiness to volunteer could be administered online as a part of a volunteer pre-training screening assessment and may offer Coordinators more time and give them greater confidence in their choice of high quality recruits.

Purpose

The purpose of this research was to develop a measure of readiness to be trained as a supporting parent volunteer for the Parent to Parent USA Network. The measure will be based on suggested attributes that P2P leaders find apparent in individuals who are high-quality support parents and appropriate to recruit as volunteers. The measure will represent attributes in separable factors possibly including giving back, successes, building capacities, building relationships, communication/ listening, positive thinking, future orientation and red flags. Parents of children with disabilities may be pressed for time, therefore such measures will be reduced to those items most closely representing the construct, keeping the number of items to a minimum with a target number of items ranging from 15 to 20. This measure will be utilized in the selection of high-quality volunteers for training. As the recruitment and training processes can be costly for this primarily volunteer organization, this tool can help coordinators focus their resources on the highest caliber recruits. The measure will assist coordinators to weed out volunteers who may need more time or experience as a parent before they gain the desirable traits of a ready volunteer, or may not ever be suitable in this role which will be discussed in greater detail in a later section of this paper.

Research Questions

1. What are the key elements that comprise the measure of readiness?
2. Is there evidence of convergent validity in the measure of readiness?
3. Does the measure of readiness display a difference in scores between parents who are or have been trained as peer support providers and parents who have not?

Overview of Theoretical Framework

Parents of children with disabilities may suffer from isolation, stress and depression due to increased burden of caregiving, stigmatization by community and family and/or reduced family income. Given recent cuts to important family supports such as respite care, parents of children with disabilities may experience a heightening of these negative responses and, lacking the support and access, find emotional support and additional resources to fill in the gaps left by cuts in social services in the wake of the 2008 recession.

Peer support programs have been shown to provide such emotional and informational support for various groups of individuals such as breast cancer patients, nursing mothers and those in recovery from addiction. Most peer support programs are informal, employing volunteers to provide support. Efficacy of such programs can be attributed to the equanimity of the relationship, the flexibility of the support, and shared experience of the peers, which can lend credibility to advice shared between the peers.

Social support from informal sources such as peers is theorized to be a form of coping assistance, where the person providing support facilitates the help seeker in the construction and reconstruction of a narrative in a therapeutic manner, through active listening strategies and the sharing of positive perceptions culled from their own experiences. No one person can be expected to be positive at all times, but a high positivity to negativity ratio is believed to reduce the negative effects of care-taking and increase family quality of life. Additionally, women may be predisposed biologically to seeking out social support in times of high stress. Organizing themselves in groups with the purpose of tending to youngsters and providing support to one another has proven historically protective to women and children in a manner that the male response to danger, fight or flight, is not.

What leads a person with a full schedule focusing on the care and education of their child with a disability and keeping a family balance find time to volunteer to provide support to someone else? Empathy for another's suffering is a known motivator for all kinds of prosocial behavior including volunteerism, but the similarity of experience between parents of children with disabilities heightens this empathy leading to an overlap between the self and the other, which some parents have described as paying it forward. This motivation for service can be to ameliorate the pain of a negative experience similar to their own experience, or to prevent such experiences from occurring by imparting knowledge and positivity.

Peer support programs for parents of children with disabilities is an under-researched topic in Special Education, often small in scale and qualitative in nature. With the push toward evidence-based practices in Special Education, funding sources prefer a universal scientific link between parent services and student educational outcomes. While this challenge lies beyond the scope of this project, it does figure into the rationale for the improvement of peer support services, peer support recruitment, and training processes as a primary step on the road to the establishment of an evidence base.

Overview of the Methodological Framework

The steps involved in the development of a new measure begin with the development of a "precise and detailed conception of the target construct and its theoretical context," (Clark, & Watson, 1995, pg. 310) which in this case comes from a pilot qualitative interview study and subsequent grounded theory. Then, the researcher begins to write items believing they represent the construct as defined, and only that construct (Cook, & Beckman, 2006). The next concern is to identify separable dimensions and determine which items load onto which factors, and to maximize the amount of variance explained (Floyd, & Widaman, 1995) through exploratory factor analysis (EFA). If the test developer is working from an existing theory of the construct, employing confirmatory factor analysis should determine how well the model fits the data. In this case, EFA is most appropriate. Readiness to become a peer support provider for P2P is a new construct and the theory is based on data from a small number of participants. Data is thus reduced and the measure refined in an iterative process. Reliability is estimated by test-retest or internal consistency procedures. Internal consistency is the more popular method, as reported in terms of coefficient alpha (Furr, 2014). Convergent and/or discriminant validity can then be estimated by investigating a series of correlations between the construct and other constructs in light of theoretical predictions (Campbell and Fiske, 1959). The measure is further evaluated for "goodness of fit" with a new larger sample. "Goodness of fit" is understood as the degree that the model is consistent with actual data, and provides feedback on a measure for refinement purposes.

Significance of the Study

This study makes a useful contribution to both basic and applied research on peer support for parents of children with disabilities. The absence of established methodology for the measurement of readiness to volunteer as a peer support provider and more specifically, readiness to volunteer as a peer support provider in P2P USA represents a crucial gap in the current literature. This study advances the basic research, exploring whether this psychosocial construct is quantifiable, offering implications for researchers exploring similar constructs for different volunteer organizations. Also, a reliable measure of readiness to volunteer as a peer support provider in P2P USA would allow an opportunity for further study in the evaluation of peer support for parents of children with disabilities, perhaps as a first step to build stronger evidence base for additional funding of Parent to Parent and similar peer support organizations in the future.

Stakeholders in Parent to Parent USA could use this list of attributes that likely comprise readiness in the recruitment, selection and retention of high-quality volunteers. Many other social support agencies, relying heavily on a volunteer work force, struggle to provide services with shrinking budgets, so may also benefit from the research for an enhanced understanding of volunteer readiness in one area may provide useful insight to other organizations tasked with providing other peer support services.

Lastly, broadly speaking, this study may hold significance for local and national funding agencies and US healthcare policy makers. As healthcare costs increase, the budgets for services designed to support people with disabilities and their families have been slashed, leaving individuals overwhelmed and underserved. Gaining support locally and nationally for high quality peer support provided by a trained volunteer workforce may be a useful and inexpensive stopgap in the wake of the fiscal downturn and further may have a positive effect on individual and family health outcomes.

Chapter Summary

The chapter presented the problem of determining readiness of a potential help-giver to another parent of a child with a disability as posed by the Parent to Parent executive board several years ago. Hypotheticals such as, “is it okay if their still crying a lot?” led to the development and implementation of an interview study of P2P leaders to gain a greater understanding of significant attributes a parent ready to serve the organization embodies. Furthermore, the following study was designed with the purpose of determining if the psychosocial construct of readiness could be meaningfully measured. The author believes the study contributes to the fields of special education and disability studies research as well as peer support programs and presents an important step in understanding how to recruit and train high quality volunteer workers.

A review of the literature is presented in Chapter 2. Chapter 3 describes the methodological processes utilized in the development of items for a measure of readiness to volunteer to be a peer support volunteer for Parent to Parent USA. Exploratory factor analysis procedures, reliability and validity checks are discussed in detail. Chapter 4 contains the results and Chapter 5 is concerned with the discussion and implications.

II. Literature Review

The following chapter contains a literature review of concerns related to the development of a measure of readiness to provide support for a volunteer peer-support organization. Issues of wellbeing pertaining to the burden of care for families of children with disabilities, as well as similarities between parents who have adapted positively and individuals who have experienced a similar construct, posttraumatic growth will be presented. The need for and efficacy of peer supports will be discussed in relation to budget cuts. The chapter will introduce a peer support organization providing emotional and informational support to the parents of children with disabilities and other health care needs. Empathy and its role in motivating volunteering behavior and as a mechanism for the effectiveness of the Parent to Parent matching protocol will be discussed. The chapter will also present the results of a pilot interview study exposing attributes of individuals deemed ready to support others and discuss the subsequent grounded theory developed. Finally, an outline of the methods proposed for the development of a measure of readiness will be presented.

Families and Disability

The negative impacts of caring for a child with a disability or special health care needs is a frequent a staple of research in special education and psychology, and continues to be a popular field of study. Many scholars found a relationship between caring for a child with a disability and elevated parent stress and increased report of depressive symptoms. When compared to the parents of typically developing children, parents of children with disabilities exhibit greater stress related to their child's symptoms coupled with a more pessimistic vision of their future (Dyson, 1997) and higher levels of depressive symptoms (Olsson &

Hwang, 2001). Certain child and family characteristics, as well as the severity of symptoms, have been shown to further increase the levels of stress and depression in families of children with disabilities. Child characteristics such as behavior problems and Autistic characteristics and severity of medical symptoms are associated with higher levels of stress and depression in families (Floyd & Gallagher, 1997; Olsson & Hwang, 2001; White, & Hastings, 2004). In their 2005 review of the literature, Blacher, Neece, & Paczkowski confirmed the link between Autism, behavior problems and increased stress and depressive symptoms in parents. Additionally, Hassall and associates reported the behavior of school age children with intellectual disabilities explained a substantial portion of the variance in parent stress (Hassall, Rose, & McDonald, 2005). In mothers of children with Juvenile Arthritis, the severity of the child's illness and its impact on family life correlates to the mother's mental health in that increased arthritis symptomology was associated with a greater psychological symptomology (Lustig, Ireys, Sills& Walsh, 1996). Family characteristics that may lead to increased levels of stress and/or risk for serious depression in parents of children with disabilities include both single parenthood (Olsson, & Hwang, 2001) and low socioeconomic status (Blacher, Neece, & Paczkowski, 2005). The constant demands related to the dual burden of care for a disabled child and elderly parents are also noted to decrease the stress resiliency of caregivers putting them at greater risk for illness and burnout (Perkins, 2010).

Although many families of children with disabilities are two-income households, often the burden of care for the child with a disability falls mostly on the mother. For this reason, much research concerning families and children with disabilities has concentrated on the negative effects on the health and wellbeing of mothers. A quantitative study of two-parent families having sons with and without a developmental a disability reported the fathers generally assume less responsibility of care for the child with the disability even when the mother maintained full-time employment, which intensified when the child exhibited behavioral atypicalities (Bristol, Gallagher, & Schopler 1998). Additionally, parents of children with disabilities or chronic healthcare needs often experience a reduced sense of parenting efficacy when dissatisfied with the support they receive from their spouse (Bristol, Gallagher, & Schopler, 1988). The increased burden of care on mothers may account for higher reported stress and depressive symptoms, and highlights the importance of interventions that facilitate healthy adaptation for the entire family unit.

In addition to bearing the greater responsibility for caretaking, mothers of children with disabilities often express more feelings of social isolation and stigmatization in the community as well as within their own social circles. Family members and friends may have difficulty relating to the mother's experience or provide a role as a supportive ally. Families may not feel they can participate in formerly enjoyed activities due to difficulties associated with physical boundaries or child behaviors, reducing their access to recreation and leisure. In a review of the literature on social supports and stress in mothers of children with Autism, low levels of social support were most powerful predictor of depression and anxiety in mothers, with mothers who had the least reliable supports displaying increased negativity towards their child and pessimism regarding their child's independence in the future (Boyd, 2002). Research conducted with families of children with intellectual disabilities and severe behavior problems has shown worry about future and pessimism about their children's future are significant issues for this group, and often lead to parents giving up in seeking services to help their child (Floyd & Gallagher, 1997).

Heiman (2002) conducted interviews with 32 parents of children with intellectual, physical and learning disabilities from special education schools in Israel to identify barriers and facilitators to achieving successful family routines, reactions to initial diagnosis, the benefits and difficulties of parenting a child with a disability, and feelings and plans for the future. Many families expressed feeling physical and emotional fatigue, social isolation, a general lack of information needed to make planning decisions for their child, having to fight for services and supports, a lack of recreation activities across the family and worries about the impact of the child with a disability on siblings. Jones and Passey (2005) reported parents experiencing somewhat self-imposed social isolation due to the stress of everyday dealings with friends and family who lack understanding of their situation. The research was conducted with 48 families in Great Britain with children with developmental disabilities and behavior problems. Measures included; parental stress, family resources, coping strategies and parental locus of control. Stepwise multiple regression analysis was conducted to investigate predictors of stress. The most potent sources of stress reported were social isolation, interaction with professionals, receiving a diagnosis and lack of information available regarding their child's disability and services available.

Stressed and depressed parents may parent differently than non-depressed parents (Hastings & Beck, 2004), as exposure to an increased number of family and environmental stressors contributing to child abuse risk (Brown, Cohen, Johnson, & Salzinger, 1998). According to a study of all students enrolled in Omaha public schools, the incidence of abuse for children with a known disability is three times that of children without, with children with behavioral disorders and intellectual disabilities being represented in disproportionately high numbers (Sullivan & Knutson, 2000). A longitudinal study in New York examined several family, parental, demographic and child characteristics, and found children with low verbal IQ were associated with a three-fold risk for parental neglect. Sexual abuse risk was nearly twelve times the average for children educated in self-contained special education settings (Brown, et al., 1998). In 2010, the Fourth National Incidence Study of Child Abuse and Neglect (NIS-4) examined the relationship between the incidence of maltreatment and child's disability status for the first time. Their report to the United States Congress stated children with disabilities had lower reported rates of physical abuse than the general population of children, but experienced significantly higher rates of emotional neglect, and when they were physically harmed, they experienced more serious injuries than their typically-developing peers (Sedlak, Mettenburg Basena, Peta, McPherson, & Greene, 2010).

The impact of having a child with a disability can overwhelm a family and the support of another parent with similar experiences can share helpful information. Their ability to listen and empathize could be a powerful agent of change for both parent and family. Such a relationship may serve to reduce isolation, provide exposure to a more positive way of thinking and link a parent with resources that can reduce stress in their household thereby increasing the wellbeing of the entire family.

In today's unstable economy following the great recession of 2008, funding for service providing assistance to needy individuals has been drastically reduced, leaving already vulnerable populations limited access to support. Resource limitations in funding agencies have highlighted the importance of providing evidence for the effectiveness of interventions for individuals with disabilities and their families, so as to use limited funds in the most efficient and effective ways possible. The Parent to Parent social support organization will be discussed in light of empirical research on family stress and coping, peer support and posttraumatic growth, with recommendations for further validation of the program to establish a firm evidence base in order to increase consumer access to this valuable resource.

In 2011, the government allotted $4 billion for family support for families who care for a relative with a disability, a rather small portion of the nearly $57 billion spent on individuals with intellectual and developmental disabilities (Braddock, Hemp, Rizzolo, Tanis, Haffer, Lulinski, & Wu, 2013). At least 29 states and the District of Columbia have made cuts to home care and medical services for persons with disabilities or have increased the share of the cost burden individuals must contribute for these services (Johnson, Oliff, & Williams, 2011). Individuals with disabilities and their families are among the group of individuals who must bear reductions in the availability of already scarce funds and supports. According to a national online survey regarding disability supports for individuals with intellectual disabilities and their families conducted by The Arc in 2010, over sixty percent of families experienced a reduction in services and supports for their family member with a disability. Roughly, a third of individuals had been on a waitlist for a government-funded service for over five years (The Arc, 2011).

Family-focused supports such as respite, which provides caregivers of family members with disabilities access to increased employment and recreation opportunities by funding short-term care from an outside provider, has been increasingly more in demand (Reinhard, Houser, & Choula, 2011) as more individuals with disabilities across the lifespan live at home with their families. Family supports in many states include, in addition to respite, funds for goods and services not covered by insurance and trainings for parents and family members to better care for their child. Unfortunately, increased demand for services to assist families had not been met with increased availability of supports to foster the wellbeing of those involved in caregiving, and program waitlists have grown in response to entitlement program budget caps in the wake of the fiscal downturn (Hewitt, Agosta, Heller, Williams, & Reinke, 2013). These services also are in danger of being cut or eliminated altogether in many places across the United States, thereby increasing the burden of care on responsible family members.

Social Support

A growing body of literature documents the effectiveness of peer support for a variety of purposes such as increasing the time for breastfeeding (Dennis, Hodnett, Gallop, & Chalmers, B. 2002), improving the mental health of cancer patients (Hoey, Ieropoli, White, & Jefford, 2008), and supporting parents of children with chronic illnesses (Ireys, Chernoff, DeVet, & Kim, 2001). Further, specifically targeted parent to parent support helping raise children with disabilities (Kerr, & McIntosh, 2000; Law, King, Stewart, & King, 2002; Singer, Marquis, Powers, Blanchard, DiVenere, Santelli, Ainbinder, & Sharp, 1999), has contributed to this growing literature.

Peer support can be provided in a variety of formal and informal contexts, such as: groups moderated by professionals (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003), on crisis warm-lines (Pudlinski, 2005), or in the hallways before a child's music class (McCabe, 2008). Most evidence for the effectiveness of peer support for families with disabilities comes from qualitative interview studies of parents. In one such study, the parents of children with congenital upper limb deficiency involved in peer support programs reported receiving emotional, social and practical support experienced a buffering effect to stress. For many participants, contact with another parent whose child had the same disability and was a bit older than theirs marked a turning point, providing them with a potential future imparting a sense of positivity (Kerr & McIntosh, 2000). In Horton & Wallender's 2001 assessment of hope and social support in mothers of school-age children with chronic physical and health care needs, they concluded perceptions of hope were associated with maternal distress, so mothers who expressed high levels of hope during times of high stress related to their child's disability reported lower levels of distress (Horton & Wallender, 2001). The positivity and hope transmitted by the Parent to Parent support parent through the close one-to-one match is an important component of the efficacy of the program and has been shown to decrease stress and depressive symptoms for the help-seeking parent.

According to Thoits, empathic understanding is "based on sociocultural and situational similarities between a distressed person and a helper" (Thoits, 1986, p. 416), and further contends empathic understanding is necessary for social support coping to be sought, accepted and effective in helping an individual adapt to a difficult situation. This similarity between the self and other involved in the provision of peer to peer support has also been supported by interview research of parents of children with Autism. They reported enjoying conversing and sharing their experience as a parent of a child with a disability, learning from each other. This informal sharing provided moral support and the opportunity to engage in a more egalitarian relationship free of stigmatization (McCabe, 2008).

In a 2007 interview study of the mothers of seriously ill and dying children, participants reported having a one-to-one support relationship with another more experienced parent who had displayed successful adaptation provided them with practical suggestions, encouragement to seek out information regarding their child, and encouragement to advocate on behalf of their child. Although these parents believed their partnerships with professionals were important, they felt the relationship with a peer mentor was more authentic due to their shared experience (Konrad, 2007). Members of peer support programs like Parent to Parent tend to share a positive focus on life, their abilities, and their children, imparting a sense of belonging and empowerment (King, Stewart, King, & Law, 2000). This is in contrast to information and suggestions received from professional service providers, who are often be perceived by parents as expressing things in a negative, deficit-oriented way (Hastings, Allen, McDermott, & Still, 2002).

Social support is conceptualized as a network of behaviors providing another person with assistance in coping with stressors. Help can be provided in the form of encouragement, companionship, direct assistance, affection, or advice, and support. It can come from a variety of sources such as family members, friends, neighbors or religious groups (Cutrona & Russell, 1990). Social support has proven an effective buffer to parenting stress (Kerr, & McIntosh, 2000, Dyson, 1997), and reliable support can help parents and families gain a better quality of life (Blacher, et al., 2005; White and Hastings, 2004). In fact, mothers of children with disabilities who report a greater number of helpful supports also tend to have lower levels of stress in general (Boyd, 2002) and more specifically, related to their parenting (Hassall, 2005). Mothers who receive social support from a spouse, family and/or another parent of a child with a disability tend to exhibit lower levels of depressive symptoms, increased parenting efficacy and have happier marriages (Boyd, 2002; Weiss, 2002). Harmony in the parental relationship may be related to child wellbeing (Bristol et al.1988), and further, improved child behavior (Blacher, et al., 2005).

Peers can assist an individual in coping with stress by helping them change or manage the stressful situation itself, or to reduce their negative feelings from stress (Thoits, 1986). The two types of coping most consistently found to be beneficial to parents of children with disabilities are active coping strategies (planning, problem solving, information seeking), and positive reframing (Beresford, 1994). Social support may enable a person under stress to assign cause or meaning to event so they may reestablish sense of control over the stressor. A supporter may also encourage the individual to learn new skills, further imparting a sense of mastery and control within a stressful situation. Additionally, social support may lead an individual to reappraise their situation as more positive, leading to enhanced self-esteem (Summers, Behr, & Turnbull, 1989). In a study of mothers of school-age children with intellectual disabilities, researchers found acquisition of social supports, especially from informal sources, such as other parents with children with disabilities, and positive reframing strategies most reliably predicted personal growth for mothers. Positive reframing also was associated with increased happiness, fulfillment and strength for mothers, and predicted family closeness (Hastings, Allen, McDermott, & Still, 2002).

Social support may be related to many facets of wellbeing for parents of children with disabilities, but the type of social support provided be matched specifically to the facet of coping best suited to confronting the specific stressor (Cutrona & Russell, 1990). Stressors can be divided into two groups, controllable and uncontrollable. For those perceived as uncontrollable, emotion-focused coping, such as positive reappraisal, validation and thoughtful listening, are best suited to adaptation. Stress experienced due to controllable events, such as the loss of social integration due to unemployment, are best approached with problem-focused coping. Resources, strategies and tips can be shared to assist the individual in their job hunt (Cutrona & Russell, 1990). Parent to Parent support parents are trained to respond to stress-creating issues and provide support targeted to address the specific individual needs expressed by the help-seeking parent.

Patterson's Family Adjustment and Adaptation Response model (FAAR) presents a theory of family response to stress. A family of a child with disability may experience increased obligations and limited resources, leading to a "pile-up" of family demands. This may lead the family into "a period of significant disequilibrium and disorganization" (p. 351), during which crisis occurs. In order to restore balance in the family, adaptive families can reduce demands, increase their capabilities or change the meaning of stressors. Vulnerable families do not recover from a crisis, and subsequent stressors only add to their unbalance and risk for negative outcomes (Patterson, 2002). A more experienced other parent could provide the family with access to resources, such as respite, after-school care or practical examples of how they cope with stress in adaptive ways, aiding the family in recovery from disequilibrium.

Unfortunately, most families do not seek out social support from informal sources, relying generally solely on school-based services for their child. Pessimism and fatigue often lead them to give up seeking additional support (Floyd, & Gallagher, 1997). Parents of children in known high stress-inducing sub-groups such as those with challenging behavior (Boyd, 2002; Floyd, & Gallagher, 1997) are more likely to join social support organizations. As part of a state-sponsored effort to improve services for individuals with Autism in Pennsylvania, researchers utilized a 92-question survey to measure participation in and the quality of different services. One thousand five caregivers of children with autism responded to questions regarding support group participation, interactions with the healthcare system, and child characteristics, as well as demographic information. The authors found parents of children who exhibited self-injurious behavior, sleep disorders or severe language deficits, in addition to those referred to a group by a physician, were more likely to seek out social support in some form (Mandell & Salzer, 2007). Many families do not seek out social support before their family has reached a point of crisis, as families in this state are fragile, and require support from knowledgeable and patient high-quality trained providers.

At this point in the argument, the known differences in families with positive adaptive coping and poor coping must be discussed. In 2002, Taanila, Syrjälä, Kokkonen, Järvelin set out to identify frequently used coping strategies of families of children with physical and intellectual disabilities, and to differentiate characteristics of high and low coping families in Finland. Through face to face interviews, which were coded according to grounded theory methods, the authors discovered well-adapted families had extensive and supportive social networks, whereas families having difficulty adapting to their child's disability had small support networks consisting of predominately formal supports. Additionally, high copers held a more optimistic attitude towards their life, family, child and the future, believing their child would have enough supports and abilities to maintain a good quality of life. Low coping families carried substantial fear and uncertainty about the future for themselves and their child and had given up on recreation activities they enjoyed due to their child's disability (Taanila, Syrjälä, Kokkonen, & Järvelin, 2002). The pairing of a high-level coper with a low-level coper may impart positivity through models and help grow their social network through exposure to additional resources.

Families who experience crisis in the form of the shock of the diagnosis of a child with a disability and do not experience negative outcomes over the long term, or even come through the experience improved are said to exhibit resilience. In reality, many families do fall in this category, but research on maladaptation continues to be predominant. According to a 2006 meta-analysis by Singer, although mothers of children with disabilities display an increased prevalence of elevated depressive symptoms as measured by instruments, such as the Beck Depression Inventory, as compared to mothers of typically developing children, over 70 percent of mothers with disabled children assessed do not exhibit these symptoms (Singer, 2006). Certain subgroups of parents such as those with children with autism and severe behavior disorders have more consistently shown increased risk for divorce. Divorce rates amongst couples with children with disabilities are not significantly higher than those in the general population (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond, & Bolt, 2010). So, what can be learnt from families who are doing well, and what can that teach us about the provision of social support to families who are in need of coping assistance?

As stated earlier, many resilient parents of children with disabilities report positive perceptions of their child's gifts and abilities, personal growth and increased family closeness even as they deal with stress and negative events. Scorgie and Sobsey (2000) deem these "transformational outcomes" in that they are significant and positive changes in the lives of families parenting children with disabilities. These transformations may be related to three areas; improved relationships, personal growth, and changes in spiritual or philosophical values. Parents reported strengthened marriages, improved cooperation in the family, new roles taken on within the disability community, increased advocacy for their child, a new orientation to serving others, cherishing every day, and building strong friendship networks for support. Additionally, parents often attribute this growth to the positive contributions of the child with the disability to the family (Summers, Behr, & Turnbull, 1989).

Similar outcomes are reported in the literature on meaning making and posttraumatic growth (Park, 2010; Park & Folkman, 1997; Tedeschi & Calhoun, 1996). According to Park and Folkman, traumatic events like the diagnosis of a child with a disability, often leave parents feeling a loss of the sense of control in their life. In response to the stress caused by the loss of control, they will make attempts to regain control by trying to solve the problem. This may lead to rumination (repetitive, intrusive thoughts) in an attempt to process the unpleasant information. The authors suggest a reappraisal process is more appropriate in this situation as:

> Some of the most persistent stressors, however, are impervious to problem solving, discouraging active ameliorative coping efforts. In circumstances that are not amenable to problem solving, the stressful impact of the problem may be buffered by responses that control the meaning of the problem (p. 124).

Further, in her 2010 article on meaning-making, Park asserts the end result of successful “meanings-made’ is not only acceptance of the traumatic event, but access to new goals, opportunities and a sense of personal growth. Tedeschi and Calhoun developed a measure to assess positive outcomes reported by those who have experienced traumatic events based on the literature of post-traumatic growth. Their scale contains five factors most frequently reported as areas of growth by individuals after significant traumatic events such as rape, HIV infection, and natural disasters. They were called relating to others, new possibilities, personal strength, spiritual change and appreciation of life (Park, 2010). Further exploration of the moderating effects of positive perceptions, and their utility in the provision of social support coping interventions, is warranted (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Hastings & Taunt, 2002).

Parent to Parent is a program matching parents of children with disabilities or other health needs with a more experienced, trained support parent. Parents are matched based on factors important to the help-seeking parent; child age, child's disability, culture, primary language, geographic area, specific information or systems navigation amongst others (Santelli, et al., 1996). The Parent to Parent Coordinator gives the support parent the contact information for the help-seeking parent generally within two days time (Santelli, Turnbull, Marquis, & Lerner, 1995).

Evidence-based practice for appropriate matches indicate matches where children and families are most similar are more beneficial to parents, as the information and support shared seemed credible to the parent seeking help, facilitated by a sense of "perceived sameness" (Ainbinder, Blanchard, Singer, Sullivan, Powers, Marquis, & Santelli, 1998). According to a 1999 mixed-methods, randomized trial which evaluated the Parent to Parent program in three regions of the US, the benefits of these matches match include, meeting the specific need originally prompted their contact with Parent to Parent, improved perception of the ability to cope with their child and family situation, and a more positive appraisal of their life circumstances (Singer, et al., 1999).

According to the *Parent to Parent USA Endorsed Practices for Parent to Parent Support*, support parents should make at least four contacts within the first two months of the match, as the satisfaction of the referred parent increases with the number of contacts with the support parent (Santelli et al., 1996). Referral coordinators responsible for arranging the match, call the referred parent to make sure first contact has been made, to check the goodness of fit between the two parents, and to answer any parent questions. The coordinator then contacts both the referred parent and the support parent after eight weeks to evaluate the match in a manner that will address the needs initially prompted the referral.

Matches were not effective when supporting parents were too busy to make contact or lost contact information, could not afford to call long distances, children were too different from one another, or parent values or personalities were perceived to be incompatible. Recommendations were made for further work in quality control of Parent to Parent matches concentrating on the perceived sameness of the referred parent and support parent as well as consistent follow-up by coordinators so if the match is found incompatible, a new match could be made in short time if needed. The training of support parents was also discussed underscoring the personal readiness of support volunteers in future parent trainings (Ainbinder et al., 1998).

The “Broaden and Build Theory of Positive Emotions” may help us better understand one important component in the mechanism for the efficacy of Parent to Parent support. (Fredrickson, 2001) In her theory, Fredrickson proposes experiencing positive emotions broadens one’s thought-action repertoire, which builds physical, social, intellectual and psychological resources. Negative emotions such as fear, anger and sadness limit the possible reactions from which a person can choose. Similar to the fight or flight response, these reactions are intrinsically programmed for situations of immediate danger. A sense of limited agency may plague a parent of a child with a disability or chronic health condition who is having difficulty coping with their child’s disability.

The referred parent may be inspired try a new strategy their support parent has shared, thereby entering a new phase in which problem-focused coping strategies. Supports can be online resources or conferences on relevant topics (Thoits, 1986). Planful problem solving is associated with a reduction in negative emotions and an increase in positive coping (Folkman & Lazarus, 1988). New choices are subsequently revealed. Subsequent successes help the child, increasing efficiency, and family balance is first experienced. The occurrence of positive events, even within the context of chronic stress, can cut off non-adaptive rumination and prevent future depression (Folkman & Moskowitz, 2000). Further, successful attempts directed at solving a problem are associated with increases in self-esteem, positive mood and sense of control (Folkman & Lazarus, 1988; Folkman & Moskowitz, 2000; Nezlek & Gable, 2001; Pottie & Ingram, 2008).

Unlike traditional grief theory, which is conceptualized as having distinct stages marked by behaviors of denial, anger, bargaining with God, depression and culminating in acceptance (Kubler-Ross, 1969), the process by which parents update, rebuild and replace the expectations held before the birth of their child with the realities of their child's disability is an ongoing effort (Barnett et al., 2003). Each family may express different needs for coping assistance. Interventions designed to support emotional coping may not be helpful to a family at peace with their child's diagnosis, but is in need of information or resources in the community; likewise, the sharing of information and resources with a parent who has not accepted their child's prognosis may negatively impact their wellbeing by making them feel overwhelmed. According to a qualitative research study of nine parent peer support groups in Canada, balancing group activities with the needs of parents is a significant challenge to group-support organizations. Although groups were designed to assist parents of children with disabilities, group philosophies and effectiveness varied greatly. Some groups were oriented towards providing emotional support, while others focused on advocacy and promoting social justice issues (King et al., 2000).

For many mothers of children with disabilities, the period immediately following the diagnosis of a disability can be a time of emotional turmoil, marked by feelings of guilt, shame and jealousy of mothers with typical babies. Mothers' first experiences following the birth of a child with physical deformities manifest in the loss of expected social role due to not being able to "show baby off." (Kerr, & McIntosh, 2000). Social support a new mother seeks initially may focus on emotional coping as she experiences the initial trauma of diagnosis. Family stressors tend to change in nature as children age, transitioning from home to school, school to school, and school to post-school life transitions are as difficult times for families of children with disabilities. According to research conducted in the United Kingdom by White and Hastings, support needs often change as children enter their adolescence. The researchers assessed wellbeing, social support, and child characteristics of 33 parents of children with moderate to profound intellectual disabilities between the ages of thirteen and nineteen years old. Practical support was found to associate with parental wellbeing whereas emotional support was not (White & Hastings, 2004). This finding is at odds with research on families with children of younger ages who benefit from both types of support (Kerr & McIntosh, 2000; Rahi, Manaras, Tuomainen, & Hundt, 2004), and may be due to the existence of those parents who have accepted their child's disability by their child's adolescence. No longer in turmoil, parents may be more likely to seek informational and tangible support. Accordingly, needs for support families change as they make attempts to adapt to new situations, necessitating the support offered be flexible to meet the changing needs of the individual.

According to research conducted by Konrad, participants reported one-to-one support provided by a trained mentor allowed the support to be individually tailored to expressions of support required (2007). One of the most important and valued characteristics considered in matching parents involves asking the help-seeking parent which are the most salient issues for which they are seeking support. Coordinators then match the help-seeker with another parent who, through their experiences and/or training feels qualified to provide the needed support. This suggests that Parent to Parent matches are designed to be as specific as possible, thereby reducing frustration and ensuring a positive experience for all parties involved (Santelli et al., 1995). The specificity of the match underscores the flexibility inherent in the structure of the Parent to Parent program.

Budgetary constraints in the healthcare system require the development and promotion of valuable adjunct systems that provide information and support to individuals with disabilities and their families. Hastings and Beck conclude, in their 2004 review of the literature on parent stress interventions, the Parent to Parent model is effective in its reduction of parent stress due to its detailed matching process, and also is cost-effective, as it relies mainly on volunteer workers to provide support to help-seeking parents (Hastings & Beck, 2004). As many Parent to Parent programs are sponsored by another service provider agency such as a local family resource center, access is given to meeting rooms, and training assistance and promotion costs are kept at a minimum by sharing resources (Santelli et al., 1995). Additionally, longitudinal research conducted with a variety of organizations concluded participation in self-help activities lead to reduced use of costly professional services (Humphreys, 1997). Doctors and other professionals may benefit by referring parents of patients to Parent to Parent networks in their area causing a reduction in parent questions and uncertainty, and increased adherence to prescribed interventions (DiMatteo, 2004). Furthermore, Mandell and Salzer found that parents were more likely to access social support networks when referred by their physician (2007).

Empathy and Volunteerism

What drives an already busy parent of a child with a disability to volunteer? Empathy is a well-researched psychosocial construct theorized to have a strong relation to prosocial volunteer behavior. Although there are many theories as to how, when and why empathy leads to helping or not helping others in need, it is universally accepted empathy and prosocial behavior are linked. There are however, different conceptions of what empathy is and how it is best measured. Several theories will be discussed in this section in light of how they may or may not relate to Parent to Parent volunteerism.

The empathy-altruism model is described as the ability to comprehend another person's distressing experience and behave prosocially as a result (Davis, 1983). In line with this hypothesis, Penner and associates developed a measure called the Prosocial Personality Battery (PSB) by examining existing measures of prosocial behavior and choosing items most consistently predicting a variety prosocial actions. The resulting instrument contains two factors, other-oriented empathy and helpfulness. The first factor concerns primarily prosocial thoughts and feelings, whereas, the second factor measures behavioral tendencies. Helpfulness was found to be a slightly better predictor of prosocial behavior as it was associated with a sense of self-efficacy and self-confidence, which may encourage action. The authors also conclude the main motivation for helping others may be demonstrating one's self-efficacy rather than empathic concern as it is for many others (Penner, Fritzsche, Craiger, & Freifeld, 1995).

When an individual relates more closely to another in need, they are more motivated to help and perhaps the close matching process has proven to be effective in Parent to Parent pairs. Parent to Parent leaders also affirm this “having walked in your shoes” idea is a motivation for volunteers to self-refer for training as a P2P support parent. Perceived similarity is a social psychology term meaning the compassion we feel for another person is related to how similar to ourselves we perceive them to be. Perceived similarity seems to be the main motivator for peer support volunteers (to help others who have similar struggles) as well as its mode of efficacy as information and emotional support provided by a similar other is deemed more trustworthy and valuable. Cialdini, Brown, Lewis, Luce and Neuberg (1997) conducted three experiments investigating the impact of empathic concern on a subject’s willingness to help. Their results suggest high empathy-inducing situations brought about a state of oneness between the self and other in an individual’s mind, leading to increased prosocial behavior. Additionally, early work by Stotland (1969) also proposes increased perceived similarity between an individual and another in need will increase empathy and therefore increases the likelihood of the individual offering help.

Batson and associates conducted two experiments to assess the validity of the perceived similarity theory by having participants read an empathy-inducing passage regarding an individual who was either demographically quite similar or quite different Results did not support the perceived similarity theory, as empathy reported for the similar condition was actually lower than reported in the dissimilar condition. Their second experiment in which the same empathy-inducing scenario was described for a college-aged woman (same), a child, a dog and a puppy, also did not support the perceived similarity theory, as reported empathy was higher in the different conditions. The results were consistent with the theory of nurturant tendencies, an evolutionary theory that individuals feel empathy for others due to our human extension of the nurturant tendencies mammals exhibit in behavior designed to protect and care for offspring (Batson, Lishner, Cook, & Sawyer, (2005).

The "oneness" as discussed by Cialdini is closely related to the evidence-based practice for matches in P2P USA. Research indicates matches where children and families are most similar are more beneficial to parents, as the information and support shared seem more credible to the parent seeking help, facilitated by a sense of "perceived sameness" (Ainbinder, Blanchard, Singer, Sullivan, Powers, Marquis, & Santelli, 1998). Penner's finding proves some test subjects may help others out of a sense of self-efficacy rather than purely selfless motives. This finding aligns well with sub-themes derived from an interview study of Parent to Parent leaders (Dodds, 2014). Participants in this study mentioned that parents who are ready to support another parent have often found things that help their child and/or their family, possibly through trial and error, and want to share their findings with others to save them the frustration of searching. Participants also reported building capacities by reading books and attending workshops, and at some point realizing the skills and information gathered could be valuable to others, prompting them to volunteer.

In an earlier study, Cialdini proposed helping behavior is an egoistic response to relieve the sadness empathizing with a person in need rather than a selfless response to reduce the other's suffering. The researchers performed two experiments to provide evidence for their Negative State Relief Theory. In the first experiment, sadness and empathic concern were experimentally separated, resulting in helping behavior predicted solely by personal sadness of the subjects, not by empathy for the other. The second experiment supported an egoistically-based interpretation of helping under high empathy conditions, as subjects were informed helping would not improve their mood and unlikely to provide help to a suffering individual (Cialdini, Schaller, Houlihan, Arps, Fultz, & Beaman, 1987). Batson and his colleagues further tested the Negative State Relief Theory through a series of three experimental studies (1989). First, the researchers told participants they would receive a mood improving experience regardless of whether they chose to provide help to the individual in need or not. Confirming Cialdini's theory, participants were unlikely to provide help. In the second and third experiments, Batson separated participants into two groups, one comprised of individuals with a high level of empathic concern, and another of individuals reporting high personal distress in a peer shock scenario. The researchers repeated the first study's protocol. The results of these two experiments revealed high empathizers were equally as likely to help when they anticipated receiving an artificial mood enhancer, as they were when no mood enhancement was suggested. This series of studies provides evidence although many individuals provide assistance to suffering individuals as a means to reduce their own distress, individuals who exhibit higher levels of empathic concern help for purely altruistic reasons (Batson, Batson, Griffitt, Barrientos, Brandt, Sprengelmeyer, & Bayly, 1989). High empathizers may prove to be the best P2P support parent. They can feel for others without becoming overly distressed, offering help for altruistic purposes.

Parent to Parent matches are known to be beneficial to the wellbeing of both the helper and the helpee in well matched pairs. This balanced relationship may relate to the idea individuals assist others partially to relieve their own discomfort, but I assert the good feeling one receives by doing good is more highly related to true altruism. Furthermore, it has been shown when an individual is able to imagine themselves in the position of a needy person and engage then in conversation, they are increasingly likely to provide assistance, as this interaction may also heighten empathy and leading to increased prosocial behavior (Andreoni & Rao, 2011). The Parent to Parent leaders interviewed in the pilot study for this project mention the desire to give back as a motivator to volunteer (Dodds, 2014). This is likely an avenue for a person who has struggled to make meaning of their difficulties and utilize what they have learned in a manner positive and inspiring to others in a similar situation.

Empathy avoidance is a related concept developed to explain why people often fail to respond to individuals in need. It is hypothesized individuals actively resist feeling empathy for an individual in need in order to avoid being motivated to act prosocially. When faced with a high-cost helping scenario, individuals are less likely to listen to an empathy-inducing plea, possibly to avoid feeling motivated to help (Shaw, Batson, & Todd, 1994). This phenomenon is also noted in professionals whose job requires frequently being put in high-empathy inducing situations such as social workers and psychologists. Goubert, Craig and Buysse examined the cost of accurate empathizing in such careers and assert individuals who consistently display high levels of empathy for those in need could be perceived as oversensitive and may have difficulty providing effective assistance to others due to their high levels of distress in hearing the troubles of others. Individuals who feel another's pain deeply subsequently put themselves at risk for vicarious traumatization and professional burnout. Service providers who are able to regulate their own emotions in response to another's distress of may be more likely to remain well adjusted socially over the long term and provide more effective care to suffering individuals. Downgrade one's own distress response leaves an individual motivated to help one who is suffering for selfless reasons, and may provide the helper with more flexible responses tailored to the needs of the person they intend to help (Goubert, Craig, & Buysse, 2011).

Negative state relief and empathy avoidance are theories focusing on the personal distress an individual experiences in response to witnessing another in pain. Occasionally Parent to Parent coordinators will come across an individual at a training who is exhibiting traits non-conducive to being placed in a matched relationship with a parent seeking assistance. The leaders interviewed called these traits red flags, ways a trainee speaks about their life with their child with a disability demonstrating they are not ready or may not be appropriate to be trained as a Parent to Parent support. An individual exhibiting these red flag behaviors may be negative, judgmental, searching for cures for their child, be constantly overwhelmed and/or not having control over their emotions.

The interview study with P2P leaders revealed the most common red flag subtheme was "uncontrolled emotions," This category alludes to the personal distress a parent who is not ready or not appropriate to provide support to another parent may experience when listening to another person's story. This is evidenced by a quote from a P2P USA leader in response to the question, "What if they are still crying a lot?"

> If every parent they talk is going to bring up the emotions… if they're crying a lot and …the emotions are so much with every single match, then we are going to say they are not quite ready yet…If they can't limit that, those conversations, if they feel like that anger is something that has to come out during every match, then they're not ready yet.

Parents who do not have control over their emotions are often given volunteer duties for the organization that do not include direct contact with help-seeking parents. This practice seems practical in light of the literature on personal distress, as Goubert and colleagues claim increased personal distress leads to ineffective helping behavior, whereas high empathizers who are able to regulate their emotions are superior helpers and flexible problem-solvers.

Peer support services have also emerged as resources to the mental health community as adequate professional services become less available to consumers. An analysis of emotive responses to the communication of trouble on a peer support line for individuals with mental illness revealed strategies for communicating empathy over the phone. Empathy can be communicated effectively in several different ways. Sharing a similar experience or feelings was theorized by the author to be the most potent method of empathic response to troubles telling. It displays a strong sense of understanding the issue and feelings at hand, normalizes the feelings of the caller, and indicates a higher level of concern due to shared experience (Pudlinski, 2005). These findings were also found to be true in a population of newly diagnosed breast cancer patients who reported preference for peer supporters who displayed high levels of empathy and self-disclosure, valuing the patience, listening skills, and appropriate sharing of her own experiences to assist an individual in coping with their illness (Pistrang, Solomons & Barker, 1999). Additional research highlights reflective listening and empathic inquiry as valuable tools for communicating empathy for another (King & Holosco, 2012). Reflective listening involves two steps. First, a practitioner listens attentively, then restating their understanding of what was said for confirmation (Rautalinko, Lisper, & Ekehammar, 2006). Empathic inquiry entails asking an individual how they feel regarding a shared event (Huitt, 2009).

Parent to Parent routinely trains their volunteers in effective communication and listening skills, as most peer support in P2P USA is provided over the telephone. Due to the lack of visual input in telephone communication, what is said, how it is said, and how well one listens become very important in accurately displaying empathy. Volunteers are taught to engage in active listening and validation techniques, and to share pieces of their own experiences when appropriate to the situation. A benefit of validating a peer is the normalization of experience (Pudlinski, 2005). As parents of children with disabilities are often isolated by their experience, normalization serves to reduce stress and increase the bond between the pair.

The "Tend and Befriend" theory was proposed by Shelley E. Taylor and her colleagues in the paper, *Biobehavioral Responses to Stress in Females: Tend and Befriend, Not Fight or Flight*. Taylor describes the evolutionary practices women have developed in response to threat in order to maximize survival of the individual and offspring (2000). While a fight or flight stress response may be adaptive for males, females generally are in charge of caretaking for infants and children, and therefore implementation of these traditional male strategies would likely put women and youngsters at increased risk to predators. Out of this dilemma, another set of instinctive responses, tend and befriend evolved, proving to be more beneficial to mothers and dependent children, where a larger group of females living together would likely keep threats at bay.

Tending is "quieting and caring for offspring and blending into the environment" (Taylor, Klein, & Lewis, 2000, pg. 412). Befriending is defined as "seeking social contact for one's own protection and solace" (Taylor, 2006, pg. 273). According to "Tend and Befriend," a hypothesized biological mechanism signals when social supports are low, and leads individuals to seek similar others as allies (Taylor et al., 2000). Positive contact with like supports leads to decreased stress responses, possibly via neurochemical reward-based systems (Taylor, 2006) and this behavior seems to have been maintained socially by women for centuries.

Tend and Befriend is an evolutionary theory of social organization based in the behavior of women. As Parent to Parent is comprised nearly exclusively of women, it seems a useful bio-behavioral model for understanding the organization. Parents who have children with disabilities may find themselves isolated with few social supports due to their unique set of circumstances. Evolutionarily, isolation is dangerous for mothers and offspring, so, reaching out to a group for social support is calming, as it reduces stress (Kerr, & McIntosh, 2000, Dyson, 1997) and depressive symptoms (Boyd, 2002). It is also protective for caregivers and offspring, increases access to information, goods and services. The cultivation of relationships and creating a sense of belonging is the foundation upon which all peer-support programs are built. The social component of P2P was evident in the subtheme, building relationships from the grounded theory analysis. Participants judged parents ready to become a peer support as those who had enlarged their social circles and had worked to develop good rapport with professionals. Furthermore, it has been shown when an individual can imagine himself or herself in the position of a needy person and engage them in conversation, they are increasingly likely to provide assistance, as this interaction may also heighten empathy and lead to increased prosocial behavior (Andreoni & Rao, 2010).

A recent trend in the study of empathy and prosocial behavior is the use of functional magnetic resonance technology (fMRI) to investigate the activation of different areas of the brain. These studies indicate a partial overlap in the neural processes involved in the personal experience of pain and the experience of pain in others, so many areas of the brain activated in the witnessing of the pain of another are also activated when pain is registered personally (Jackson, Meltzoff, & Decety, 2005). Continued fMRI research revealed more complex information regarding how the brain responds to the suffering of another. Three dimensions of human empathy, affective, cognitive and regulatory, are now known to use interacting but not overlapping neural mechanisms. Additionally, these dimensions develop at different trajectories, so early childhood responses to empathy-inducing stimuli primarily produce displays of innate emotion, whereas adults tend to have a more carefully appraised response (Decety, 2011a).

fMRI evidence has shown empathy in animals and humans activates similar parts of the brain as well as corresponding biological systems regulate bodily states, emotion and reactivity. Humans have the added capacities of executive function, language, and mentalizing, which are centered in the prefrontal cortex. These higher-order cognitive abilities are transposed above the more primitive emotional and social capacities discussed earlier. The more complex neural network involved in human empathy may explain human prosocial behaviors such as helping out-group members and animals (Decety, 2011b).

Parent to Parent volunteers likely are matched with someone they have never met, and may never meet in a face-to-face setting, as communication generally takes place over the telephone. Although the individual receiving help and the one providing help have many things in common as far as their child's diagnosis and demographic indicators, they do not know each other. Decety's assertion that our ability to show empathy toward unknown others relates to higher-order neurological processes like the capacity for language is intriguing in this light, as the satisfaction of the referred parent increases with the number of telephone conversations with the support parent (Santelli et al., 1996). The more the pair communicate, the greater their bond and more beneficial the helping relationship. This also highlights the importance of having good communication skills as a prerequisite for readiness and the teaching of active listening techniques at most P2P support parent trainings.

The motivation of a volunteer is important for an organization to understand, as motivation and role should be matched for the satisfaction of the volunteer and the organization. Clary and associates (1998) developed a measure of the motivations to volunteer called the Volunteer Functions Inventory (VFI) based on the hypothesis people engage in the same volunteer activities for a variety of different reasons. The six motivational factors they propose are values, understanding, social, career, protective and enhancement. Values is a function of volunteerism related to the opportunity to express their values related to helping others in need and has been found to be significantly related to extended volunteering. Understanding relates to access to new learning and opportunities to use skills otherwise unused. The social function of volunteering has to do with meeting new people, spending time and being viewed favorably in social circles of friends. Career function was associated with the use of volunteer experience to further work-related goals. The protective factor was associated with guilt over being more fortunate than others as a motivation to help. Enhancement views volunteering behavior as a means of personal growth. The measure was later tested for utility in matching the most salient motivations of a volunteer with a particular type of helping behavior in order to improve recruitment practices of volunteer reliant organizations (Clary, Snyder, Ridge, Copeland, Stukas, Haugen, & Miene, 1998).

Results of a follow-up study indicated intrinsic motivation was associated with volunteer positive self-concept, a prosocial personality and the establishment of a volunteer role identity. Extrinsic motivation (career goals) was associated closely with external motivation, which required an outcome separate from the work as a volunteer to be fulfilled (Finklestein, 2009). Individuals with a high level of empathic concern and low personal distress are most likely to volunteer in direct service to those in need, and subsequently find the work satisfying. If such an individual were assigned the task of pricing items in a charity thrift shop, they may not feel fulfilled by their volunteer work. Therefore, the match between disposition and work is essential in volunteer assignment and retainment (Davis, Mitchell, Hall, Lothert, Snapp, & Meyer, 1999). Parent to Parent peer supporters should ideally be individuals exhibiting a high level of empathic concern while maintaining a low level of personal distress in empathy-inducing situations. This combination of traits allows the volunteer to help another person in need without becoming upset themselves. Individuals recruited to provide one-to-one support would likely find this work fulfilling if they were motivated intrinsically in order to express their values around helping others in need, building knowledge in how to support another parent, building relationships and/or protecting vulnerable others by providing information and sharing experiences. If an individual were motivated to volunteer for extrinsic reasons such as career advancement, peer-support may not be a suitable role.

In response to extensive study of the negative psychological consequences of traumatic events on individuals, researchers began to study those who developed perceived emotional benefits. Changes in individuals who have experienced post-traumatic growth may include: a deepening of relationships, increased empathy for others, higher degree of emotional intelligence, a greater sense of being able to handle circumstances as they arise, increased appreciation of the simple things in life and a change in values and priorities (Calhoun & Tedeschi, 1999). Tedeschi and Calhoun developed the Post Traumatic Growth Inventory

(PTGI) to measure the coping success of individuals in the aftermath of trauma, and the reconstruction of meaning in their lives. Test items were based on reported benefits reported in the post-traumatic growth literature. Reliability and validity were assessed through factor analytic and correlational processes. The 21-item scale consists of five factors: new possibilities, relating to others, personal strength, spiritual change, and appreciation of life (Tedeschi & Calhoun, 1996).

Hastings and Taunt (2002) conducted a review of literature regarding raising a child with a disability. Despite the findings of studies focusing on the negative effects such as stress, divorce and depression, they found families can adapt very well to having a child with a disability, and nearly all families report similar or greater positive perceptions of their child than families of children without. The authors posit positive perceptions serve a purpose in fostering adaptation, and further, a better understanding of different types of positive perceptions might offer insight how to assist families experiencing psychological distress in coping with the diagnosis of a child with a disability (Hastings & Taunt, 2002). In a subsequent review of post-traumatic growth literature, many variables were found to be consistently associated with adversarial growth. These include: problem-focused coping, acceptance, positive reinterpretation, optimism, and positive affect amongst others. Additionally, individuals exhibiting and maintaining post-traumatic growth were less likely to experience distress in subsequent traumas, pointing to post-traumatic growth as a protective factor as well as an outcome (Linley & Joseph, 2004). Accordingly, some individuals who have suffered a trauma have been noted to cope by actively helping those in need and preventing suffering in others. Helping behavior can be mediated by empathy and reduced in-group bias for those who have recovered from trauma, meaning they are the best suited to understand another person's experience, as well as help those who are unfamiliar to them, bringing them into their social circle (Vollhardt & Staub, 2011).

Vollhardt and Staub's research found individuals experiencing significant trauma were more likely to help unknown others, surprising in light of the data from the pilot interview study of P2P USA leaders. Women who volunteer for this organization often feel compelled to "pay it forward." Giving back to the disability community by sharing the knowledge and skills developed through their journey with their child, they hope to prevent difficulties for other parents of children with special needs. The women who were deemed ready to provide such support were described as projecting positivity. This relates to Hastings and Taunt's positive perceptions of the child and family, as well as appreciation of life factor in the PTGI and Linley and Joseph's finding of variables; positive reinterpretation, optimism, and positive affect as some of the most consistently linked to post-traumatic growth.

Cognitive reappraisal techniques for the regulation of emotions in response to aversive events have been shown to modulate activity in multiple emotion-processing systems in the brain (Ochsner, Bunge, Gross, & Gabrieli, 2002). CBT focused on self- regulation of emotional responses can re-wire the brain, according to fMRI studies, modifying the neural circuitry in individuals with phobic anxiety disorders (Paquette, Lévesque, Mensour, Leroux, Beaudoin, Bourgouin, & Beauregard, 2003), and patients with major depressive disorders (Ritchey, Dolcos, Eddington, Strauman, & Cabeza, 2011). According to such a fMRI study by McRae and associates, women's brains respond somewhat differently to cognitive reappraisal strategies, perhaps due to women's tendency to access positive emotions to counteract the effects of negative experiences. Men more directly down-grade negative emotional responses (McRae, Ochsner, Mauss, Gabrieli, & Gross, 2008). A cognitive behavioral therapy, which emphasizes the addition of positive perceptions, like those discussed in Hastings and Taunt's review of the literature on families of children with disabilities, might be effective in this organization comprised of mainly women to help volunteers consistently regulate their emotions and provide high quality social support to parents in need.

Synopsis of Pilot Study

The main question posed in the pilot study was how P2P Coordinators (who are responsible for recruiting and training help-giving parents) know when a parent volunteer is ready to provide support to a help-seeking referred parent. The question of readiness was important to these parent leaders because a major on-going effort in these grassroots organizations is recruitment and training of peer support providers. Ten interviewees participated in this study. They were all identified as persons who had experience in recruiting and training volunteer parents in state, regional, or local Parent to Parent programs, and most had been a support parent themselves. The average length of experience in Parent to Parent leadership was 17.3 years with a range of four to 26 years. All participants were female and considered contact persons or leaders of the Parent to Parent network in their geographic area. Nine of the ten participants were biological or adoptive parents of at least one disabled child. One participant was the aunt and primary advocate for three nephews with special needs.

A semi-structured interview guide was developed to provide a general structure for the researcher, ensuring subtopic areas were addressed. Flexibility to follow the participant's lead was incorporated to allow for discovery, as no formal literature review was conducted prior to the interviews as a search revealed no direct research exploring the question of readiness to volunteer among parents of children with disabilities. Following the framework of grounded theory analysis, themes identified in the interviews were reduced and grouped into five master categories; traits and concerns of Parent to Parent leaders, traditions of P2P, red flags, signs of (approaching) readiness, and challenges in the 21st century. The two categories most directly pertain to the research question, “What does it mean to be ready?” are those of signs of readiness and red flags. An analysis of the ten interview transcripts identified a collection of attributes and their outward signs belonging to ready volunteers who will likely become excellent support parents to other parents in need, as well as signs raising suspicion a volunteer may need further support before being trained to support others, or whether they may never be ready.

Signs of readiness included: building relationships, positivity, building capacities, communication skills/listening, having/sharing successes, future orientation, and feeling the need to give back. Building relationships constituted reaching out for social support, joining parent groups, and strengthening bonds with family and friends. Positivity was defined in terms of how an individual with a disabled child viewed their child and their overall outlook on life. Ready parents saw the inherent goodness in things. Participating in activities such as workshops and trainings, internet searches and advocating for services at an I.E.P. meeting evidenced building capacities. Improved communications skills were noted when a parent spoke coherently about their journey as a parent of a child with a disability, as was listening to others and validating their feelings. Parents achieving some success in navigating systems such as Medicare or, through trial and error, finding reliable modes of communication for their child, often will share these successes with others who may benefit from the information and/or share in their joy. Having a future orientation was an attribute common amongst good support parents. These parents could predict events and potential obstacles and make realistic, measured goals and plans for their child and family. Ready parents often report feeling a sense of obligation to pay it forward to another family with a child like theirs. When a parent has gathered resources and developed skills, at a certain point, they come to discover they can help someone else, to save them from stress and to impart a sense of hope.

The theme of red flags is important to consider in the development of a measure of readiness, as many interviewees found it easier initially to discuss they know a parent is not suitable to volunteer as a peer support provider. These personality traits red flags commonly attributed to parents of children with disabilities deemed unready to serve as a supporting parent are negativity, being stuck, being judgmental towards other parents, looking for cures, being in crisis, feeling overwhelmed and expressing uncontrolled emotion. These parents will express negativity in conversations about their child or their life view. They may consistently complain about a variety of service providers and feel persecuted in some way. Being stuck is defined as being unsure of how to move forward in helping their child and assisting their family in the adaptation to the child's disability. Parents who exhibited judgmental behavior were described as telling others what to do rather than allowing individuals to make their own choices. They were seen as being inflexible in their positions and unaccepting of methodologies or strategies did not match up with their experiences, and looking for cures as displaying lack of acceptance of a diagnosis and an active struggle to make a child's disability disappear. Parents who place faith in the latest treatment purporting to eradicate disability devote a great deal of energy to this process, which leaves little to give to others. Parents in newly diagnosed families, and those who are short on resources, may feel overwhelmed or experience a crisis. For these families, additional services focused on their specific needs may help them adapt, but subjects felt support parent training compounded their perceived burden. Additionally, participants added support parents with great potential might choose to withdraw from their volunteer duties during times of crisis or difficult transitions within their family.

The findings of the aforementioned study resulted in the development of a theory of change around the central categories of signs of readiness and red flags (see Figure 1). Data focusing on the recruitment and training of support parents, data on the experiences of the informants (leaders in Parent to Parent), the journey as parents of special needs children and within Parent to Parent, contributed to theory development. This represents an idealized journey of a parent, beginning in a state of negativity and limited agency (red flags), progressing to a state of positivity and personal development (readiness) via the support of a one-to-one match, and into volunteerism and possibly leadership roles.

This theory did not suggest parents begin their journey in negativity and progress into volunteerism in an orderly fashion. Its purpose was to illustrate a possible mechanism by which peer to peer support via a P2P match facilitates change in a help-seeking individual. Although parents do not always choose to engage in volunteering and leadership activities, many informants stated those with successful matches with a trained support parent tended to volunteer themselves for trainings to become support parents, often moving beyond the organization into leadership positions in other disability-related organizations and becoming involved in local and national advocacy.

Parents of children with disabilities who go on to contribute their time to the greater disability community through volunteer work (e.g. P2P support parents), advocacy, or leadership (like many participants in this study), can be viewed through the lens of posttraumatic growth (PTG). PTG is noted when an individual experiences positive psychological changes after struggling with a traumatic event (Tedeschi & Calhoun, 2004). Changes in individuals who have experienced posttraumatic growth may include: a deepening of relationships, increased empathy for others, higher degree of emotional intelligence, a greater agency and ability in handling new circumstances, increased appreciation of the simple things in life and a change in values and priorities (Calhoun & Tedeschi, 1999).

The initial shock of the diagnosis of a child with a disability is often described in the literature on parental adaptation as a traumatic event (Scorgie & Sobsey, 2000, Gupta, & Singhal, 2004). Tedeschi and Calhoun compare this traumatic event to an earthquake in their article, *Posttraumatic Growth: Conceptual Foundations and Empirical Evidence*. They define a "seismic event" as a traumatic experience significantly challenging or destroying an individual's understanding of identity, values and/or world-view. A resilient individual will go about the task of cognitive rebuilding incorporates the trauma, and therefore may protect the individual from extreme effects in the case of future traumatic events (pg. 5).

Another theory of flourishing in response to traumatic events is the Tend and Befriend theory proposed by Shelley E. Taylor and her colleagues in the paper, *Biobehavioral Responses to Stress in Females: Tend and Befriend, Not Fight or Flight*. She describes the evolutionary practices women have developed in response to threat in order to maximize survival of the individual and offspring (2000). As females generally are in charge of caretaking for infants and children, the more masculine fight or flight impulse could increase risk to women and children in stressful encounters. Another set of instinctive responses evolved and proved more beneficial to mothers and dependent children, where a larger group of females living together, providing social support and "quieting and caring for offspring" would likely keep threats at bay (Taylor, Klein, & Lewis, 2000, pg. 412).

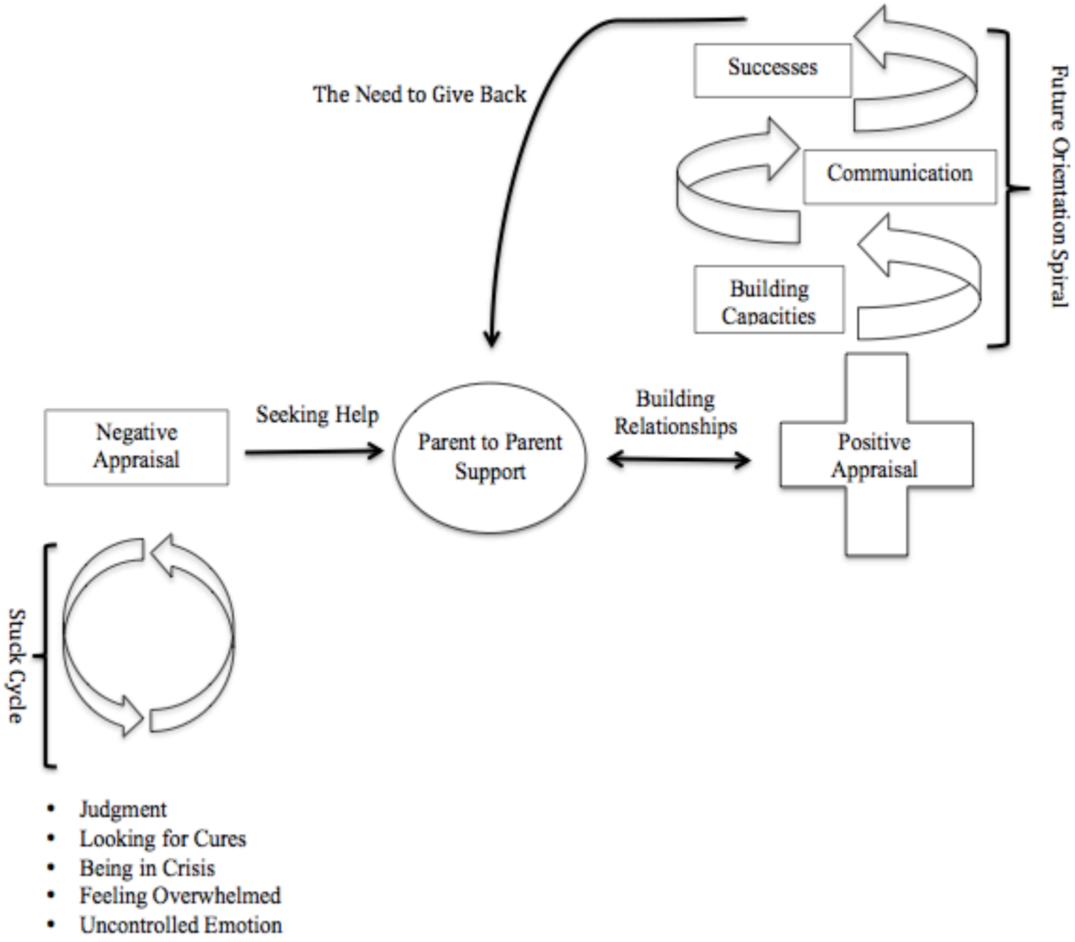

Figure 1. Theory of change. This figure depicts a hypothesized path of adaptation in parents of children with disabilities supported by Parent to Parent derived from interview themes.

Women who have a child with a disability may find themselves socially isolated, as their family and friends lack understanding of the impact of their child's disability on every aspect of their lives. According to "Tend and Befriend," a hypothesized biological mechanism signals when social supports are low, leading individuals to seek similar others as allies (Taylor et al., 2000). Positive contact with like supports leads to decreased stress responses, possibly via the opioid and dopamine reward-based systems (Taylor, 2006). Women are noted to be far more likely to seek out social support and continue to organize in collectivist communities when resources are scarce, particularly in low-income families who make use of female kinship networks for childrearing and resource exchange (Stack, 1975).

When a parent of a child with a disability repeatedly exhibits negativity about their current situation or displays a negative appraisal roughly more than six months after the diagnosis, that may be an indication that they are in a cycle of being stuck. Figure 1 depicts the theory of change in parents of children with disabilities derived from the grounded theory analysis. The stuck cycle can be seen in the lower left portion of the diagram. Repeating the story of the traumatic event over and over again without reaching a sense of closure is a common characteristic of those who underwent a trauma and have not yet recovered from its effects (Herman, 1997). This cycle is dominated by looking for cures for their child, expressing judgment towards others and uncontrolled bursts of emotion. These outward signs of being mired in the stuck cycle are often due to the parent being overwhelmed or in a crisis. These crisis events may include transition, hospitalizations, job loss, divorce, or legal battles with the school. These experiences may lead a parent to experience increased isolation from community and family and feelings of stigmatization or guilt regarding their child's disability and their childrearing skills or prenatal care. During this phase, a parent may reach out for information or support, seeking help from a local agency, and be connected to a Parent to Parent support parent, which is depicted in the center oval of Figure 1.

This connection may reduce isolation experienced by a parent of a child with a disability by building a relationship between the two parents who bond over similar experiences. The positive appraisal imparted by the support parent further along in her journey can give hope to the referred parent, and the advice given is imparted with a higher degree of credibility due to the dyad's shared experience. This potential newfound can-do attitude can lead the referred parent to seek out understanding of their child's disability by attending trainings and building a knowledge base as noted in the future orientation spiral on the right side of the diagram in Figure 1. As the parent seeks information and learns to navigate relevant systems, they may be noted to take on an air of confidence and build valuable communication skills through increased interactions. The parent may then try different strategies to help their child and find more balance in their life. People are drawn to them and they start to share successes with others in the community who might benefit from what the parent has learned. This process of change and growth takes place over the course of years. At a certain point, the referred parent may realize they have accumulated a body of knowledge and experience too great to keep to themself and feels compelled to share with others by volunteering to be trained as a support parent. Feeling the need to give back is represented as an arrow leading from successes back to Parent to Parent Support at the center of Figure 1.

Consistent with the literature on meaning making, having a child diagnosed with a disability or serious health condition is likely to lead to a discrepancy between a parent's appraised meaning (initial understanding or reaction to an event which is constantly reevaluated) and global meaning (personal beliefs, goals and feelings about how the world works), creating distress (Park, 2010). A parent of a newborn with a chromosomal disorder may appraise the child's diagnosis as life-threatening and hopeless, standing at odds with their global view having read all the prenatal books and eaten all the nourishing foods; they were well prepared for parenthood and a healthy baby. The distress varies with the magnitude of the discrepancy, and drives meaning-making efforts. The appraisal of the current situation (having a disabled child) and the parent's beliefs, expectations and goals, may lead them to an intense need to reduce the discrepancy (Plaks, Grant & Dweck, 2005). This drive to reconcile appraisals will likely lead a parent of a child with a disability or special health need down the path to meaning-making, but alternately, some individuals may become unable make meaning without a reduction in discrepancy. This interpretation is in line with the "stuck cycle" and is evidenced by rumination causing increased distress for the individual (Nolen-Hoeksema & Larson, 1999).

When a person is stuck in the rumination cycle, they may need help to escape the endless reappraisals without meaning-making. The influence of a peer mentor with similar experiences, situations and feelings may help a parent struggling with a new diagnosis or health crisis begin to make a positive reappraisal, revise goals, engage in problem-focused coping or engage in spiritual practices. These strategies are associated with meaning-making coping that involves redeveloping one's goals and beliefs to reestablish consistency amongst them, and incorporate new appraisals of challenging events (Folkman, 1997). This process may lead a parent to acceptance of their situation, growth in their ability to communicate with others, expansion of their knowledge about certain topics and begin to appreciate life more than ever before (Park & Helgeson, 2006). They may also find as a result of this process began out of crisis, they have a new sense of purpose and new goals, leading them to volunteer to help others, or possibly enter leadership in the disabilities field. Conversely, as evidenced by the words of one participant in this study, there will always be that parent who "just didn't get it." According to resilience theory, the difference between parents who remain in negativity and those who can reappraise their situation as positive may be their emotional intelligence, or the ability to process your own and others' emotions and use this information in a decision-making context (Salovey & Mayer, 1989).

The mechanism for the efficacy of Parent to Parent support resulted from this study also shares attributes with the "Broaden and Build Theory of Positive Emotions." (Fredrickson, 2001). In her theory, Fredrickson proposes experiencing positive emotions broaden one's thought-action repertoire, allowing an individual to build physical, social, intellectual and psychological resources. Further, negative emotions such as fear, anger and sadness limit the possible reactions from which a person can choose. Similar to the fight or flight response, these reactions are intrinsically programmed for situations of immediate danger. A sense of being trapped or having limited agency may plague a parent of a child with a disability or chronic health condition who is overwhelmed, in crisis and exhibits a negative appraisal of their current situation.

If an individual were able to find a more positive appraisal of their situation within a community of belonging introduced by the P2P match, the positive emotions experienced may grant them access to an increased array of actions that are more flexible, creative, open-minded and efficient. They then gain a sense of control and pride in their ability to handle formerly baffling situations. The compounding of positive emotions experienced by individuals leads to the building of resources and increased overall wellbeing (Cohn & Fredrickson, 2006). Positive emotions can also serve to undo negative emotions initially encountered after a stressor, or as a regulator of lingering negative emotion (Fredrickson & Levenson, 1998). By engaging in strategies such as creating a gratitude list or activating humor in response to a negative stressor, a person can undo the effects of negative emotion. As a support parent shares positive appraisals, embodying a can do attitude, they model these skills for the referred help-seeking parent in an authentic way that can be trusted, as they have lived similar experiences. The internalization of this example by the referred parent may mark the turning point between an individual exhibiting red flags and beginning the process of becoming ready.

The referred parent may be inspired to exit their negative cycle of rumination and cure-seeking by trying a new strategy their support parent has shared, thereby entering a new phase in which problem-focused coping strategies are sought through internet searches and/or attending trainings and conferences on relevant topics (Thoits, 1986). New choices are subsequently revealed. Successes in helping their child such as increasing efficiency and family balance are first experienced. These positive events are associated with decreased signs of depression and increases in self-esteem, positive mood and sense of control (Folkman & Lazarus, 1988; Folkman & Moskowitz, 2000; Nezlek & Gable, 2001; Pottie & Ingram, 2008).

As more successes build up through this phase, the parent may be sought out by others in their community to share their positive experiences and expanded knowledge-base. Their newly increased sense of worth and safety within a group of other parents of children with disabilities who understand their situation, allows the parent opportunities to share their successes with others. This sharing imparts positivity to those doing the seeking, but also contributes to the sharing individual's sense of wellbeing and greater life satisfaction. Additionally, when the sharing of a positive event/success is enthusiastically received, the positive effects are even greater, the bond between the sharer and seeker strengthened (Gable, Reis, Impett, & Asher, 2004). Once an individual creates a habit of positivity, it can become a protective factor in the event of future crises, a predictor of resiliency and overall wellbeing, building on itself in an upward spiral (Fredrickson, 2001) as depicted in this study's theoretical model (see Figure 1.) This positive spiral of sharing then spills over into giving back to the community (P2P) helped the individual move through difficult times. A now ready individual will begin to volunteer and purposely place themselves in circumstances to share relevant knowledge or successes with parents in need.

Expecting any person to embody only positivity on a daily basis is unrealistic. Parents of children with disabilities have bad days from time to time and may express negativity in the form of frustration or judgment in response to unexpected setbacks or changes in plans; it is more likely a resilient parent will experience positivity in the form of gratitude or pride simultaneously with these negative emotions. These parents will recover more quickly due to a high positivity/negativity ratio, and their family will exhibit higher levels of adjustment (Trute, Benzies, Worthington, Reddon, & Moore, 2010). Their utilization of positive coping strategies is beneficial to themselves, their family and to the parents they support.

Methodological Concerns

According to Buston and colleagues in their 1998 article reviewing the utility of qualitative methodology in psychiatric research, "qualitative strategies may fulfill an important hypothesis generating function." (pg. 197) Whereas quantitative research is limited to the study of already defined constructs, qualitative inquiry lends itself to the holistic investigation of situations, preserving the complexities of the insider experience in order to increase understanding of phenomena (Buston, Parry-Jones, Livingston, Bogan, & Wood, 1998). Therefore, in seeking to understand a new social construct like readiness to be trained as a peer supporter, a modified grounded theory qualitative approach was appropriate for the pilot study. The methodology was utilized to develop a theory of readiness, define attributes associated with the construct and serve as a basis for the development of a measure to be used in Parent to Parent volunteer recruitment and selection.

The validity of a qualitative research study concerns the reality of representation of the social phenomena of interest (Schwandt, 1997). Procedures important to include in qualitative research as evidence for validity are member checks and triangulation. Member checks involve sharing data and interpretations with participants in order for credibility confirmation (Creswell & Miller, 2010). Triangulation involves the researcher using multiple sources and methods to collect information such as interviews, newspapers and observations in the process of data collection, analysis and theory development (Lincoln & Guba, 1985). In the pilot study, P2P leaders were briefed on the themes emerging from the interview data and given opportunities to communicate their relevance to their experience in the Parent to Parent organization and their experience, personally, of raising a child with a disability. Triangulation was performed by comparing data and themes to published Parent to Parent materials available on their website and members only web link for which the Director provided access. These procedures ensure weak points in data collected from one source, in this case interview notes and transcripts, are strengthened by those gathered by alternative means increasing data reliability (LeCompte, Preissle, & Tesch, 1993).

Choosing a representative sample of appropriate size also helps to protect against threats to validity (Opdenakker, 2006). Researchers, especially student researchers, have concerns related to how many subjects to recruit in order for their research to be deemed credible. In the utilization of purposive sampling, where subjects are selected because of their relationship to the phenomenon of study, the concept of data saturation is pivotal to making the determination of when to conclude interviewing. Saturation is a concept introduced to the field by Glaser and Strauss (1967), referring to the point in data collection when a conceptual category is not further developed by continued collection. A study conducted by Guest, Bunce, and Johnson (2006) using data from another project for which they interviewed over 60 female participants in Western Africa found saturation was achieved within the first twelve interviews, and the basic themes emerged within six interviews (Guest et al., 2006). In the Parent to Parent pilot study, saturation was indicated in the last two of the ten interviews as interviews became markedly shorter and new themes did not emerge in the coding of the transcript, providing the researcher with the confidence to move forward to the item development stage of the study discussed in the next section.

Development of a new measure and subsequent assessment of reliability and validity are somewhat more clearly defined in the literature. Generally, the process begins with the development of a “precise and detailed conception of the target construct and its theoretical context” (Clark, & Watson, 1995, pg. 310). This was be done by utilizing data from an interview study of leaders of the Parent to Parent organization to develop a grounded theory of readiness to volunteer as a support parent. Next, the researcher writes items they believe fully represent the defined construct, and only that construct (Cook, & Beckman, 2006). These items, developed from theory and interview data was presented to a group of experts in the recruitment, selection and training of P2P volunteers for further refinement and content validity purposes. The next concern is the identification of separable dimensions and to determine which items load onto which factors, and to maximize the amount of variance explained (Floyd, & Widaman, 1995) through exploratory factor analysis. If the test developer works from existing established theory of the construct, they may want to employ confirmatory factor analysis to determine how well the model fits the data. In the case of readiness to volunteer, however, EFA proved most appropriate (despite the theory developed from the grounded theory analysis), as this is the first known study on this psychosocial construct. Data were thus reduced and the measure refined in an iterative process.

Reliability is estimated by test-retest or internal consistency procedures. Internal consistency is the more popular method, as only one testing opportunity is required, and it is reported in terms of coefficient alpha. Internal consistency measures the reliability of a measure by assessing the level of consistency among different parts of the test. If there are high levels of correlation amongst the parts, the measure is deemed more reliable (Furr, 2014). Convergent and/or discriminant validity can then be estimated by investigating a series of correlations between the new measure and established measures of other constructs in light of theoretical predictions (Campbell and Fiske, 1959). In the case of the measure of readiness, assessments of both empathy and post-traumatic growth were theorized to be moderately positively correlated with readiness, for reasons discussed in the literature review in Chapter 2. Accordingly, depression is likely to display a moderate negative association with readiness. These related constructs will be measured at the same time as readiness to provide concurrent validity for the new measure.

Confidence in the choice to move on to developing a measure comes from the understanding measure development is an iterative process. The larger samples used in the process of developing a measure are an added advantage as the measure will become more generalizable to the population as the process of development and refinement continues, whereas the continuation of interviewing will likely not increase understanding of the concept in meaningful ways due to smaller samples and likely saturation of data. Finally, the goal of this project has always been to not only gain a better understanding of what it means to be ready to provide peer support, but also to design a suitable assessment of the construct for use of Parent to Parent in their ongoing recruitment and selection process.

Chapter Summary

A review of current research and theory regarding peer support provision for parents of children with disabilities presented in this chapter emphasizes the lack of literature on who support providers are and what attributes a ready volunteer may share. Therefore, the review was expanded to include research on empathy as it is theorized feeling for others is often the catalyst for volunteering behavior. Methodological concerns, namely reliability and validity in the development of a measure of a novel psychosocial construct were discussed, providing a rationale for moving forward into test development.

III. Research Design and Methodology

The research questions in this measure development study are related to the overarching pragmatic goals of improving the process of recruiting and training P2P peer support volunteers and maintaining a high quality volunteer work force for the organization. The first question regarding whether items from the readiness measure logically cohere around the constructs/main terms from the theory developed in the pilot study was explored to provide evidence for (or against) the validity of the construct of readiness. Construct validity is the degree to which the test measures what it purports to be measuring. If the survey behaved as expected through the factor analysis process and displayed factor loading patterns related to the important themes derived in Study I, this would provide solid evidence for construct validity insomuch as the measure would be reflective of the theory.

The second research question proposed sought to investigate whether there is evidence of convergent validity for the measure of readiness, as it measured the strength of the relationship between accepted theory in the literature of psychology, families and disability and the measure of readiness. If readiness displayed moderate positive relationships with empathy and post-traumatic growth and a moderate negative relationship with depression, the measure of readiness would establish a more esteemed evidence base as the original theory was explained via the current and foundational literature on the aforementioned concepts. The measure of readiness would consequently be seen as more likely to be measuring the psychosocial construct it had intended to measure.

The third research question looked to discover whether the measure displays differences in scores between parents who have experience as peer support providers in P2P and those who have not. According to the literature on parental adjustment, changes in coping levels of parents change over time such that in general, parents who are further along from diagnosis would be hypothesized to be coping more successfully than parents of a newly diagnosed child. As some P2P groups stipulate they do not train parents whose children are under a certain age or less than a specific time since diagnosis, most support parents are likely to have had more time to adjust to their child's disability, and possibly superior coping. Support parents for Parent to Parent often request to be trained and matched rather than being recruited directly by P2P coordinators, possibly due to an increased state of readiness they sense within themselves. If the measure were sensitive, the theorized group differences between experienced, trained supporting parents and non-volunteers it would provide additional evidence for the validity of the measure.

Methods

First, around one hundred items were developed from the qualitative data described above. These items were given to a group of experts in the field of Parent to Parent support for feedback. The experts rated items from one to five, with one being completely irrelevant to the concept of readiness and five being extremely relevant. Items with average scores above 3.5 were then retained for further testing. Items not meeting this threshold were discarded or reworded in response to expert comments if deemed particularly important to the overall concept of readiness by the researcher. Around 60 items were retained at this stage. Additional items were written in order to ensure at least eight items were included per item category. Some items were revised for consistency in wording at this time under the advisement of a researcher with experience in measure development. The University of

California Santa Barbara Office of Research and Human Subjects approved the following research plan.

Two hundred ten English speaking/reading participants who are or were parents of children with disabilities and/or special healthcare needs of any age were recruited through the P2P USA Listserv and by the direct referral of coordinators for local P2P groups. The only requirement for participation was they were the parent of a child with a disability and/or special healthcare need. A variety of parents including P2P support parents, P2P support recipients and parents who have not yet received support were represented. The researchers did not have contact with participants, as they were provided with a link to an anonymous online survey. The measures included in the online platform required about thirty minutes for participants to complete in a single session.

Qualtrics is a secure online survey software tool that was utilized to collect responses to the refined 70-item pool and additional measures collected for construct validity test purposes. The quantitative information was collected online in a password-protected account. Participants indicated they had read the consent form by clicking on a box to proceed to the online survey.

Measures

The study utilized several different self-report measures; A demographic questionnaire, the newly-developed readiness scale, the Toronto Empathy Questionnaire, the Post Traumatic Growth Inventory-Short Form and the Beck Depression Inventory II. All online forms used upper elementary-level language and participants could stop and restart the survey at their convenience. Participants were informed the online surveys would take approximately less than an hour to complete.

Demographic data were collected for participant gender, ethnicity, age, total family income, marital status, age of the child(ren) with a disability and primary diagnosis of the child with a disability.

Additional measures were assessed concurrently with the measure of readiness in order to assess the validity of the measure according to a priori theoretical assumptions regarding the relationships between other psychosocial constructs and readiness to volunteer. Comparing the theorized associations between the new measure and established measures with their actual relationships from the data set assesses convergent validity.

Toronto Empathy Questionnaire

Empathy has been linked to prosocial motivation as well as length and duration of volunteer activity as discussed in the literature review in Chapter 2. For these reasons, a measure of empathy was theorized to exhibit a moderate positive relationship with the measure of readiness. This could be interpreted to mean that a high score on the measure of empathy would predict a high score on the readiness measure.

The Toronto Empathy Questionnaire (Spreng, McKinnon, Mar, & Levine, 2009) is a 16 item self-report measure developed to measure the emotional processes of empathy. The TEQ was developed to create a parsimonious measure of empathy encompassing what various conceptions of empathy hold in common and removing concepts belonging exclusively to specific theories. As there are multiple theories of empathy, measures created from these theories measure different aspects of the concept. The TEQ utilized factor analysis to force items from various accepted measures of empathy to load onto a single factor, creating a grouping of highly related items, a unidimensional measure of empathy. This unidimensional measure, thought to be the core of the construct, primarily reflects the emotional processes involved in empathy, accurately identifying and sensing the feelings of another, and also contains items related to altruism and prosocial helping behaviors. As seen in other measures of empathy, women reported moderately higher scores on the TEQ. Good internal consistency (α = .85) and high test–retest reliability were noted in a sample of college students.

Since supporting parents are expected to provide emotional support, accurate appraisal of the emotional state of another is a required skill. As communication between helpers and helpees is generally done over the telephone a higher degree of skill in this area may be required to compensate for the loss of body language and facial expression cues. The inclusion of questions regarding altruistic feelings and behaviors is also important to consider in reference to Parent to Parent volunteers, as high levels of prosocial urges and responses would likely be a motivating factor for an individual to engage in long-term high-quality volunteering behavior. Taking all these together, this measure of empathy is appropriate for use as a measure of convergent validity as it captures key concepts related to readiness and would likely be associated with the new measure. Therefore, a moderate positive relationship was predicted between empathy and readiness.

Post Traumatic Growth Inventory

Changes in individuals who have experienced post-traumatic growth have been found to include: a deepening of relationships, increased empathy for others, higher degree of emotional intelligence, a greater sense of being able to handle circumstances as they arise, increased appreciation of the simple things in life and a change in values and priorities (Calhoun & Tedeschi, 1999). These changes closely align with those reported in previous research with parents of children with disabilities (Miller, 1994) and in the data collected in the pilot phase of this study. The Post Traumatic Growth Inventory is comprised of five factors, relating to others, new possibilities, personal strength, spiritual change, and appreciation of life. These factors share much in common with the proposed factors for the measure of readiness. Relating to others corresponds well to building relationships, new possibilities may share similarities to future orientation, personal strengths is related to successes, and appreciation of life shares commonalities with positivity. Spiritual change was mentioned by two informants in the pilot phase of this study, but was not common enough to rise to the thematic level, but may represent an aspect of change in individuals who become ready. These individuals may not feel comfortable sharing information regarding their move toward religion or spirituality, as faith can be a personal matter.

What is not included are themes of give back, building capacities, communication/ listening, and red flags which are also important components of the theory of readiness. Therefore, although the PTGI-SF has several similarities with concepts represented in the readiness measure, it is an incomplete representation of the concept, pointing to the relatedness of the two concepts, but not interchangeability. Additionally, the concept of posttraumatic growth was not developed in reference to parents of children with disabilities and other health care concerns, and the measure PTGI-SF has not been validated for use with this population.

Utilizing the PTGI-SF may be seen as controversial, as having a child with a disability may not be inherently traumatic for a parent. In response to extensive study of the negative psychological consequences of traumatic events on individuals, researchers began to study those who have come through trauma with some perceived benefits. The PTGI-SF is included to highlight the positive adaptations and adjustment of many parents in response to the addition of a child with a disability to their family. The initial shock of the diagnosis of a child with a disability is often described in the literature on parental adaptation as a traumatic event (Gupta, & Singhal, 2004; Scorgie & Sobsey, 2000). They define a “seismic event” as a traumatic experience which significantly challenges or destroys an individual’s understanding of their identity, values and/or world-view. A resilient individual will go about the task of cognitive rebuilding, incorporating the trauma, and this may protect the individual from extreme effects in the case of future traumatic events (pg. 5).

Although not every parent of a child with a disability experiences trauma in response to their child’s diagnosis, P2P leaders, described their own experience of the diagnosis of their child as a pain that never goes away (Dodds, 2014). As these women are long-term and effective support providers, it was theorized they might have experienced a high level of posttraumatic growth. This level of growth and volunteer commitment may not be required from all support providers, but it was predicted recruits who scored high on a measure of PTG would likely also have scored high on the measure of readiness and a moderate correlation would be displayed between the two tests.

The Post Traumatic Growth Inventory-Short Form (Cann, Calhoun, Tedeschi, Kanako, Vishnevsky, Triplett, & Danhauer, 2010) is a 10-item self-report measure of posttraumatic growth. The PTGI (Tedeschi & Calhoun, 1996) was developed after a review of the literature of responses to trauma. Good internal consistency was reported in a sample of bereaved parents (α =.84), with higher alpha scores reported for additional groups such as cancer patients and widowed spouses.

Beck Depression Inventory

The Beck Depression Inventory (BDI) is frequently used in research with many different populations, including the parents of children with disabilities, consistently displaying high levels of reliability. The BDI II (Beck, Steer, & Brown, 1996) was created to correct issues with content validity, aligning it more closely with the DSM-IV definition of depression than its predecessor, the BDI. The inventory is a 21 item self-report measure of depressive symptoms. Items are rated on a 0 to 3 scale, with summary scores ranging from 0 to 63. In a 1998 evaluation of the measure, the BDI II was found to be a stronger measure than its predecessor, the BDI (Beck, Ward, Mendellson, Mock, & Erbaugh, 1961), and exhibited high internal consistency for both women (α= .91) and men (α= .92) (Dozois, Dobson, & Ahnberg, 1998).

The cognitive-affective aspects of depression are represented in the BDI II with items related to past failure, worthlessness, self-dislike, pessimism, self-criticalness, indecisiveness, guilty feelings, suicidality, punishment feelings, and sadness. The somatic-vegetative items consist of changes in sleep, fatigue, loss of energy, irritability, agitation, loss of interest in sex, loss of interest, loss of pleasure, and changes in appetite. Taken together, many of these items reflect subthemes of red flags represented in the measure of readiness such as negativity, being stuck, feeling overwhelmed, and uncontrolled emotion. Examples such as always crying in response to being asked about their child, or expressing inappropriate anger towards others were noted by P2P leaders as possibly detrimental to help-seeking parents if paired with such an individual for support. This fear of pairing a parent exhibiting these behaviors may be related to emotional contagion mentioned in Chapter 2 literature review in that a help-seeking parent may take on the emotions of the parent providing them support.

Depression may be present in an individual struggling with uncontrolled emotions of sadness and anger. According to the DSM V, excessive crying and/or irritability may be indicative of a depressive disorder, and therefore, depression will be measured concurrently with the measure of readiness to assess convergent validity. Depression was theorized to display a moderate negative correlation with readiness such that a high score on the readiness measure would predict a low score on the depression measure. Theoretically, therefore the BDI was predicted to demonstrate a stronger relationship with the red flags dimension of readiness than the positive aspects or readiness total score.

Readiness Measure

The readiness to volunteer measurement instrument contained seventy items based on information gathered from the previous interview study described in an earlier section. DeVellis (1991) provides a guideline the initial pool of items should be three or four times that of the final scale. As time constraints are an issue for many parents of children with disabilities, the initial scale item pool was piloted with the intent to end up with a final scale of twenty or fewer items. A 1 to 5 point Likert scale format was employed as it provides interval or quasi-interval data compatible with factor analytic procedures (Furr, 2014). A group of experts in the recruitment and selection of Parent to Parent volunteers determined content validity. They assessed whether the content of the items included all aspects of the construct, were clear, readable and resonated with their experience. Five Parent to Parent experts evaluated around 100 initial items on a scale of one to five with five being very relevant. Items with scores over 3.5 were retained and possibly refined in wording in response to feedback from a scholar experienced in measure development. Additional items were added to ensure each category from the grounded theory was represented adequately in the final measure.

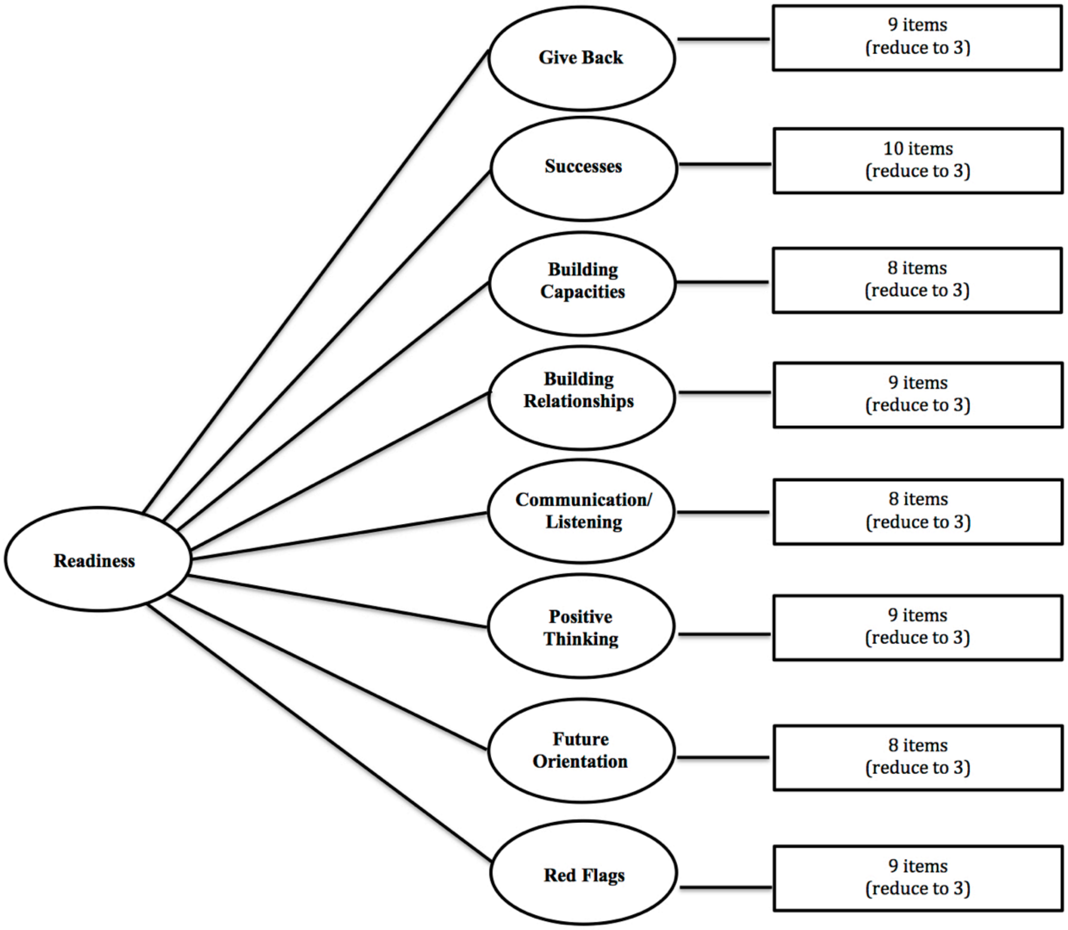

Figure 2. Hypothesized factor structure of readiness measure. This figure illustrates the hypothesized factor structure of the measure of readiness derived from interview themes.

Floyd and Widaman's presentation of issues related to sampling in measure development make it clear while there is no rule of thumb for sample size in exploratory factor analysis, accurate solutions can be produced with samples of 100 to 150 participants. Before proceeding in the analysis, data should be assessed for normality and examined for outliers (Bollen, 1989). If serious violations occur, due to the relatively large number of items in the readiness measure and relatively small number of participants included in the final analysis, item reduction strategies are employed prior to analysis.

When moving on to the process of extracting factors, the exploratory factor analysis method, Maximum Likelihood, was chosen as an extraction method, suggested by Floyd and Widaman as it allows for a greater number of statistical analyses (1995). Eigenvalues larger than 1.0 and scree plots (one factor less than the flattening out point) were examined to determine the appropriate number of factors. Those were then extracted and factor rotation conducted to clarify the psychological meaning of the factors (Furr, 2014). This process is helpful in the development of measures of constructs not derived from an established theoretical base. Oblique rotation was utilized as it allows factors to be correlated or uncorrelated as they will, and provides a clearer understanding of associations between factors (Fabrigar, Wegener, MacCallum, & Strahan, 1999; Floyd & Widaman, 1995).

Item-factor solutions were then examined. Pattern coefficients are the standardized regression weights, and represent how well a respondent's answer to the individual item can be predicted by their factor score. Factor loadings have a range of -1 to 1, and larger (absolute) values indicate a higher degree of association between the item and factor. Items accounting for a meaningful portion of the total variance were retained on each factor. A multiple factor solution with inter-correlated dimensions was predicted to align with important terms from the theory developed in Study I such as readiness, red flags, communication, building relationships, positive appraisal, successes and being stuck.

Once the scale was treated as described above, the reduced and refined measure was assessed for reliability. For the purposes of the present study, internal consistency, which is the consistency of results across items within a measure, is the most appropriate measure of reliability. Cronbach's alpha (1951), a function of inter-item covariances and total test variance was calculated (Furr, 2014). Cronbach's alpha is represented mathematically as,

α=K/K-1$(1-\frac{\sum_{i=0}^{K}\sigma_{Y_i}^2}{\sigma_X^2})$ is understood to be a measure of how well the summed score on the items represents the true or expected score. Measures with alpha scores closer to one are considered more reliable, and a general rule of thumb is to aim for an alpha coefficient of .70 or greater (Nunnally & Bernstein, 1978).

Validity of a measure is generally conceived as the degree to which a test measures the construct it is supposed to measure. Convergent validity and discriminant validity are elements of construct validity. Convergent validity is conceived of as the similarity of scores on the new measure with established measures of the same or similar psychosocial construct, whereas divergent validity is the degree the measure distinguishes between related conditions (Appelbaum & Center, 2011). Validity of the measure of readiness to volunteer was further tested through comparisons of scores on the P2P volunteer readiness measure with scores of concurrently measured constructs with reliable, valid measures. A matrix of correlations between the measure and theoretically related constructs was examined in light of a priori predictions regarding similar constructs. Posttraumatic growth and empathy were predicted to be positively related to readiness to volunteer as a peer support to another parent of a child with a disability, and depression was theorized to display a moderate negative correlation, providing evidence of convergent validity.

IV. Results

A quantitative study of parents of children with disabilities who have and have not had experience with Parent to Parent support was conducted with participants from across the United States. The goal of the study was to determine the factor structure, reliability and validity of a new measure of readiness to be trained as a peer support provider for Parent to Parent USA. An eight-factor solution was hypothesized from the findings of a preliminary interview study (Dodds, 2014) conducted with leaders in the Parent to Parent organization, and was explored with factor analysis techniques. Reliability and validity of the measure were assessed using Cronbach's Alpha and construct validity was assessed examining correlations between the readiness measure and additional measures to which it was hypothesized to be related. Finally, further evidence for the validity of the instrument was assessed by comparing the readiness scores of parents who have and have not been trained as supporting parents, as it was predicted trained parents would score significantly higher than those who had not been trained.

Sample

A participant group of 175 people was recruited from existing P2P USA volunteers, help recipients and non-affiliated parents referred to the survey by P2P coordinators. Two hundred ten participants logged in to the survey with 175 giving responses for most items. This represents a 17 percent attrition rate. Of the participants, 46% had been a supporting parent for P2P and 39% had received support at some time from a P2P support parent. Most participants were white (87%) middle to upper class women with a mean age of 46 years, with no significant difference in age between parents who have served as supporting parents and those who have not.

Data Import

All data analysis was performed in the statistical software SPSS version 23. A list of all items by category and their assigned labels are shown in Table 1 below. These categories were drawn from original interview research (Dodds, 2014). It was hypothesized these categories would represent separate factors, which would load onto a latent variable, readiness to volunteer. All reverse coded items were recoded and the final data was stored with the Likert scale; 1 "Strongly Disagree", 2 "Disagree", 3 "Neither Agree nor Disagree", 4 "Agree", 5 "Strongly Agree".

Table 1

Readiness Items by Category and Assigned Labels

Category	Label	Item
Give Back	giv_1	I want to keep other families from having the same difficulties I experienced.
Give Back	giv_2	No one helped me when my child was diagnosed, so I don't need to help other parents.
Give Back	giv_3	I can share examples of times I have helped another parent of a child with a disability.
Give Back	giv_4	I feel it is important for me to give back to the disability community.
Give Back	giv_5	I feel compassion for other parents of children with disabilities.
Give Back	giv_6	Many people have been kind to me and I would like to do the same for another.
Give Back	giv_7	I take so much-- I want to also give something back.
Give Back	giv_8	If people like me don't pay it forward, how will new parents find help?
Give Back	giv_9	I feel ready to support another parent.
Successes	suc_1	I have developed strategies to deal with life's unpredictability.
Successes	suc_2	Other families ask me for advice to help their child.
Successes	suc_3	I have developed strategies that have helped my family.
Successes	suc_4	I have found ways to make time for myself.
Successes	suc_5	I have become an expert on my own child.
Successes	suc_6	I could write a book about my experiences as a parent.

Successes	suc_7	My family has daily routines that work for us.
Successes	suc_8	My family makes time to have fun.
Successes	suc_9	My child with a disability takes up all my time.
Successes	suc_10	My child has accomplished more than I expected him to.
Building Capacities	cap_1	I'm not a teacher so I can't help my child.
Building Capacities	cap_2	I have built a body of knowledge in the course of helping my child.
Building Capacities	cap_3	My child with special needs has taught me about being a better parent.
Building Capacities	cap_4	I have learned how to do research on resources for my child.
Building Capacities	cap_5	When a problem arises in my child's program I know whom to contact.
Building Capacities	cap_6	I attend disability/medical conferences or trainings to learn more about my child.
Building Capacities	cap_7	I gather information before I make decisions.
Building Capacities	cap_8	I have learned to advocate for my child.
Building Relationships	rel_1	I am kind even when someone is very different from me.
Building Relationships	rel_2	I can work with others to achieve a goal.
Building Relationships	rel_3	I have a strong social support network.
Building Relationships	rel_4	I am a collaborative partner in my child's education and/or medical care.
Building Relationships	rel_5	I can put myself in another parent's shoes.
Building Relationships	rel_6	I make people feel comfortable.
Building Relationships	rel_7	I have reached out to an individual or an organization for assistance.
Building Relationships	rel_8	People see me as dependable.
Building Relationships	rel_9	I have difficulty trusting the professionals who serve my child.
Commun/Listening	lis_1	Friends say I am a good listener.
Commun/Listening	lis_2	I talk more than I listen.
Commun/Listening	lis_3	I can explain why and how I made certain decisions for my child.
Commun/Listening	lis_4	I am comfortable sharing my journey with my child with others.
Commun/Listening	lis_5	Talking with another parent of a child with a disability makes my day.
Commun/Listening	lis_6	I am good at communicating on the phone.
Commun/Listening	lis_7	It is important to keep conversations with other parents confidential.
Commun/Listening	lis_8	I can tell how people are feeling when I talk with them on the phone.
Positive Thinking	pos_1	Even when things are tough, I always have hope.
Positive Thinking	pos_2	I have confidence in my parenting abilities.
Positive Thinking	pos_3	My child has gifts and talents that I value.
Positive Thinking	pos_4	I have confidence in my ability to navigate school or medical systems.
Positive Thinking	pos_5	I'm happy to help others.
Positive Thinking	pos_6	I believe most people will try to take advantage of you if you let them.
Positive Thinking	pos_7	I am a positive person.
Positive Thinking	pos_8	I am proud of my child with special needs.
Positive Thinking	pos_9	I appreciate the little things in life.

Future Orientation	fut_1	I have given up on having dreams for my child.
Future Orientation	fut_2	I have long-term goals for my child.
Future Orientation	fut_3	I want my child to be as independent as possible.
Future Orientation	fut_4	I have a vision for my child's future.
Future Orientation	fut_5	I want my child to make his own decisions regarding his future.
Future Orientation	fut_6	I want my child with a disability to have a full life.
Future Orientation	fut_7	Working together, parents can make a better world for their kids.
Future Orientation	fut_8	My child and I will keep on learning no matter what.
Red Flags	flg_1	I expect other parents to handle a situation the same way that I would.
Red Flags	flg_2	I don't agree that my child has a disability.
Red Flags	flg_3	I cry often about my child's disability.
Red Flags	flg_4	I have never really talked about my child's disability with another parent.
Red Flags	flg_5	It is difficult for me to hear about another parent's experience.
Red Flags	flg_7	There is a right way and a wrong way to approach each situation.
Red Flags	flg_8	I usually get upset when I talk about my child's needs.
Red Flags	flg_9	I will find a cure for my child.

In the following discussion, the steps conducted in analyzing data to derive key psychometric properties of a measure of readiness to volunteer for parent to parent self-help programs as a peer support provider, and a final model for the measure of readiness are presented. The data analysis proceeded in the following steps, which are subsequently indicated by the subheadings: Data Import, Exploratory Factor Analysis, Examining Communalities, Evaluating Convergent Validity, and Group Differences in Performance on the Readiness Measure.

Data was incomplete for 21 of the 175 respondents on the readiness items. In order to address the problem of missing data, pairwise deletion was employed. Pairwise deletion involves deleting a case that is missing for a variable required for a particular analysis, however, the case is included in analyses for which it is complete for all variables required in that particular analysis. For example, if a respondent chose not to complete the BDI but answered all other questions, their data would be included for the factor analysis of the readiness measure, but not for the correlation analysis between the readiness measure and BDI. When pairwise deletion is used, the total number of analyzed cases is not consistent across parameter estimations. Pairwise deletion was chosen in dealing with missing data, as it is yields accurate solutions if the missing data is random in nature and makes use of as much data as possible (Allison, 2001), which is important for accurate model development.

In the given study, there were a relatively large number of items included in the readiness measure (69) as compared to number of respondents (175), which are approximately 2.5 respondents per item. This ratio is not uncommon in current factor analysis practice, in fact, according to Costello and Osborne, approximately 40 percent of published EFA studies are implemented with fewer than five participants per item (pg.4, 2005). Responses were not captured for one readiness variable due to software error. An important step in the EFA process however, was to iteratively reduce the number of items before attempting to extract factors to decrease redundancy and create a more reliable measure (Churchill, 1979).

Once the data was imported and recoded, it was assessed for normality through the examination of boxplots, skewness and kurtosis statistics. Thirteen items with kurtosis statistics greater than five were removed from the analysis. Inter-item correlations for the remaining 56 items were then examined and items that did not perform as expected due to low correlations with items intended to be similar, or displayed several negative correlations with other items were removed from the analysis, as they are likely not representative of the same construct. At this point, all reverse coded items were eliminated (this included all red flags items). Ten cases that exhibited extreme values (nearly all "5s") over a majority of readiness items were then removed from the analysis. Thirty-five remaining items were retained for the next step of the analysis.

The goal of the next process was to find a reduced subset of items for each of the remaining hypothesized readiness categories (give back, successes, building capacities, building relationships, communication/listening, positivity and future orientation) with the maximum Cronbach's Alpha value. Subscales were reduced in accordance with Pett and associates' suggested sequential approach to measure development (Pett, Lackey & Sullivan, 2003). Items that did not optimize Alpha were removed by utilizing the "Cronbach's Alpha if Item Deleted" feature of SPSS, reducing items in an iterative process until only items that optimized alpha remained, thereby increasing the overall internal consistency of each hypothesized subscale. This process further reduced the number of items to 23.

Exploratory Factor Analysis

The exploratory factor analysis (EFA) process was initiated for the purpose of identifying the underlying structure of the readiness scale. The maximum likelihood extraction method with Oblimin rotation was utilized in the process. Maximum likelihood extraction was chosen because it enables the computation of goodness of fit indexes and the testing of the statistical significance of factor loading. With maximum likelihood extraction, the researcher is also able to calculate correlations among factors and compute confidence intervals for these parameters (Cudeck & O'Dell, 1994). Oblimin is an oblique rotation, which allows factors to be correlated, as they will. This method was utilized because when assessing a psychosocial construct in the social sciences, it is accepted that the factors are related (Beavers, Lounsbury, Richards, Huck, Skolits & Esquivel, 2013; Harman, 1976). If factors happen to not be correlated however, the solution will be nearly identical to one derived from an orthogonal rotation.

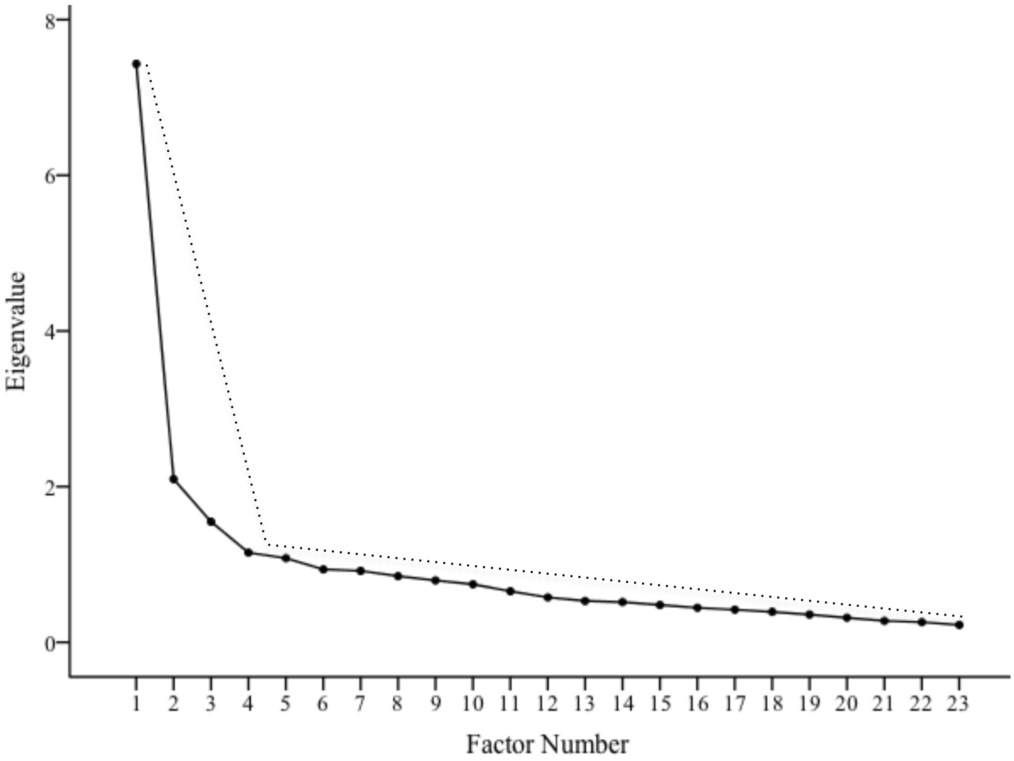

Figure 3. Scree plot of 23 items of the readiness scale. This plot indicates either a three or four factor solution, as the flattening out point (emphasized by the addition of the converging dotted lines) is located between factors four and five.

The scree plot for the remaining 23 items seen in figure 3 above was examined to determine how many factors to retain. The scree plot of appears to flatten out between factor four and five (dotted lines added to aid interpretability) indicating plausibility of a three or four factor solution (Cattell, 1958). In accordance with Costello and Osborne's suggestions for best practices in EFA, after performing factor rotations, item loading tables were examined to determine the best factor structure to fit the data. Items with poor factor loadings (below .30), which loaded onto multiple factors and/or exhibited low communalities (below .30) were removed iteratively from the analysis through successive applications of the EFA process (Costello & Osborne, 2005).

Table 2
Factor Loadings, Alpha Scores and Communalities for 3-Factor Readiness Solution

	Into action	Wellbeing	Skills and navigation	Communalities
Cronbach's Alpha	.86	.75	.77	
I feel it is important for me to give back to the disability community.	.77			.52
I feel ready to support another parent.	.68			.60
I can work with others to achieve a goal.	.67			.49
I can share examples of times I have helped another parent of a child with a disability.	.65			.53
I am good at communicating on the phone.	.50		.	.53
Other families ask me for advice to help their child.	.50			.40
I have built a body of knowledge in the course of helping my child.			.41	.51
I can share strategies that helped my family.	.43			.45
Even when things are tough, I always have hope.		.69		.52
My family makes time to have fun.		.66		.44
I am a positive person.	.	.61		.55
My family has daily routines that work for us.		.53		.38
I have a strong social support network.		.50		.31
I have learned to advocate for my child.			.74	.68
When a problem arises in my child's program I know whom to contact.			.58	.41
People see me as dependable.			.56	.32
I have learned how to do research on resources for my child.			.35	.29

Note: Extraction Method: Maximum Likelihood. Rotation Method:Oblimin with Kaiser Normalization.

A clear 3-factor solution emerged with 17 items. The first factor was comprised of seven items, the second, five items, and the third, five items. The items by factor are displayed in the diagram of the factor structure shown in figure four on page 87. The first factor was named Into Action as the items included were concerned with working with and mentoring other parents and communicating with others, such as collaboration with professionals or systems. The second factor, named Wellbeing was made up of items that focused on balanced family functioning and a positive outlook. The third factor called Skills and Navigation included items that reflect the capacities built over the course of the variety of experiences caring for a child with a disability or special heath care need. The resulting reduced subsets of items for all categories and their corresponding alpha scores are listed in Table 2 above. A correlation matrix displaying the relationships between all readiness variables can be viewed in Table 3 below.

Table 3

Matrix displaying the correlations between the 17 items of the readiness measure

	pos_1	suc_2	cap_2	rel_2	giv_3	suc_3	rel_3	giv_4	cap_4	cap_5	lis_6	suc_7	pos_7	suc_8	cap_8	rel_8	giv_9
pos_1	----	.163	.108	.273**	.132*	.273**	.380**	.266**	.093	.085	.184**	.318**	.576**	.344**	.075	.052	.279**
suc_2	.163*	----	.458**	.430**	.466**	.340**	.279**	.441**	.366**	.304**	.433**	.346**	.307**	.201**	.369**	.198**	.468**
cap_2	.108	.458**	----	.476**	.480**	.432**	.231**	.410**	.384**	.422**	.445**	.283**	.211**	.213**	.569**	.264**	.483**
rel_2	.273**	.430**	.476**	----	.493**	.466**	.243**	.489**	.263**	.142*	.413**	.268**	.432**	.157*	.262**	.113	.440**
giv_3	.132*	.466**	.480**	.493**	----	.532**	.204**	.432**	.541**	.364**	.486**	.215**	.337**	.119	.402**	.208**	.541**
suc_3	.273**	.340**	.432**	.466**	.532**	----	.266**	.361**	.248**	.312**	.489**	.381**	.368**	.259**	.427**	.290**	.502**
rel_3	.380**	.279**	.231**	.243**	.204**	.266**	----	.280**	.174*	.311**	.191**	.344**	.367**	.355**	.176*	.121	.293**
giv_4	.266**	.441**	.410**	.489**	.432**	.361**	.280**	----	.290**	.216**	.445**	.192**	.293**	.024	.264**	.193**	.602**
cap_4	.093	.366**	.384**	.263**	.541**	.248**	.174*	.290**	----	.361**	.276**	.187**	.189**	.137*	.393**	.346**	.290**
cap_5	.085	.304**	.422**	.142*	.364**	.312**	.311**	.216**	.361**	----	.425**	.260**	.177*	.181*	.508**	.360**	.313**
lis_6	.184*	.433**	.445**	.413**	.486**	.489**	.191**	.445**	.276**	.425**	----	.231**	.378**	.158*	.568**	.356**	.594**
suc_7	.318**	.346**	.283**	.268**	.215**	.381**	.344**	.192**	.187**	.260**	.231**	----	.354**	.460**	.285**	.223**	.340**
pos_7	.576**	.307**	.211**	.432**	.337**	.368**	.367**	.293**	.189**	.177*	.378**	.354**	----	.363**	.226**	.080	.405**
suc_8	.344**	.201**	.213**	.157*	.119	.259**	.355**	.024	.137*	.181*	.158*	.460**	.363**	----	.226**	.135*	.175*
cap_8	.075	.369**	.569**	.262**	.402**	.427**	.176*	.264**	.393**	.508**	.568**	.285**	.226**	.226**	----	.480**	.444**
rel_8	.052	.198**	.264**	.113	.208**	.290**	.121	.193**	.346**	.360**	.356**	.223**	.080	.135*	.480**	----	.201**
giv_9	.279**	.468**	.483**	.440**	.541**	.502**	.293**	.602**	.290**	.313**	.594**	.340**	.405**	.175*	.444**	.201**	----

**.$p <$ 0.01, * $p <$ 0.05

The proposed study used the following guidelines in interpreting Cronbach's alpha results from these analyses; $\alpha < .5$ = unacceptable; $.5 \leq \alpha < .6$ = poor; $.6 \leq \alpha < .7$ = questionable; $.7 \leq \alpha < .8$ = acceptable; $.8 \leq \alpha < .9$ = good; and $\alpha \geq .9$ = excellent (George & Mallery, 2010). Reliability for Into Action was good ($\alpha = 0.86$) and acceptable for both Wellbeing ($\alpha = 0.75$) and Skills and Navigation ($\alpha = 0.77$). Factor loadings for the measure were between 0.35 and 0.77, with an average factor loading of 0.58.

Although the factor structure of the final readiness measure shown below in Figure 4 did not include all eight factors hypothesized as seen in Figure 2 on page 71, the model derived from factor analysis retains much of the information deemed important to the construct of readiness to be trained as a peer support provider for Parent to Parent, and may provide a more succinct understanding of this construct. The model will be discussed further in the final chapter of this document in reference to theory and interview data presented in the literature review as well as future implications and limitations.

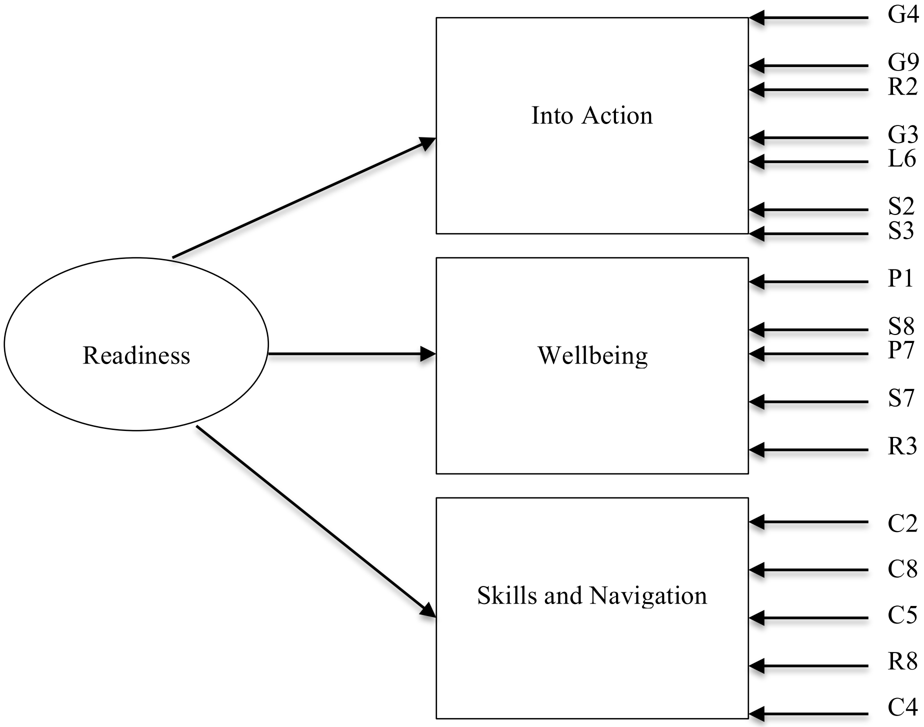

Figure 4. Factor structure of the measure of readiness to volunteer for Parent to Parent. This figure illustrates the factor structure of the measure of readiness derived from exploratory factor analysis.

Examining Communalities

Communality is a statistic that indicates the proportion of each variable's variance that is explained by the factors retained in the measure. The magnitude of the communality can be understood similarly to a correlation coefficient. Values more than 0.70 are considered high, but are rarely seen in social science research. Costello and Osborne suggest items display at least 0.40 communality in order to be retained in a measure, and that communalities lower than this threshold may indicate the presence of an additional factor if such items are deemed important to the understanding of the construct by the researcher (Costello & Osborne, 2005). Child, in the 2006 edition of his text, *The Essentials of Factor Analysis,* suggests a lower threshold for retention of 0.20, stating that variables below this level of communality are suspect and that the researcher should consider removing them from the final measure (p. 47). Table 2 on page 83 presents the items included in the final model in the first column and their corresponding factor loadings in the columns two through four. Communalities are presented in column five.

If we look at the communalities item by item, some items fare better than others. Well performing items include, “I feel ready to support another parent,” and “I have learned to advocate for my child.” The four items with the lowest communalities (below 0.40) included, “I have a strong social support network (0.31),” “I have learned how to do research on resources for my child (0.29),” “People see me as dependable (0.32)” and “My family has daily routines that work for us (0.38).” Low communalities do not necessarily indicate poor fit but may be taken as evidence that the given variable has little in common with the others. These four items were retained, as they were deemed important to the understanding of the construct of readiness, and although their communalities were low, they were above Child’s suggested cut off, and factor loadings were strong enough to warrant their inclusion in the final measure (Pett, Lackey & Sullivan, 2003).

Average communalities for each factor were above the Costello and Osborne's .40 threshold, with the Into Action highest at 0.50, Skills and Navigation factor and Wellbeing both displaying a 0.44 average communality. The proportion of the total variation explained by the three-factor solution is equal to total communality (which is the same value as eigenvalue) divided by the total number of items. Altogether, the Readiness measure average total communality is 0.46, which is adequate for a newly developed measure of a psychosocial construct derived from a small initial sample (Costello & Osborne, 2005). This can be understood to mean that approximately 46 percent of the variation in readiness is explained by the new model. Future assessment of communalities with a larger sample is necessary for measure refinement and to determine if an additional factor may emerge given greater statistical power.

Evaluating Convergent Validity

Research question 2 stated, "Is there evidence of convergent validity in the measure of readiness?" It was hypothesized that the readiness measure would display moderate positive correlations with the Toronto Empathy Questionnaire (TEQ) and Posttraumatic Growth Inventory Short Form (PTGI). This means that a parent who scored high on the measure of readiness would be likely to score high in empathy and posttraumatic growth. A moderate negative correlation was predicted between the readiness measure and the Beck Depression Inventory II (BDI). This could be interpreted as if an individual displayed a high score on readiness, they would likely a display low score on the depression measure.

The score for the Total Readiness measure was computed by summing the scores for each factor. Factor scores were calculated by adding item scores for that factor and dividing by the number of items included in the factor. Factor scores therefore could vary between one and five, and Total Readiness scores could be between three and 15. Means and standard deviations for the measures utilized for validity are displayed in Table 4 below.

Table 4

Descriptive Statistics for the three scales, total readiness and measures of convergent validity

	Mean	Std. Deviation	N
ita_factor	4.22	.55	157
skills_factor	4.40	.49	161
well_factor	3.99	.60	156
ready_tot	12.61	1.31	150
teq_tot	66.31	5.53	151
ptgi_tot	32.41	7.90	63
bdi_tot	6.51	6.51	144

Note: ready_tot=Total Readiness score, ita_factor= Into Action Factor, skills_factor= Skills and Navigation Factor, well_factor= Wellbeing Factor, teq_tot=Toronto Empathy Questionnaire total score, ptgi_tot=Posttraumatic Growth Inventory Short Form total score, bdi_tot=Beck Depression Inventory total score

To determine the convergent validity of the new 17-item readiness measure, a correlation matrix was examined. The correlation matrix of the measures is shown below in Table 5. Asterisks next to a correlation indicate correlations significant at the level of 0.05; double asterisks indicate significance at or below 0.01. The values shown for each combination are the correlations and the number of non-missing records used to compute the correlation. Correlations were assessed for each of the three readiness factors, Skills and Navigation, Into Action and Wellbeing, as well as the Total Readiness measure score.

The Total Readiness measure score displays the highest correlation with the BDI score (r=-.566, N=130, p< 0.01). The readiness score also displays a significant moderate correlation with the Toronto Empathy Questionnaire (r=0.437, N=139, p<0.01). A nonsignificant relationship was displayed between the readiness measure and the Post Traumatic Growth Inventory, although there may not have been enough power to establish this relationship. The PTGI offers a choice to skip a question by marking six and many participants chose this option several times in the completion of this instrument. For data analysis, only participants who skipped two or fewer of the ten items on the PTGI were included in the analysis. This left a maximum of 63 possible participants to be included in the correlational analyses (N varies by analysis due to the implementation of pairwise deletion processes), limiting the power of the test and possibly reducing the significance of the relationship.

Table 5

Correlations Between Readiness and Empathy, Posttraumatic Growth and Depression

	ita_factor	skills_factor	well_factor	ready_tot	teq_tot	ptgi_tot	bdi_tot
ita_factor	----	.615**	.468**	.860**	.501**	.217	-.444**
	(157)	(156)	(151)	(150)	(145)	(60)	(137)
skills_factor	.615**	----	.324**	.767**	.280**	-.032	-.288**
	(156)	(161)	(154)	(150)	(148)	(62)	(140)
well_factor	.468**	.324**	----	.777**	.233**	.249^{n}	-.576**
	(151)	(154)	(156)	(150)	(143)	(60)	(135)
ready_tot	.860**	.767**	.777**	----	.437**	.165	-.556**
	(150)	(150)	(150)	(150)	(139)	(59)	(130)
teq_tot	.501**	.280**	.233**	.437**	----	-.083	-.278**
	(145)	(148)	(143)	(139)	(151)	(59)	(136)
ptgi_tot	.217	-.032	.249	.165	-.083	----	-.274*
	(60)	(62)	(60)	(59)	(59)	(63)	(55)
bdi_tot	-.444**	-.288**	-.576**	-.556**	-.278**	-.274*	----
	(137)	(140)	(135)	(130)	(136)	(55)	(144)

Note: ready_tot=Total Readiness score, ita_factor= Into Action Factor, skills_factor= Skills and Navigation Factor, well_factor= Wellbeing Factor, teq_tot=Toronto Empathy Questionnaire total score, ptgi_tot=Posttraumatic Growth Inventory Short Form total score, bdi_tot=Beck Depression Inventory total score. Values in parentheses indicate the number of cases included in the analysis.

**.*p*< 0.01, * *p*< 0.05, ^{n} *p= 0.055*

Individually, the three factors that comprise the readiness measure were also assessed for their relationships to the theoretically related constructs of empathy, posttraumatic growth and depressive symptoms. The Into Action factor was most closely related to empathy (*r*=0.501, N=145, p<0.01). This is consistent with the understanding that readiness is related to empathy in that having empathy for other parents of children with disabilities is critical in working with parents in a nonjudgmental way. Wellbeing was most closely associated with depressive symptoms (*r*=-0.576, N=135, p<0.01) with those scoring highest on Wellbeing displaying the least depressive symptoms. This finding is consistent in both direction and magnitude with other studies exploring the relationship between wellbeing and depression

(Ryff & Keyes, 1995). Although it is likely that most parents of children with disabilities will experience positive and negative feelings simultaneously, exhibiting a positive balance in life as measured by the Wellbeing factor is likely protective against depressive symptoms. Wellbeing also displayed a near significant relationship with Post Traumatic Growth (r=0.249, N=60, p=0.055). As PTG is closely related to a positive outlook and positive change, it may be that given a larger sample of respondents on the PTGI, a significant relationship between posttraumatic growth and Wellbeing would emerge.

Predictive Validity/ Group Differences in Performance

A measure of readiness to volunteer as a support provider for Parent to Parent should be able to discriminate parents who have been trained to provide such support and those who have not. Research question 3 states, "Does the measure of readiness display a difference in scores between parents who are or have been peer support providers and parents who have not?" It seems logical that parents who have served as peer support providers would exhibit higher scores on the readiness measure due to greater experience in the disability community with resources and systems navigation, and given that many support parents are hand-picked by Parent to Parent Coordinators, the individuals who are charged with training peer supports and matching parent pairs. Conversely, if the data were to show that people who had already volunteered were "unready" it would logically call into question the meaning of the measure. Additionally, parents who had received support from a peer support provider in a one-to-one match would likely score better on the readiness measure than a parent who has not, as it is hypothesized that peer support is a valuable form of coping assistance moving a parent toward readiness.

The two demographic questions of interest when reviewing the newly created readiness measure are “Have you been trained or worked as a Parent to Parent peer support provider?” and “Have you received support from a Parent to Parent peer support provider?” In the data collected nearly half of the 175 respondents included in the total analysis (46%) have been trained as a supporting parent for Parent to Parent and 39% reported having received support from another parent. Two-sample t-tests were performed for both demographic variables to determine whether there were significant group differences in score on the readiness measure. Table 6 presents the results of a two-sample t-test for trained and untrained parents on their total readiness score. There was a significant effect for training $t(160) = 5.95$, $p < .001$, with those who have been trained as a support parent reporting significantly higher scores on the readiness measure than those who have not. The effect size for this difference is 0.95, which is considered large according to Cohen’s guidelines (1992), and has a 95 percent confidence interval with a lower bound of 0.75 and upper bound of 1.51.

Table 6
Two-sample t test of total readiness scores for trained and untrained parents

	Obs.	Mean	Std. Deviation	Std. Error	*d*	*t*	*df*	95% Conf. Interval Lower	95% Conf. Interval Upper
trained	68	13.23	0.99	0.12					
untrained	82	12.10	1.33	0.14					
combined	160			0.17					
difference		1.13**			0.95**	5.95	146.33	.75	1.51

$^{**}p < 0.001$

In addition to the effect of training, according to a two-sample t-test shown in Table 7, there was also a significant effect for receiving support from another parent $t(150) = 2.09$, $p < .05$, with those who have been supported by another parent of a child with a disability reporting higher scores on the readiness measure than those who have not. Effect size for this difference was significant in the small to medium range (0.35), with a 95% confidence interval lower bound of 0.01 and upper bound of 0.68.

Table 7
Two-sample t-test of total readiness for parents who have and have not received support

	Obs.	Mean	Std. Deviation	Std. Error	*d*	*t*	*df*	95% Conf. Interval Lower	95% Conf. Interval Upper
received support	54	12.91	1.03	0.14					
Not received support	96	12.45	1.43	0.15					
combined	150		1.30	0.17					
difference		0.46*			0.35*	2.09*	148	0.01	0.68

$^*p < 0.05$

Research question 3 is supported by the significant difference between parents with disabilities who have been trained to provide peer support and those who have not, which were hypothesized according the theory of readiness presented in Chapter 2 beginning on page 50.

Chapter Summary

In this chapter, results of the analyses performed on the measure of readiness were presented to detail the steps involved in creating a measure of readiness to be trained as a peer support provider for Parent to Parent organizations. Additional analyses performed on the measure were presented a manner to create an argument for reliability and validity for use with a population of parents with children with disabilities or chronic healthcare needs. Data reduction and exploratory factor analysis were employed to create a 17-item, three-factor version of a readiness scale. The 17-item scale was determined to represent the latent construct of readiness adequately and exhibited good internal consistency and factor loadings. This version of the readiness scale was then assessed for validity by comparing it with additional measures for which relationships were predicted a priori. The readiness measure displayed significant relationships with two of the related constructs (empathy and depressive symptoms) as hypothesized, establishing partial evidence for convergent validity. A relationship between readiness and the construct of posttraumatic growth was not been found to be significant. This will be discussed in more detail in the final chapter. Group differences between trained and untrained parents as well as those who have and have not experienced being supported by a parent support were significant adding to the evidence for construct validity in light of the theory presented in the literature review.

VII. Discussion

This study was conducted to answer the following research questions: 1. What are the key elements that comprise the measure of readiness? 2. Is there evidence of convergent validity in the measure of readiness? and 3. Does the measure of readiness display a difference in scores between parents who are or have been trained peer support providers and parents who have not? In addition to this particular difference, the measure was also tested to assess whether differences in score were significant between parents who had received support from a parent volunteer and those who had not. This research was initiated at the request of leaders of a national parent to parent support group, Parent to Parent USA as a resource for their Coordinators whose task it is to recruit, train and match the volunteers who provide peer-to-peer support to help-seeking parents of children with disabilities or chronic healthcare needs. Based on these questions, the purpose of this study was threefold: (a) to explore the factors involved in the readiness to serve as a P2P support parent scale, (b) to assess the relationships between readiness and empathy, depression and posttraumatic growth and (c) to determine whether scores on the readiness measure were significantly different between parents who have and have not been trained as supporting parents for Parent to Parent groups.

While the study had these pragmatic origins and derivative questions it also casts light on a longstanding question about the process whereby mothers of children with disabilities adapt positively to a life circumstance that is often difficult for these parents. Although there has been a shift in focus in research in this area in the past roughly 15 years, still little is known about positive adaptation and the processes whereby it occurs. The theory of change derived from grounded theory research with leaders of the Parent to Parent USA organization completed in preparation for the development of the measure of readiness to volunteer, suggests that there are stages through which parents of children with disabilities move. Parents often begin in a state of negativity and crisis. This model proposes that a parent may brought over to a more positive point of view by way of the peer support relationship, making way for seeking new knowledge and abilities. The parent then may move beyond mere adaptation and into service to give back to the disability community. This theory incorporates research on the negative aspects of caregiving as well as aspects of theories related to post-traumatic growth and empathy, bridged together by the introduction of the peer support relationship. The findings from the analysis of the measure of readiness and how they support this theory will be presented in the discussion of the findings for research questions 2 and 3.

In response to the first research question, the present study established a framework for understanding the latent factor structure of a measure of the psychosocial construct, readiness to be trained as a Parent to Parent peer support. This study supported a three factor measure of readiness comprised of 17 items. Given the relatively small sample size of this study, the significant findings regarding the factor structure of the readiness scale and its relationships with theoretically related variables is preliminary but has significant implications for future research. The measure was then assessed for convergent validity by comparing the correlations between it and measures of empathy, posttraumatic growth and depression. Readiness was positively related to empathy and displayed a negative relationship with depression as hypothesized. The relationship between readiness and posttraumatic growth was not found to be significant. Group differences were then tested for parents who had and had not been trained to work as support providers as well as those who had and had not received support. Both t-tests displayed significant differences between groups on the readiness measure, so that parents who had been trained outperformed untrained parents, and parents who had received support had higher scores than those who had not been supported. These findings will be discussed in this chapter in relationship to the literature and grounded theory presented in Chapter 2. Implications for the field, limitations and future directions will also be presented.

Factor Analysis

In terms of the study's main objective to explore the factor structure of a new measure of readiness to volunteer as a peer support provider to other parents of children with disabilities, the eight factor hypothesized model was not supported. After data reduction techniques were employed and items were assessed for normality, an exploratory factor analysis was conducted on the 23 remaining readiness items. A three factor 17-item solution was attained. The measure of readiness contained items from six of the original hypothesized factors give back, successes, building capacities, building relationships, communication/ listening and positivity. Future orientation and red flags items were not found to contribute to the overall concept of readiness, and were all removed from the analysis during data reduction or factor analytic processes.

The finding of a three dimensional solution did not fully support the hypothesized model, which was presented in Figure 2 (p. 71), but it is reasonable to think that many of the items comprising the readiness to volunteer measure were highly related to one another. For instance, the Into Action factor contained three items that were written to represent giving back, two from successes, and one each from building relationships and communication/

listening. Into Action encompasses not only the concept of a desire to give back to the disability community, but putting forth some effort to connect with others and having some success emerge from the hard work. The factor named, Wellbeing includes two items each that were written to capture the theorized concepts of positivity and successes as well as an item from building relationships. Wellbeing thereby encompasses concepts of a positive outlook built upon the experience of facing difficulty and coming through it in a positive way. The Building Relationships item that is included in this factor, "I have a strong social support network" is important to the concept of wellbeing as social support is shown to reduce depressive symptoms and stress and increase overall wellbeing (Thoits, 1986). Items included in the Skills and Navigation factor come predominantly from the building capacities category. These items are related to learning new skills and knowing how to navigate systems related to educational, medical and social service systems. One building relationships item is also included, "People see me as dependable." This item is important to the concept of Skills and Navigation in that knowledge is only as good as the effort that is put in to make it useful.

The concepts represented by the three subscales of the readiness measure: Wellbeing, Skills and Navigation and Into Action, are similar to those reported in a recent study of Parent to Parent support for parents of children with deafness and hearing loss. The authors organized 39 peer-reviewed articles thematically to develop a conceptual framework around the most salient components of Parent to Parent support. The three concepts included in their model were well-being, knowledge and empowerment. The model was bidirectional, depicting the beneficial nature of the relationship for both the learning parent and the supporting parent (Henderson, Johnson & Moodie, 2014). Well-being was concerned with family balance and adaptation, knowledge included understanding of systems and an accumulation of skills, and empowerment emphasized engagement of the parent in decision-making and self-awareness (pg. 442).

Coordinators for Parent to Parent USA interviewed for the pilot study, which preceded measure development, stated that they choose recruits who, in the process of telling the story of their journey with their child at a training, display strong communication skills, a positive appraisal of life, have supportive relationships and can share successful outcomes they have attained. Coordinators also routinely survey parents at trainings to list skills and trainings they have attended as well as answer why they would like to volunteer to support another parent (Dodds, 2014). Much of this valuable information is accounted for by the three factors of the readiness measure, which, along with similar results from Henderson et al. regarding Parent to Parent for families with children who are deaf or hard of hearing, indicates that the readiness scale is likely measuring the construct that was intended.

Convergent Validity

Convergent validity was assessed by comparing correlations between the readiness measure and measures of empathy, posttraumatic growth and depression to a priori predictions. The construct of readiness to volunteer was hypothesized to have much in common with empathy as it is often cited as the motivator to prosocial helping and volunteer behavior. Parent to Parent matches help seeking parents with parents who are very similar to them, and thereby empathy is heightened due to shared experience, creating a strong bond between helper and helpee. Additionally, empathic communication strategies are valued by the organization, as skills such as active listening and validation of experience are a large component of many P2P volunteer trainings. Empathy, as measured by the Toronto Empathy Questionnaire, was significantly correlated with the readiness measure, and most highly related to the Into Action factor. The TEQ measures the emotional processes involved in empathy which include accurately identifying and sensing the feelings of another, and also contains items related to altruism and prosocial helping behaviors. The theme of giving back which is directly related to helping behaviors was hypothesized to be the penultimate step in the theory of change presented in Figure 1 on page 50, with the final step being volunteering to be trained as a support parent. In light of the literature on empathy and the theory of change discussed in Chapter 2, the relationship between empathy and readiness to volunteer, and the strong representation of give back items in the Into Action factor, a case for the validity of the measure as representing the construct of readiness is beginning to be built.

The readiness to volunteer construct was also hypothesized to have traits in common with the construct of posttraumatic growth. Although having a child with a disability is not a traumatic experience for all parents, many parents do report that the moment of diagnosis is a deeply felt pain that never goes away. Despite this pain, we know that many families adjust well to their child's disability, and some thrive in the wake of a traumatic beginning. Posttraumatic growth was thought to be similar to readiness in that parents who would be ready to volunteer to be trained as peer support providers would likely display characteristics similar to those represented by four of the five Post Traumatic Growth Inventory factors, relating to others, new possibilities, personal strength, and appreciation of life. These factors corresponded with several markers from the theory of change, which are addressed in the following discussion.

The PTGI relating to others factor is marked by the deepening of relationships, a need for increased sharing, and increased empathy for individuals who are under similar circumstances (Calhoun & Tedeshi, 1999). This is similar to the building relationships theme represented in the theory of change as a bidirectional arrow between P2P support and positivity. Parents who reach out to Parent to Parent who are dealing with negative effects of their child's disability are encouraged to share their experiences with a similar and empathetic peer who has "been there." The arrow is bidirectional as both the help-seeking parent and the support parent are building a strong bond due to the increased empathy associated with their shared experience.

New possibilities is the PTGI factor associated with the recognition that there are now paths and opportunities available that were not there before the traumatic event. Parents who have moved into a more positive appraisal of their child's disability, according to the theory of change, move upward through what is termed the future orientation spiral. According to P2P leaders, it is the ability to look into the future and plan for positive outcomes that helps parents think more flexibly, learning new skills and trying new approaches. When they find they have successfully helped their child and family, they are often driven to give back further to others who are in a situation similar to theirs. They may choose to give back through becoming a supporting parent or by changing their career to one serving the disability community.

The factor on the PTGI termed personal strength, marked by a belief that the individual can handle situations that they once thought were difficult (Calhoun & Tedeschi, 1999) is similar to several constructs featured in the theory described in Chapter 2. The attributes presented as components of the future orientation spiral, building capacities, communication and successes illustrate a possible mechanism by which a parent may come to believe in their personal strength. The theory of change for parents of children with disabilities shows that by being brought over into positivity, the parent is inspired to learn new things to help their child and family adapt which is called building capacities. Then, through increased participation in the disability community, they improve their ability to communicate with others, finding ways to advocate for their child or family needs and navigate systems. Finally, parents experience successes associated with their new knowledge and skills, reinforcing their hard work and leading to a belief that they can handle situations successfully. At this point, other parents of children with similar needs may begin to notice the successes and solicit information or advice from the parent, further solidifying this belief in their abilities.

The factor called appreciation of life, was associated with finding joy in the small things and a shift in priorities related to what is important, an appreciation for things formerly taken for granted (Calhoun & Tedeschi, 1999). Help-seeking parents who have experienced a one-to-one match through Parent to Parent USA, often report that the match was pivotal in changing their outlook in life from negativity to a more positive appraisal of their child and situation. This is depicted in the theory of change by a plus sign, which comes from the parent match relationships and leads the help-seeking parent on to a journey of learning, discovery and accomplishment via the future-orientation spiral.

Taken together, the theory of change may be viewed as a representation of the path a parent who begins in a state of overwhelming negativity, and is assisted in adaptation and beyond to work in the disability arena by way of their relationship with a trained Parent to Parent peer support provider. This assertion was unfortunately not supported by a significant relationship between the readiness measure and the measure of posttraumatic growth as predicted. The PTGI-SF gave the option for participants to skip any question, and many parents, likely uncomfortable with the items due to their framing of their child's disability as a trauma, chose to skip several of the items. Due to the lack of complete data on the PTGI, power was reduced for the correlational analysis as the number of participant that could be meaningfully included in the analysis was reduced to 59. The posttraumatic growth measure may need to be adapted further for use with this population to ensure an adequate number of responses are obtained.

The final measure used in evaluating convergent validity of the readiness to volunteer measure was the Beck Depression Inventory. This measure is frequently used in research with parents of children with disabilities and has been used to show relationships between the severity of a child's disability or child behavioral difficulties with parent depressive symptomology (Floyd & Gallagher, 1997; Olsson & Hwang, 2001; White, & Hastings, 2004). It should be noted, however, that other research has shown that although at greater risk, most parents of children with disabilities do not present with depressive symptoms at levels thought indicative of clinical depression (Singer, 2006). In the current sample, parents average score on the measure of depressive symptoms was 6.51, which is in the lowest scoring category on the BDI. These scores are lower than those drawn from a general sample of parents of children with disabilities, suggesting that individuals who participated in this study may have adapted further or have not experienced as difficult an impact due to their child's disability as most. This study solicited participants through online Parent to Parent listservs and bulletin boards, and therefore likely drew a more positively adapted sample than the general population of parents of children with disabilities. Parents who know to access online disability-related boards or make time to attend trainings are more likely to be further along in their adaptation than a parent who is struggling or feels isolated because of their child's disability.

The BDI displayed a moderate to strong negative correlation with readiness, showing that parents who scored well on the readiness measure were those who had low levels of depressive symptoms. This was consistent with a priori predictions. Parent to Parent leaders revealed in the pilot study that they were not willing to train volunteers who displayed a lack of control over their emotions, so that a parent who was consistently angry or crying would not be a suitable peer support. They also stated that they look for individuals who display a positive outlook towards their child and their life. Individuals who are depressed often display uncontrolled emotional outbursts similar to those described by P2P coordinators, so finding that an individual who displayed higher levels of depressive symptoms would score poorly on the readiness measure supports the validity of the measure. Parents who express positivity regarding their situation and their child would also be unlikely to be depressed. This finding supports the measure of readiness to be trained as a peer support provider for Parent to Parent as a valid measure of this specific construct.

The measure of readiness displayed significant moderate correlations with two of the three measures selected for their theoretical relatedness to the construct. These results provide partial but strong evidence supporting the convergent validity of the Parent to Parent readiness measure, as it was expected to exhibit positive correlations with empathy and posttraumatic growth and a negative correlation with depression. The lack of a significant correlation between readiness and posttraumatic growth will be discussed further in the future directions section of this chapter.

Group Differences

Research question 3, which asked whether the measure of readiness displays a difference in scores between parents who are peer support providers and parents who are not, was answered by the significant group differences in readiness scores between the two groups, with trained parents having significantly higher scores on the measure. Additionally, group differences were found to be consistent with the fore mentioned grounded theory, in that parents who had received support from a Parent to Parent match scored significantly higher than those who had not. Together these findings provide additional evidence that both being supported by a peer and being a peer supporter are beneficial roles for positive adaptation of parents of a children with disabilities. The theory of change presented on page 50 depicts the journey of a parent of a child with a disability beginning in a state of negativity, where they may search for a cure for their child and feel overwhelmed just getting by day-to-day. It is by way of the Parent to Parent peer support relationship that the help-seeking parent is brought over to positivity, depicted on the right-hand side of Figure 1, through the modeling of positive emotions and the normalization of shared experience. This is analogous with the "shift in life-purpose" described by Nancy Miller (1994) in her stage theory of parent adaptation to their child's disability discussed in more detail in the literature review as well as the "appreciation of life" described in the literature on posttraumatic growth (Calhoun & Tedeschi, 1999). The finding that parents who had experienced a match with a supporting parent scored higher on the readiness measure supports the movement toward positive adaptation depicted in this theory of change.

The difference in scores of parents who have and have not been trained to be peer support providers further supports the discriminant validity of the readiness measure. The theory of change in Figure 1, follows the parent who began in crisis to the positivity imparted via the one-to-one match with a supporting parent, up through a spiral of growth leading to positive adaptation and beyond to empathy-provoked volunteerism or readiness. Identifying the type of parent who not only does well managing day-to-day, but also moves beyond adaptation to giving back to the disability community is the target of this research. By discriminating between Parents who have and have not been recruited to be trained as Parent to Parent support providers, the measure of readiness shows strong signs of being able to predict which recruits will make effective peer supporters.

Future Directions

Future plans for the P2P measure of readiness to volunteer include a field-testing phase ($n \geqq 400$) using previous pilot testing and the results of the exploratory analyses discussed in this paper as a framework for the hypothesized structure. In this stage, confirmatory factor analysis (CFA) will be performed to assess the goodness of fit of the measure to support and/or to refine the instrument. Confirmatory factor analysis is similar to exploratory factor analysis, but imposes constraints on the model based on a priori hypotheses. By imposing these constraints, a researcher is forcing the model to "match up" with their theory. Adjusted goodness of fit index (AGFI) is a statistic that measures the fit between the hypothesized model and the observed covariance matrix. If an acceptable goodness of fit is found it would provide evidence of construct validity which corresponds to how consistent the measure is with its theoretical hypothesis, or in this case, the three-factor structure. This process can also provide information necessary for the refinement of the readiness instrument. During this study, posttraumatic growth will be modified for use with this population by altering wording, and reassessed without an option to skip questions to enable the researcher to analyze the relationship between readiness and PTG in a larger sample with greater statistical power. Additionally, after CFA is performed on the measure, examining readiness scores of Parent to Parent peer support volunteers before and after P2P supporting parent training can assess validity further by looking for a significant effect for training.

Utilizing the data from CFA study, an additional study exploring the theory discussed in this research can be conducted. The newly developed measure of readiness can be used to examine part or all of the theory presented in Chapter 2 through structural equation modeling (SEM). SEM is a statistical approach used to test hypotheses about the relationship among observed and latent variables (Hoyle, 1995). It tests the patterns of both directional and non-directional relationships in a model assessing how well the theory matches with the data (MacCallum & Austin, 2000). The two main objectives of structural equation modeling are to understand the relationships among the variables by examining the patterns of correlations and covariances, and to explain as much of their variance as possible with the specified model (Kline, 1998). SEM is conducted by first, specifying a model consistent with the literature or a theory derived from the literature, and then, selecting the variables to be measured. Next, parameter estimates are obtained and the model is assessed for fit. If the theory of change, which hinges on the peer support relationship, is found to be a good fit to this larger sample data, it could have an impact on how individuals in the disability community perceive the path to adjustment and highlight the importance of the Parent-to-Parent relationship in this process.

Significance for the Field

This study has several strengths. This is the first study that examined the concept of readiness to volunteer for a peer-to-peer support organization. This study focused on the desirable traits that Parent to Parent Coordinators look for in potential recruits as well as related stage theories, the negative impacts of caring for a child with a disability, theories of coping and adaptation, and literature regarding flourishing in response to difficult experiences.

Similarly to grief stage theories such as Kubler-Ross (1969), the theory of change begins with a parent being stuck in a cycle of negative emotions where looking for cures can be equated to denial or a lack of acceptance of the child's disability. This stage is marked by rumination, the product of unsuccessful attempts at meaning-making related to the difficult experience of diagnosis or another crisis situation (Park, 2010). Rumination and the daily stress of caregiving are known to take their toll on parents of children with disabilities in the forms of depression and isolation of parents of children with disabilities (Olsson & Hwang, 2001).

The theory proposed in this study hypothesizes that it is by way of the P2P support relationship that a parent is moved to a more positive perception of their circumstances. Social support has been shown to be effective in reducing stress levels and depressive symptoms and is considered an effective form of coping assistance, providing access to a more optimistic outlook on circumstances (Thoits, 1986). This positivity brings about opportunity for new choices in attempting to address difficult situations according to the "broaden and build" theory (Fredrickson, 2001). Consistent with Fredrickson's theory, the help-seeking parent's experience of positive emotions by way of the peer support relationship brings about an expanded field of coping options more conducive to solving the problems at hand. These options may include building resources by attending conferences or doing research, communicating with agencies to request services and sharing strategies that are working to bring balance to the family. This opening up of the "thought action repertoire" discussed in Fredrickson's theory is seen in the future orientation spiral which builds upon itself by the experience of successes, and is marked by an ability to make short and long-term plans for the child and family unit.

Once a family has experienced several successful experiences in helping their child or family, they may feel compelled to give back to the disability community. This aspect of the theory of change is likely motivated by a strong feeling of empathy for others in a similar situation, brought about by the initial suffering consistent with research on the empathy-altruism connection (Cialdini et al., 1987; Stotland, 1969), and the appreciation for the assistance that was provided to them when they were seeking help. It should be noted that going beyond adaptation and into service is not expected of all parents. The Parent to Parent peer support relationship is hypothesized here to not only facilitate positive adaptation for the help-seeking parent, but to also inspire them to engage in service to others. This trajectory is similar to that seen in an individual who has experienced posttraumatic growth. The experience of their journey with their child and the peer support relationship has somehow improved the individual in their outlook on life and skill set in ways they can no longer keep to themselves.

What the theory of change, developed in preparation for this study, adds to the literature on families and disability is the connection of both negative and positive perceptions of the impact having a child with a disability has on a family. The theory bridges these two, somewhat opposing literatures by the addition of Parent to Parent social support as the turning point between a cycle of negativity and a positive spiral associated with growth, adaptation and moving on to volunteerism. The measure of readiness relates to the theory of change in that once a parent has moved through the growth spiral and has experienced successes in assisting their child and family, they will be ready to give back to the disability community through service as a Parent to Parent peer support provider.

The measure developed from this study will assist Parent to Parent coordinators in the screening of potential peer supporters, increase the likelihood of a beneficial match, reduce waste in training costs, and indicate readiness in unfamiliar recruits who volunteer through online portals rather than after having established a relationship with P2P. The theory of change discussed in this research, along with the measure of readiness may also bring new attention and understanding to the unique path of adaptation parents of children with disabilities experience, and aid professionals in assessing the needs in parents they serve by taking note of the markers of adaptation and need discussed in this paper. Professionals who encounter parents who are exhibiting attributes associated with the stuck cycle could be encouraged by this research to refer the parent to a peer support organization who can assist them in their adaptation to their child’s disability. The measure could also potentially be utilized by other peer support organizations with slight modifications to suit their particular needs.

Limitations

The limitations of this research include the exploratory nature of the study, as readiness is a psychosocial construct, which has not been studied before. The initial item pool was developed from qualitative interview data gathered from interviews with only ten participants, so there is a possibility that saturation was not reached in the data due to a small sample size. As for the factor analysis, many experts in the field of measure development suggest that an optimal sampling ratio is ten to twenty participants per item in the initial pool. Considering that the current study has approximately two and a half participants per item, findings should be tested with a larger participant pool. Costello and Osborne found in their examination of the effects of sample size on EFA results that analyses using sample sizes with ratios between 2:1 and 3:1 failed to converge on a solution nearly one third of the time (2005). A greater sample size would be beneficial in the future in order to reexamine the factor structure of the measure of readiness to volunteer as a Parent to Parent support parent.

Another limitation of this study was the homogeneity of the subjects. The majority of the interview participants for the qualitative preliminary study were Caucasian, middle-class women, and the subject pool for the exploratory factor analysis was similar. Due to this overrepresentation of subjects in this category, the concept of readiness and the readiness measure are likely generalizable solely to this particular group. Future research should include an evaluation of the suitability of the instrument for use with fathers of children with disabilities and with members of culturally, linguistically and economically diverse populations. The measure may require revision for use in these groups, and additional interviews with individuals from these specific populations to inform such revisions.

Conclusion

In summary, the findings of this study, despite the limitations, suggest that this scale objectively measures readiness to be trained to serve as a Parent to Parent peer support. This is an important step in improving the quality of support that parents of children with special needs seeking help receive. Further, this study supports a new theory of change which includes defined stages through which many parents pass, moving from a position of negativity and uncontrolled emotion to positivity and success in meeting their families' needs by way of a peer-support relationship built upon effective communication of empathy and the sharing of practical information. It is the researcher's hope that the development of this measure is the beginning of a line of research into how best to serve families of children with special needs. Positive outcomes of this work could lead not only to enhanced adaptation of parents and wellbeing of families, but by linking these outcomes with emotional and educational improvements for children with special needs, a strong evidence base for Parent to Parent support will be established.

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Appendix A

Consent to Participate in an Online Survey of Parent to Parent Support

PURPOSE:

You are being asked to participate in a research study. The purpose of the study is to develop a measure of readiness to become a trained volunteer peer helper for parent to parent peer support programs for parents of children with disabilities. Your responses to survey items will help to create a short measure to be utilized by the Parent to Parent USA Network in the process of recruiting, selecting and training volunteers who will provide emotional and informational support to other parents of children with disabilities or other health care needs. The measure is likely to be useful to other similar volunteer programs.

PROCEDURES:

If you decide to participate, we will ask for you to provide answers to online survey items that will take approximately 30 minutes to complete.

RISKS:

The survey items could bring up difficult or painful memories or feelings. There is a small risk that someone not part of the research team could see a computer screen and identify who you are. To protect against disclosure of personal information we will never collect your name or information about where you live. You will be identified in our records only by a number and we will have no way of recontacting you. The data you provide will only be reported as group averages so that no individual's data will every appear in written reports. All data will be kept on a password protected hard drive that will be kept in a locked cabinet in a locked room at the University of California, Santa Barbara. All of the data will be destroyed within three years of the completion of data collection.

BENEFITS:

The measure developed from this research will help Parent to Parent Coordinators to select volunteer support providers of high quality and may increase the effectiveness of the support provided to help-seeking parents of children with disabilities or or other health care needs. It may also be useful for leaders of other peer support programs to help determine whether or not a peer is a good candidate as a volunteer person to person helper.

CONFIDENTIALITY:

Only the investigators will have access to the data collected in this study. The refined measure created from the data will be made available for use by the Parent to Parent USA

Network in the recruitment, selection and training of support parents, but they will not have access to the raw data used to select the items for the measure. The data we collect will not be linked to your identity in any way. Data will never be reported for individuals; it will be added together with a large data set and described only in terms of group averages.

RIGHT TO REFUSE OR WITHDRAW:

You may refuse to participate. You may change your mind about being in the study and quit after the study has started with no penalty. You can simply close the document on your computer screen. If you have already sumitted the data you may request that your data be erased from the computer data base where it will be stored. There will be no negative consequences to you or your child if you chose not to participate or to withdraw from the study. You can request that your data be erased by contacting the researchers listed on this form.

PRINCIPAL INVESTIGATORS DISCLOSURE OF PERSONAL AND FINANCIAL INTERESTS IN THE RESEARCH AND STUDY SPONSOR:

An investigator is an Executive Board member of the Parent to Parent USA Network. She has no financial interest in the study.

QUESTIONS:

If you have any questions about this research project or if you think you may have been injured as a result of your participation, please contact:

Robin Dodds, Doctoral Candidate in Special Education, (805) 722-4956, rdodds@education.ucsb.edu

or George HS Singer, Professor of Special Education, (805) 893-2198, singer@education.ucsb.edu

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

Appendix B

Survey Questions for Parent to Parent Study

1. What is your gender?

[ ] Male [ ] Female [ ] Other

2. What is your current marital status?

[ ] Single [ ] Married [ ] Domestic Partnership [ ] Divorced

3. Enter your age? ____

4. What is your family income?

[ ] $0- 14,999

[ ] $15,000- 24,999

[ ] $25,000- 34,999

[ ] $35,000- 44,999

[ ] $45,000- 54,999

[ ] $55,000- 64,999

[ ] $65,000- 74,999

[ ] $75,000- 84,999

[ ] $85,000- 99,999

[ ] $100,000 and above

5. What is your race/ ethnicity?

[ ] Asian

[ ] Hispanic/ Latino

[ ] African American/ Black

[ ] White non-Hispanic

[ ] More than one race

6. Enter the age of your child with a disability or health care need. ___

7. Enter the primary diagnosis of your child. ____________________

Appendix C

Toronto Empathy Questionnaire

Below is a list of statements. Please read each statement carefully and rate how frequently you feel or act in the manner described. Circle your answer on the response form. There are no right or wrong answers or trick questions. Please answer each question as honestly as you can.

		Never	Rarely	Sometimes	Often	Always	Skip
1.	When someone else is feeling excited, I tend to get excited too	0	1	2	3	4	5
2.	Other people's misfortunes do not disturb me a great deal	0	1	2	3	4	5
3.	It upsets me to see someone being treated disrespectfully	0	1	2	3	4	5
4.	I remain unaffected when someone close to me is happy	0	1	2	3	4	5
5.	I enjoy making other people feel better	0	1	2	3	4	5
6.	I have tender, concerned feelings for people less fortunate than me	0	1	2	3	4	5
7.	When a friend starts to talk about his\her problems, I try to steer the conversation towards something else	0	1	2	3	4	5
8.	I can tell when others are sad even when they do not say anything	0	1	2	3	4	5
9.	I find that I am "in tune" with other people's moods	0	1	2	3	4	5
10.	I do not feel sympathy for people who cause their own serious illnesses	0	1	2	3	4	5
11.	I become irritated when someone cries	0	1	2	3	4	5
12.	I am not really interested in how other people feel	0	1	2	3	4	5
13.	I get a strong urge to help when I see someone who is upset	0	1	2	3	4	5
14.	When I see someone being treated unfairly, I do not feel very much pity for them	0	1	2	3	4	5
15.	I find it silly for people to cry out of happiness	0	1	2	3	4	5
16.	When I see someone being taken advantage of, I feel kind of protective towards him\her	0	1	2	3	4	5

Spreng*, R. N., McKinnon*, M. C., Mar, R. A., & Levine, B. (2009). The Toronto Empathy Questionnaire: scale development and initial validation of a factor-analytic solution to multiple empathy measures. *Journal of personality assessment*, *91*(1), 62-71.

Appendix D

Post Traumatic Growth Inventory- SF (Short Form)

Indicate for each of the statements below the degree to which this change occurred in your life as a result of having a child with a disability or other health need, using the following scale.

0= I did not experience this change as a result of having a child with a disability or other health need.
1= I experienced this change to a very small degree as a result of having a child with a disability or other health need.
2= I experienced this change to a small degree as a result of having a child with a disability or other health need.
3= I experienced this change to a moderate degree as a result of having a child with a disability or other health need.
4= I experienced this change to a great degree as a result of having a child with a disability or other health need.
5= I experienced this change to a very great degree as a result of having a child with a disability or other health need.
Skip= You may skip any item.

	Item	**0**	**1**	**2**	**3**	**4**	**5**	**Skip**
1.	I changed my priorities about what is important in life.							
2.	I have a greater appreciation for the value of my own life.							
3.	I am able to do better things with my life.							
4.	I have a better understanding of spiritual matters.							
5.	I have a greater sense of closeness with others.							
6.	I established a new path for my life.							
7.	I know better that I can handle difficulties.							
8.	I have a stronger religious faith.							
9.	I discovered that I'm stronger than I thought I was.							
10.	I learned a great deal about how wonderful people are.							

Cann, A., Calhoun, L. G., Tedeschi, R. G., Taku, K., Vishnevsky, T., Triplett, K. N., & Danhauer, S. C. (2010). A short form of the Posttraumatic Growth Inventory. *Anxiety, Stress, & Coping, 23*(2), 127-137.

Appendix E

Beck Depression Inventory II

Please mark the number next to the sentence which best describes your symptoms for the past seven days. Choose only one sentence under each letter.

A.	0. I do not feel sad. 1. I feel sad. 2. I am sad all the time and I can’t snap out of it 3. I am so sad or unhappy that I can’t stand it.
B.	0. I am particularly discouraged about the future. 1. I feel discouraged about the future. 2. I feel I have nothing to look forward to. 3. Feel that the future is hopeless and that things cannot improve.
C.	0. I do not feel like a failure. 1. I feel I have failed more than the average person. 2. As I look back on my life, all I can see is a lot of failure. 3. I feel like a complete failure as a person.
D.	0. I get as much satisfaction out of things as I used to. 1. I don’t enjoy things the way I used to. 2. I don’t get real satisfaction out of anything anymore. 3. I am dissatisfied or bored with everything.
E.	0. I don’t feel particularly guilty. 1. I feel guilty a good part of the time. 2. I feel guilty most of the time. 3. I feel guilty all the time.
F.	0. I don’t feel I am being punished 1. I feel I may be punished. 2. I expect to be punished. 3. I feel I am being punished.
G.	0. I don’t feel disappointed in myself. 1. I am disappointed in myself. 2. I am disgusted with myself. 3. I hate myself.
H.	0. I don’t feel I am any worse than anybody else. 1. I am critical of myself for my weaknesses and mistakes. 2. I blame myself all the time for my faults. 3. I blame myself for everything bad that happens.
I.	0. I don’t have any thoughts of killing myself. 1. I have thoughts of killing myself, but I wouldn’t carry them out. 2. I would like to kill myself. 3. I would kill myself if I had the chance.
J.	0. I don’t cry any more than usual. 1. I cry now more than I used to. 2. I cry all the time now. 3. I used to be able to cry, now I can’t cry even though I want to.
K.	0. I am no more irritated now than I ever am. 1. I get annoyed or irritated more easily than I used to. 2. I feel irritated all the time now. 3. I don’t get irritated at all by the things that used to irritate me.
L.	0. I have not lost interest in other people. 1. I am less interested in people than I used to be. 2. I have lost most of my interest in other people.

	3. I have lost all of my interest in other people.
M.	0. I make decisions about as well as I ever could. 1. I put off making decisions more than I used to. 2. I have greater difficulty in making decisions than before. 3. I can't make decisions at all anymore.
N.	0. I don't feel I look any worse than I used to 1. I am worried I am looking old and unattractive. 2. I feel that there are permanent changes in my appearance that make me look unattractive. 3. I believe that I look ugly.
O.	0. I can work about as well as before. 1. It takes an extra effort to get started at doing something. 2. I have to push myself very hard to do anything. 3. I can't do any work at all.
P.	0. I can sleep as well as usual. 1. I don't sleep as well as I used to. 2. I wake up 2 hours earlier than usual and find it hard to get back to sleep. 3. I wake up several hours earlier than I used to and cannot get back to sleep.
Q.	0. I don't get more tired than usual. 1. I get tired more easily than I used to. 2. I am tired from doing almost anything. 3. I am too tired to do anything.
R.	0. My appetite is no worse than usual. 1. My appetite is not as good as it used to be. 2. My appetite is much worse now. 3. I have no appetite at all now.
S.	0. I have not lost much weight, if any, lately. 1. I have lost more than 5 pounds. 2. I have lost more than 10 pounds. 3. I have lost more than 15 pounds. I am purposely trying to lose weight by eating less. Yes_____ No_____
T.	0. I have not noticed any recent change in my interest in sex. 1. I am less interested in sex than I used to be. 2. I am much less interested in sex now. 3. I have lost interest in sex completely.

Beck, A.T., Ward, C. H., Mendelson, M., Mock, J., & Erbaugh, J. (1961) An inventory for measuring depression. *Archives of General Psychiatry,* 4, 561-571.

Appendix F

Flyer/ Listserv Announcement for Parent to Parent Study

Social Support for Parents Study

Are you the Parent of a Child with a Disability or other Special Health Care Need?

If so, please consider participating in an online research study of social support for Parents of children with special needs. The purpose of this study is to develop a measure for peer support networks to use in the recruitment and training of volunteers.

All parents of children with disabilities or other health care needs who can read and respond to survey questions in English and have access to the Internet are eligible to participate. The surveys will take about one hour to complete and are anonymous. Qualtrics is a firewall protected survey host site and the information you provide is completely secure.

Follow this link to enter the online survey: ________________________________

This study is being conducted at the University of California, Santa Barbara by Robin Dodds, and George H.S. Singer, PhD.

Please contact Robin Dodds at 805 722 4956 or rdodds@education.ucsb.edu for more information.