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Relationship Between Social Problem-Solving Skills, Quality of Life, and Family Adjustment in Caregivers of Children with Developmental Disability

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Philadelphia College of Osteopathic Medicine

Department of Psychology

THE RELATIONSHIP BETWEEN SOCIAL PROBLEM-SOLVING SKILLS,
QUALITY OF LIFE, AND FAMILY ADJUSTMENT IN CAREGIVERS OF
CHILDREN WITH DEVELOPMENTAL DISABILITY

By Bonita Ellen Fisher

Submitted in Partial Fulfillment of the Requirements of the Degree of

Doctor of Psychology

May 2009

**PHILADELPHIA COLLEGE OF OSTEOPATHIC MEDICINE
DEPARTMENT OF PSYCHOLOGY**

Dissertation Approval

This is to certify that the thesis presented to us by Bonita Fisher on the 28th day of April 2009, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

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Dedication

*“The world is round, and the place which may seem like the end
may also be only the beginning.”*

- Ivy Baker Priest

This dissertation is dedicated to the families who made it possible. They have allowed me into their hearts and their families for nearly 20 years, sharing joys, sorrows, successes and frustrations. They embody courage, patience, grace and optimism, often under the proverbial fire. They rejoice with uncommon successes: a child beginning to talk at the age of thirteen (no, it is not “too late”), persisting against the voice of current wisdom; an autistic youngster signing the Apostles’ Creed for his church on an Easter Sunday morning; regaining balance in a family after years of sleep deprivation and in the face of severe life-threatening disorders. These are life’s true heroes, and I am inspired by them. My love to you all, and many, many thanks.

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My heartfelt gratitude to each and every one.

In memory of Madeleine Anne Yoder
1955 – 2000

You always wanted me to meet a nice doctor –
I've become one instead.

Abstract

This study focused on the relationship between a caregiver's problem solving skills, their perceived quality of life, their family's adjustment to their child's disability, and the potential for mediation of those relationships by the child's behavior. A total of 111 parents completed the Social Problem Solving Skills Inventory-Revised, short form (SPSI-R:S), the World Health Organization Quality of Life Assessment, brief version (WHOQOL-BREF), the Family Impact of Childhood Disability Scale (FICD), the Nisonger Child Behavior rating Form (NCBRF) and a demographics questionnaire.

Analyses of the data by Pearson product-moment correlation coefficient identified significant correlations between scores on the problem *orientation* components of the SPSI-R:S) and quality of life (QOL) scores on the WHOQOL-BREF domains. Scores in all four domains (psychological, social, environmental, and physical) demonstrated positive correlation with Positive Problem Orientation (PPO), and negative correlation with Negative Problem Orientation (NPO).

Of the problem solving *styles*, scores on both Rational Problem Solving (RPS) and Impulsive/Careless Style (ICS) demonstrated small correlations (positive and negative, respectively) with scores on only one - the psychological - domain of the WHOQOL-BREF. Scores on Avoidant Style (AS) were negatively correlated with three of the four WHOQOL-BREF domains: physical, psychological, and environmental.

There were no significant correlations between problem orientations and scores on the FICD. Of the problem solving style scores, only Impulsive/Careless style (ICS) scores were correlated with FICD (positive subscale scores, in the negative direction). There were no correlations between any problem solving scores (orientation or style) and negative subscale scores of the FICD. There was no mediation by the child's behavior, as measured by scores on the NCBRF, in any of the correlations found. Scores on the Problem Behavior scale of the NCBRF were indeed correlated with QOL scores, but were independent of the other correlations.

Problem-solving interventions may contribute to an increase of quality of life in parents of children with developmental disability.

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Chapter 1

About every 3.5 minutes a parent is told that his or her child has a serious chronic medical illness, a health defect, a disability, a sensory impairment, mental retardation, or some combination of these disabilities. (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003). Research journals in the social sciences are replete with studies of the families into which these children are born, and the stresses experienced subsequent to their births.

In addition to the normal stressors associated with having a new baby, the parents of these children have many additional emotional and pragmatic issues to address such as frequent medical appointments and procedures, additional care needs, and increased difficulty locating alternate caregivers or sufficiently capable “babysitters” (Hauenstein, 1990). They wrestle with the meaning and implications of the diagnoses, both for themselves and for their child, and with processing medical and other specialized information regarding their child’s condition. Emotional challenges include the acknowledgement, expression and acceptance of disappointment, sadness, grief, anger and guilt that often accompany the news of a child’s serious disability (Barnett et al., 2003).

Family Adjustment

Affleck, Tennen, and Rowe (1991) found that parents of medically fragile newborns engaged in a number of psychological tasks to cope with the crisis of their baby’s illness; these include: a search for meaning, involving causation, perception of benefits, and downward social comparison; a search for mastery, to regain a sense of

control over present and future events, restoration of positive outcome expectancies, and maximizing dispositional optimism, as well as a search for social support, with affective, cognitive and instrumental (practical, everyday help) components. Men and women were found to engage in different styles of coping strategies, including the potential to strain the marital relationship (Affleck et al., 1991). Similar challenges are addressed by parents of disabled children who do not necessarily suffer difficult births, such as those with Fragile X or Down syndrome (Poehlman, Clements, Abbeduto, & Farsad, 2005). All reported some degree of mourning the “hoped for child” (Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975; Poehlman et al., 2005).

In addition to the adjustment following the birth of a child with unexpected features, there are ongoing adjustments required with each new developmental stage of his or her growth, because a parent often experiences a re-awakening of thoughts and feelings addressed in former developmental phases (Barnett et al., 2003).

Seligman and Darling (1997) identified separate areas of focus and potential stress for the following stages: childbearing (accurate diagnosis, emotional adjustments, informing other family members), school age (peer groups, educational placement, child care, social activities), adolescence (chronicity of the disability, sexual issues, peer isolation and rejection, future planning), launching (continuing family responsibility, possible residential placement, lack of social opportunities) and postparental (reestablishing spousal relationship, ongoing interaction with residential staff and providers, future planning). Poehlman et al. (2005) emphasized the fact that parental adaptation to a child’s disability is a complex and lifelong process, impacting

a family at multiple levels in an ongoing process of adjustment.

Over time, pragmatic factors may also challenge the family. The economic impact of parenting a disabled child may include increased care costs, such as ongoing medical care and supplies, adaptive equipment including adaptive household construction, ongoing incontinent supplies and more costly caregiver expenses for qualified “babysitter” services (Seligman & Darling, 1997). Income and savings were found to differ significantly between parents of disabled and non-disabled children (Parish, Seltzer, Greenberg, & Floyds, 2004). Employment patterns and social participation, especially for mothers, are often altered (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). In comparison with parents of non-disabled children, mothers of children with disabilities were found to have shorter spells at a given job, lower earnings, and were less likely be employed full time as their children aged (Parish et al., 2004). Allen (1999) noted that in some instances, a child’s intractable, challenging behavior may contribute directly to socio-economic disadvantage. Care giving in general has been associated with greater health issues for the caregiver (Holm, Patterson, Rueter, & Wamboldt, 2008; Vitaliano, Young, & Zhang, 2004; Vitaliano, Zhang, & Scanlan, 2003), and fewer preventive health behaviors (Talley & Crews, 2007).

Professionals working with families may have a profound influence on parents. In the days and months of a child’s life when parents are particularly vulnerable, they may be treated with respect and compassion, or with dismissal, misinformation, and lack of compassion (Seligman & Darling, 1997). Clinical perspectives, diagnostic

nomenclature, and professional distance may take a toll on families of children of all ages. Such problems are not limited to the medical arena, but may extend into the school and social service systems (Hornby, 1994). How society in general and professionals in particular view the child, the family and the disability may have a significant effect on family functioning, child behavior, and progress with treatment (Woolfson, 2004). The assistance most frequently appreciated was help from professionals of an instrumental or practical nature; this could have been material, financial, and effective case management to access helpful services and those benefits for which they are eligible (Quershi, 1990). The most valued characteristic was “showing competence in handling the service system and doing so vigorously on behalf of parents” (Quershi, 1990).

Impact of Child Characteristics on Family Adjustment

A child’s challenging behaviors have been most consistently linked to parental stress (Baker et al., 2003; Heller, Markwardt, Rowitz, & Farber, 1994; Heller, Miller, & Factor, 1997; Hodapp, Dykens, & Masino, 1997; Hodapp, Ricci, Ly, & Fidler, 2003; Qureshi, 1993; Ricci & Hodapp, 2003; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999; Willoughby & Glidden, 1995). Numerous studies have determined that behavior problems are the primary cause of distress among parents of children with DD (Allen, 1999; Baxter, 1989; Chetwynd, 1985; Dekker, Koot, van der Ende, & Verhulst, 2002; McDermott et al., 2002; Quine & Pahl, 1985) as well of those without

DD (Crnic, Hoffman, Gaze, & Edelbrock, 2004; Donenberg & Baker, 1993; Woolfson, 2004). Disturbed, socially intrusive behavior impacts maternal acceptance of the child over time (Gunn & Cuskelly, 1991; Hastings, 2003; Qureshi, 1993). Behavior problems are positively correlated with levels of depression among mothers (Hong & Seltzer, 1995). Potential embarrassment caused by these behaviors is stressful to parents (Baxter, 1989; Qureshi, 1990; Woolfson, 2004) and may limit the opportunity to develop the social relationships so integral to healthy adjustment (Cohen, Gottlieb & Underwood, 2001; Greenberg, Seltzer, & Greenley, 1993). Margalit, Raviv, & Ankonina (1992) noted an association between child externalizing behaviors and the parental use of avoidant coping rather than the use of more effective methods. Baker, Blacher, Crnic, & Edelbrock (2002) found that children with developmental delays were three times as likely to score in the clinical range on behavior problems. Parenting stress was found to be higher in the delayed group, and to be related to the extent of behavior problems rather than to the degree of developmental delay (Einfeld & Tonge, 1996a, 1996b). Contrarily, some have noted that children with Down syndrome can be perceived as *less* demanding or difficult in adolescence than their “typically-developing” peers (Gunn & Cuskelly, 1991; Lehman & Roberto, 1996). Aman, Tassé, Rojahn, & Hammer (1996) created the Nisonger CBRF (Child Behavior Rating Form) used in the current study to measure behavioral and emotional disturbance, specifically in children and adolescents with mental retardation, which are stressful for the child, caregivers, teachers and community. It has been shown that behaviors due to emotional disturbance in children and

adolescents with mental retardation are problematic because of their “qualitative or quantitative deviance” (Dekker et al., 2002; Hastings, Brown, Mount, & Cormack, 2001), and are not caused solely by the cognitive deficits.

Although one might expect a direct relationship between the severity of a child’s disability and the degree of family challenge, research findings are not consistent. Although some have found the degree of a child’s disability to be unrelated to positive adaptation and stress level of families (Carr, 1988; Chetwynd, 1985; Hodapp, Dykens, & Masino, 1997; Hong & Seltzer, 1995; Trute & Hauch, 1988), or to positive perceptions of mothers (Hong, Seltzer, & Krauss, 2001; Maillick, & Wyngaarden, 2001; Ricci & Hodapp, 2003) or fathers (Hornby, 1995; Seligman & Darling, 1997), others have found that both severity of disability and the presence of behavior problems were related to maternal functioning (Parrish, 2003; Nereo, Fee, & Hinton, 2003; Sloper, Knussen, Turner, & Cunningham, 1991) and physical functioning (Holm, Patterson, Rueter, & Wamboldt, 2008). Yet other studies noted differences in the types of stressors that a family faces (Hornby, 1994; Seligman, 1979; Seligman & Darling, 1997) and the cumulative impact of the chronicity of the disability (Seligman & Darling), particularly the need for constant supervision and behavioral monitoring and/or redirection (Allen, 1999; Chetwynd, 1985; Woolfson, 2004). Other researchers have noted that mothers reporting higher levels of care giving needs for their child also reported more personal growth and maturity (Hastings, Allen, McDermott, & Still (2002), perhaps due to increased sense of self-efficacy because of dealing successfully with such challenges over time (Grant, Ramcharan,

McGrath, Nolan, & Kready, 1998). The distinction between the degree of severity of a child's disability and the type of disability he or she experiences may or may not be determined from a given measure. There may be significantly different factors in operation between, for instance, a family with a severely physically ill youngster requiring intensive medical interventions and a severely cognitively disabled youngster with extensive behavior problems (McDermott, et al., 2002; Woolfson, 2004).

Although Hastings et al. (2002) found no association between the positive perceptions of mothers and demographic variables including age of the child (also Hornby, 1995), Hodapp, Ricci, Ly, and Fidler (2002) noted the child's age to be a most significant predictor, with mothers perceiving their older children less rewarding. However, this may have been a factor of maladaptive and nonendearing behaviors, with age as a related confound; of frustration with the slowing developmental rates of age (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Ricci & Hodapp, 2003; Hodapp, et al., 2003); or with age-dependent developmental issues (Hauser-Cram et al., 2001). Other parents have found their offspring with developmental disabilities to be an important source both of emotional and of instrumental support in their later years, with the family caregiver as beneficiary (Grant et al., 1998; Greenberg et al., 1993; Hastings & Taunt, 2002; Heller, Miller, & Factor, 1997; Lehman & Roberto, 1996).

Research on Family Characteristics

Abbeduto, Seltzer, and Shattuck (2004) emphasized the notion of differential experiences for family members, reflecting unique challenges posed by each different diagnosis and situational factor (also Hauenstein, 1990; Seligman & Darling, 1997; Tunali & Power, 1993). All parents of children with differing types and severities of physical and cognitive disabilities, with or without concurrent medical or mental health diagnoses, face the unique challenges of each combination of disability factors, mitigated or exacerbated by their own personalities and perceptions as well as those of their children. Erickson and Upshur (1989) concluded that “the impact of a child with a disability is a complex one that cannot be easily described or predicted” (p. 256). Wang and Amato (2000) emphasized the importance of determining the meaning of a given stressor for a given individual; that, “rather than looking at objective events and assuming they are stressful, it may be necessary to obtain peoples’ subjective judgments about the extent to which these events are experienced as aversive” (p. 665). The meaning of a given event is crucial both to the experiencing and to the physiological consequence (including health impacts) of that event on a given individual (Booth & Pennebaker, 2000), with events commonly considered negative or stressful not necessarily so, and vice versa. Trute and Hiebert-Murphy (2002) developed the Family Adjustment to Childhood Developmental Disability (FICD), used in this study to assess both positive and negative elements of parental appraisal as a potential determinant of those families most vulnerable to future parenting stress.

Concurrent with an examination of the factors impacting families with disabled children, it is important to retain their identity as *families*, first and foremost. For families of children with disabilities also wrestle with employment difficulties, parent-child struggles, adolescent issues, aging parent challenges, and so on (Antonovsky, 1993, pp. 113), with those challenges posed by the disability constituting only part of the daily hassles, and the acute or chronic stressors they may confront (also Beresford, 1996).

From the perspective of the stress and coping literature, there have been myriad studies predicated on the assumption that children with mental retardation are stressful additions to their families. They have been studied from the contexts of incidence of depression or negative affect (Burden, 1980; Olshansky, 1962), degree and perception of stress/burden (Bradshaw & Lawton, 1978; Chetwynd, 1985; Frey, Greenberg, & Fewell, 1989; Quine & Pahl, 1985), implications for quality of life in general (Bradshaw & Lawton, 1978; Carr, 1988; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001), and so forth.

Older studies have also implicated a child's disability in subsequent marital stress or dissolution (Farber, 1959; Farber, & Ryckman, 1965; Friederich & Friederich, 1981), yet others observe the contrary (Carr, 1988; Hauenstein, 1995; Marsh, 1992; Patterson, 1991b). Fathers of children with Down syndrome queried by Hornby (1995) reported more positive effects than negative effects on their marriages. Research by Scorgie and Sobsey (2000) indicated that for parents of children with disabilities there were three areas of growth, one of which was stronger marriages and

other family relationships. Beresford (1994) aptly noted that marital status is most likely not a unitary construct, but is affected in what is probably a bi-directional fashion by multiple factors such as social networks, practical resources, and economic circumstances, which may act either as risk or as resistance factors to an individual's adjustment. It may be that having a child with a disability in the family tends to strengthen strong marriages and weaken fragile ones (Hornby, 1995).

Older research in general has tended to paint a rather dreary picture of families raising children with disabilities: "[F]amilies who have a member with a disability have long been objects of pity. Society as a whole tends to view the presence of a child with a disability as an unutterable tragedy from which the family may never recover" (Summers, Behr, & Turnbull, 1989, p. 27). Hodapp, Fidler, & Smith (1998) noted that until fairly recently these families were thought of as "problem" families by researchers who focused on aspects such as divorce in couples, role tensions in siblings, and psychopathology in individual family members or in the family system as a whole.

In contrast to the earlier focus, more recent research is examining stress and coping in individuals and family systems, with the families viewed as experiencing increased stressors, but often doing so quite effectively. Thus, a major emerging interest is in individual differences, and a focus on the variables which operate, perhaps in combination, to predispose a given family to increased stress, but another family to more successful coping. In short, these parents experience, perhaps, a lifetime of non-normative life circumstances, although not necessarily of the same

degree, etiology, or consequence (Krauss & Seltzer, 1999).

It is not disputed that parents of disabled children may face additional stressors, but it is important now that researchers continue to move away from merely describing stressors and their adverse effects, and to pursue research that examines the ways that such families cope successfully with the care needs of a disabled child (Beresford, 1994).

Although prior research may have explored the additional stress of parenting a disabled child, more recent thinking suggests that such a focus is merely a part of the complete picture, complemented by later research considering the converse - that these children contribute to their households by diverse and unique means. Many have begun to explore specifically the impact of these special children on positive dimensions of family lives and parental growth. This mirrors the emerging trend in psychology in general, to move from a discipline rooted in a pathology model to greater awareness of positive aspects of psychology and a “strengths-based” model (Snyder, Tennen, Affleck, & Cheavens, 2000).

In addition to negatively formulated hypotheses, much of this dated research is not without challenge to the methodological foundations on which it is based (Glidden, 1993). The shortcomings so noted include: inadequate comparison groups (Flaherty & Glidden, 2000; Stoneman, 1989), representative samples made up disproportionately of service recipients (Scott, Atkinson, Minton, & Bowman, 1997; Sloper et al., 1991), inadequate psychometric properties of measures (Flaherty & Glidden, 2000; Glidden, 1993; Glidden & Floyd, 1997), findings not subsequently

replicated (Beresford, 1994), and inappropriate generalization of results (Beresford).

In many studies reviewed by Glidden (1993), statistical error and inconsistency rendered it virtually impossible to make comparisons across studies. Furthermore, their choice of instruments tended to equate stress with pathology, to the exclusion of interest in or research on positive adaptation and growth from the same situations (Seligman & Csikzentmihalyi, 2000). Glidden (1993) identified this focus on pathology as having influenced the development of instruments to measure it, operationalizing pathology as stress for measurement purposes. Thus, when increased levels of stress are found in these families, it is used to confirm maladjustment hypotheses. But maladjustment or adjustment is much more complex a phenomenon than the mere presence or absence of stress. The presence or absence of positive outcomes is just as essential to the determinations of adjustment. "Positive outcomes can coexist and even be orthogonal to negative outcomes but may never [be] measured if investigators are not hypothesizing that they are present" (p. 482).

Thus the endorsement of added demands on a parent does not *necessarily* imply added strains. Beresford (1994) noted that "vulnerability does not imply pathology," but that vulnerability to the cumulative impact of stressors in one's life is mediated by coping resources, defined both as resistance and as risk factors in determining vulnerability to stress. Thus vulnerability to the effects of stress is mediated by coping resources, both personal and socio-ecological.

Coping Resources

Personal Coping Resources include both physical and psychological variables, such as physical health, personal beliefs and ideologies; spiritual or religious beliefs; personality variables, such as neuroticism, extraversion and humor; adaptive or maladaptive coping strategies; beliefs about locus of control (the degree of control over one's own lives vs. others' lives or outside forces in control); previous coping experience (positive or negative outcomes), and parenting skills.

Physical health is an important personal coping resource, because parents exhausted from lack of sleep or the consequences of anxiety and worry are less able to rise to additional challenges effectively (Beresford, 1994; Carr, 1988). Impaired sleep alone impacts multiple aspects of immune function (Keicolt-Glaser, McGuire, Robles, & Glaser, 2002; Leproult, Copinschi, Buxton, & Cauter, 1997). Parents' own pre-existing medical conditions or disabilities may further compromise their physical coping resources, as may physical conditions developed secondarily to increased stress loads either from child disability-related concerns or from other personal or family issues (Glidden, 1993; Greenberg, Seltzer, & Greenley, 1993). Adverse health behaviors, such as heavy alcohol use, smoking, drug use, poor nutrition and lack of exercise may be pre-existing or may be the result of poor coping in unexpected or challenging situations.

Additionally, the field of psychoneuroimmunology reveals intricate, bi-directional pathways between the brain, the endocrine system, the nervous system, and

the immune system (Cohen & Herbert, 1996; Dantzer, 2001; Ray, 2004). Thoughts, feelings, beliefs, hopes and experiences influence physical biology through many pathways: either directly, through health behaviors or compliance with medical regimens, or indirectly, via alterations in the functioning of the central nervous, immune, endocrine, and cardiovascular systems (Keicolt-Glaser et al., 2002; Maier, Watkins, & Fleshner, 1994). Empirical studies have found demonstrable changes in immune cell activity (Brosscot et al., 1994; Guidi et al., 1999; Hiramoto et al., 1999; Schultz & Schultz, 1994), increased susceptibility to common pathogens (Cohen et al., 1998; Herbert & Cohen, 1993), poorer responses to vaccines (Glaser, Sheridan, Malarkey, MacCallum, & Keicolt-Glaser, 2000), impaired wound healing (Keicolt-Glaser, Page, Marucha, MacCallum, & Glaser, 1998; Rojas, Padgett, Sheridan, & Marucha, 2001), and increased cardiovascular reactivity (Herbert, Cohen, Marsland, Bachen, & Rabin, 1994; Sher, 1990; Walton, Pugh, Gelderloos, & Macrae, 1995), in response to increased stress levels and to negative thoughts and emotions. Biondi and Zannino (1997) determined that psychological stress appears to alter susceptibility to infectious agents, in turn influencing the onset, course and outcome of certain infectious pathologies.

Keicolt-Glaser and Glaser (1992) noted that the experience *or perception* of chronic, ongoing stress may be associated with continued down-regulation of immune function, in which aroused physiology and/or compromised immune function persists rather than abates, as opposed to physical adaptation, in which the body returns to homeostasis more quickly with repeated stressful incidents (also Keicolt-Glaser,

Dura, Speicher, Trask, & Glaser, 1991; Keicolt-Glaser et al., 1993; Malarkey et al., 1996; Peterson, Seligman, & Valiant, 1988). It is well-accepted that repeated stressful experiences are cumulative in their physical impacts, with unremitting stressors and those perceived as unpredictable and uncontrollable as the most physically detrimental (Baum et al., 1993; Eriksen, Olff, Murison, & Ursin, 1999; Keicolt-Glaser et al., 2002). Conversely, psychoneuroimmunology research also reveals psychological impacts of *physical* events and immune alterations on the emotions, with behavioral and emotional changes resulting from changes in immune function or disease states (Booth & Pennebaker, 2000) When one's physical being is charged with immunological challenge or other physiological event, sequelae may include affective and behavioral changes, in addition to common "sickness" behaviors (Maier & Watkins, 1998). Recent studies have shown that such diverse factors as age and gender, genetic susceptibility, prior stress exposure, and the biological and immunological idiosyncrasies of the subject will influence individual responses to psychosocial challenges (Schleifer, 1999).

Hence, physical health may be a *resource* (or may be a vulnerability, if absent) for the management of challenging situations and lifestyles; it may also be an *outcome* of the efficacy of an individual's challenge management, or lack thereof.

A parent's *personal and ideological beliefs* are also important personal coping resources (Beresford, 1994). A *focus on positive aspects* of the child and his or her situation has been positively associated with adjustment, as has the preponderance of positive expectations (Affleck et al. 1991). In more general terms, dispositional

optimism, or a characteristic inclination toward expecting positive outcomes in life situations, has repeatedly been correlated with health – and the converse, pessimism has been associated with increased health problems (Carver & Scheier, 2002; Greenberg, Seltzer, Krauss, Chou, & Hong, 2004; Jones, O’Connell, Ground, Heller, & Forehand, 2004; Scheier & Carver, 1985, 1987; Scheier, Weintraub, & Carver, 1986), as well as with depression (Carver & Scheier, 2002), with life satisfaction (Plomin et al., 1992), and with effective coping (Fontaine, Manstead, & Wagner, 1993; Peterson, 2000). Beresford (1994) noted the importance of *flexibility* or the adaptability of an individual’s personal beliefs and attitudes toward dramatic changes in circumstance, to a parent’s ability to readjust his or her expectations. It has also been related to more successful problem-solving (Isen, Daubman, & Nowicki, 1987; Isen & Means, 1983; Murray, Suján, Hirt, & Suján, 1990), effective coping (Cheng, 2001; Folkman & Moskowitz, 2004), and greater well-being (Lester, Smart, & Baum, 1994). However, a related concept, the intolerance of uncertainty, has been related to increased stress (Buhr & Dugas, 2002).

Spiritual or religious beliefs show diverse impacts on families. Beresford (1994) determined that religious beliefs may offer the means for parents to interpret or redefine their child’s disability, in terms of having been especially selected, and in expectation that they will be given sufficient strength for the task. Such beliefs impact personal convictions, acceptance, and the ability to resolve the “why?” in order to find a sense of purpose or meaning (Scorgie, Wilgosh, & McDonald, 1999), and the ability to “move on” (Folkman, 1997). Miltiades and Pruchno (2002) found an association

between religious coping and higher levels of care giving satisfaction, but not with a decrease in the burden. Positive states of mind have been associated with prayer that fostered gratitude, faith, trust, and wonder (Richards, Wrubel, Grant, & Folkman, 2003). Folkman and Moskowitz (2004) found that religious coping impacts the entire stress process, from the way in which events are perceived to the ways in which people respond psychologically and physically over the long term (also Park & Cohen, 1993; Seybold & Hill, 2001). It is difficult to separate religious from secular methods of coping, with such constructs as the construing of benefits (Affleck & Tennen, 1996; Nolen-Hoeksema, 2002; Tennen & Affleck, 2002) and the cultivation of gratitude (Emmons & Shelton, 2002; Emmons & McCullough, 2003) or positive illusion (Brown, 1993; Janoff-Bulman, 1989; Taylor, 1983; Taylor & Armor, 1996). Furthermore, the definitions and measurement of “religious coping,” “religiosity,” and “spirituality” vary from study to study, making consistent comparisons difficult. This variable is notably multidimensional and undoubtedly correlated with many other variables that, themselves, may influence adjustment (Glidden, Kiphart, Willoughby, & Bush, 1993). Beresford (1994) noted the important distinction between a personal *belief* as a coping resource, and support gained through *membership* of a religious organization (such as emotional or practical support from fellow members), which confounds such research. There is also potential for the maladaptive impact of religious beliefs (Pargament, Koenig, Tarakeshwar, & Hahn, 2001; Pargament, Smith, Koenig, & Perez, 1998), such as having been abandoned by God, or in fueling self-blame and guilt (Beresford, 1994).

Personality variables are considered a personal coping resource, although in complex interrelations with other factors as well. Although these are important coping resources in and of themselves, they also affect the availability of other personal and socio-ecological coping resources (Beresford, 1994; Hooker, Monahan, Bowman, Fraxier, & Shifren, 1998; Sloper et al., 1991).

For instance, neuroticism, or a tendency to experience negative affect and to be impulsive (O'Brien & DeLongis, 1996), is predictive of life satisfaction, mental and physical health (Franks et al., 1993; Hooker et al., 1998; Kemeny & Laudenslager, 1999; Sloper et al., 1991; Suh, Diener, & Fujita, 1996; Zautra, Smith, Affleck, & Tennen, 2001), the use of wishful thinking and self-blame as ineffective coping strategies (Bolger, 1990; McCrae & Costa, 1986; Stanton & Frantz, 1999; Stanton, Parsa, & Austenfeld, 2002), increased vulnerability to stressful reactions and increased reactivity (Bolger, 1990; Larsen & Ketelaar, 1991; Sloper et al., 1991; Sloper & Turner, 1993), and predisposition to interpreting ambiguous stimuli in a negative or threatening manner (Magnus, Diener, Fujita, & Pavot, 1993; Watson, David, & Suls, 1999). Individuals high in neuroticism tend to perceive everyday events as threatening and perceive themselves as incapable of effective coping (Bookwala & Schultz, 1998; Watson & Hubbard, 1996).

In contrast, extraversion, or a tendency to experience positive affect and assertiveness (O'Brien & DeLongis, 1996), was found to correlate in the opposite fashion. It has been linked to the use of adaptive coping strategies (Affleck & Tennen, 1996; McCrae & Costa, 1986; Tugade, Fredrickson, & Barrett, 2004), to higher

assessments of subjective well-being (Suh, Diener, & Fujita, 1996), as a protective factor from negative effects of stress (Beresford, 1994; Fredrickson & Levenson, 1998; Keicolt-Glaser et al., 2002; Tugade et al., 2004), and to the predisposition of individuals to experience more positive objective events (Magnus et al., 1993; Tugade et al., 2004). A *sense of humor* has also been linked to the use of adaptive coping strategies (Lefcourt, 2002) and to healing after trauma and tragedy (Bloom, 1998). Fredrickson (2002) noted that positive emotions are known to predict future increases in positive emotions, by triggering “upward spirals” toward enhanced emotional well-being (also Dingfelder, 2005; Fredrickson & Joiner, 1998).

Research in individual differences to emotional stimuli based on these personality factors has revealed a tangible distinction between those high in extraversion or in neuroticism, including individual differences in brain activation in specific brain regions engaged during cognitive-affective tasks (Canli, 2004). Thus magnetic resonance imaging offers visual confirmation of these theoretical constructs and their impact on basic brain function, and suggests potential clues to the biological basis of influence. From a social perspective, these two profiles of personality tendency have obvious connotations and consequences in the quality of interpersonal relationships and the garnering of social support networks (Beresford, 1994; Salovey, Rothman, Detweiler, & Steward, 2000).

Coping strategies may be categorized according to the taxonomies of several different theoretical approaches to coping. The adjectives *active*, *approach*, *engaged* and *problem-focused* are associated with adaptive, or effective coping methods, but the

terms *passive*, *avoidant*, and *emotion-focused* have been associated with ineffective, maladaptive methods (Billings, Folkman, Acree, & Moskowitz, 2000; Folkman, 1997; Holahan & Moos, 1985; Kim, Greenberg, Seltzer, & Krauss, 2003). However, newer research has determined that “emotion focused” coping may be maladaptive if this involves an overabundance of negative emoting at the expense of more effective approaches, but it may be adaptive if it reflects appropriate emotional responses to challenging situations (Folkman & Moskowitz, 2004; Stanton & Franz, 1999; Stanton et al., 2002). Effective coping, or the effective management of life’s problems and everyday stressors, is in turn associated with myriad other variables such as positive affect (Folkman & Moskowitz, 2004), humor (Lefcourt, 2002), hope (Snyder, 2002), gratitude (Emmons & McCullough, 2003), successful problem-solving (Chang, D’Zurilla, & Sanna, 2004), and enhanced immune functioning (Ravindran, Griffiths, Merali, & Anisman, 1996).

Those who have confidence in their problem-solving abilities tend to focus actively on a problem and attempt to resolve the cause of the problem; they assume the responsibility for personal problems, and invest their efforts in approaching, rather than in avoiding, personal problems (Heppner & Lee, 2002).

An individual’s beliefs about locus of control, or the degree to which they believe that they, rather than others or external events, impact the course of their lives, have been linked with reduced levels of perceived subjective burdens, increased levels of perceived social support and higher levels of well-being (Beresford, 1994; Green, 2004). Research on locus of control has found this to be a multidimensional construct,

with “complex individual, additive and interactive affects on ...well-being” (Green, p. 20). Mothers who believed that not only their own actions, but also chance may affect outcomes, scored higher on well-being measures than did those who believed in chance and in external others more than in their own actions (Green).

Previous coping experience, whether with positive or negative outcomes, will reinforce a caregivers’ perceptions of their ability to cope with similar events in the future (Heller, 1993), and may contribute to a sense of control, which contributes to adaptive functioning (Thompson, 2002). A sense of self-efficacy, or the expectation that they can perform a task successfully, not only affects the actions people choose and the effort they invest, but also the amount of effort they are willing to expend and the extent to which they are willing to persevere when faced with obstacles or aversive situations (DiBartolo, 2002).

Effective parenting skills, or those competencies and behaviors which enable parents to manage or deal with their children (Beresford, 1994), are a most significant personal resource for parents of all children, whether challenged by a disability or not. Because children with disabilities exhibit increased rates of behavior and sleeping problems (Baker et al., 2003; Roberts & Lawton, 2001), the need for effective parenting skills is magnified. In addition to a child’s challenging behavior exacerbating parental stress, it is also found that parental stress (whether due to child behaviors or to other causes) conversely contributes both to the frequency and to the severity of child behavior problems (Baker et al., 2003; Barnett et al., 2003; Hastings, 2002). In other words, parents who are over-stressed and ineffective in coping do not

parent well, which may precipitate an increase in stress-induced distraction and desperation in the overwhelmed parent. Hence the conundrum of the “chicken or the egg” adage, a self-perpetuating loop of escalating child behavior and parent stress, dampens the increase of effective parenting skills (Cavell, 2001; McIntyre, 2008; Smith, Greenberg, Seltzer, & Hong, 2008; Webster-Stratton, 1991; Woolfson, 2004). Increased competency in addressing behavior problems not only reduces the targeted behaviors, but also enhances the parent’s sense of competence, which has been associated with decreased stress levels regardless of the extent of improvement in the child’s behavior (Beresford, 1994; Pisterman, et al., 1992).

The list of personal coping resources could be infinite; however, the consideration of hardiness, ability to exercise control, resilience, mastery, and learned resourcefulness are just a few of the traits believed to enhance caregiver adaptation and the tendency to perceive situations with less inherent stress (DiBartolo, 2002).

Socio-Ecological Coping Resources include social support at multiple levels: informal support of spouse, extended family and friends; formal support of agencies and medical staff; maternal employment; availability of respite services; and socio-economic circumstances.

Among socio-ecological coping resources, social support features prominently. There is also a multidimensional construct; there are several levels of support: from immediate family members and close friends; from neighbors, coworkers and more distant friends; and formal or agency support (Beresford, 1994). Social support has been classified in numerous typologies: as expressive or instrumental (practical); as

emotional, tangible, or informational; and as a feature of the environment or a resource which a person must develop and use (Laszarus & Folkman, 1984). The latter example, of active seeking of social support, is also considered to be a coping *strategy*, and as such will be discussed in a later section on problem-solving.

Social support may reap positive physical benefits by mediating negative responses to stress (Atkinson, et al., 1995; Cohen et al., 2001; Keicolt-Glaser et al., 1991; Glynn, Christenfield, & Gerin, 1999; Parrish, 2003; Seeman, 1996; Taylor, Dickerson, & Kline, 2002; Uchino, Cacioppo, & Keicolt-Glasser, 1996; Uchino, Uno, & Holt-Lunstad, 1999) and more competent immune responses (Cohen, Doyle, Skoner, Rabin, & Gwaltney, 1997; Oakley, 2004). It has been linked with effective parenting (Barnett et al, 2003), life satisfaction (Frey et al., 1989; Sloper & Turner, 1993), personal growth (Armeli, Gunthert, & Cohen, 2001; Park, Cohen & Murch, 1996; Bloom, 1998), and lower stress (Hong, Seltzer & Kraus, 2001; Judge, 1998; Miller, Gordon, Daniele & Diller, 1992; Smith, Oliver, & Innocenti, 2001) in mothers and in fathers (Ricci & Hodapp, 2003) of children with disabilities. The converse, interestingly, was also noted (Seeman, 1996; Seeman & McEwen, 1996): that nonsupportive social interactions and social isolation are associated with enhanced neuroendocrine reactivity, and with greater stress impact.

Thus, it should not be assumed that all manner of apparent “support” is of positive impact or consequence. For just as the input of supportive others may provide the positive outcomes of problems shared and labeled in beneficial terms, such as sympathy, helpful information, and reduced uncertainty and worry, it is possible that

the opposite may occur, e.g., negative outcomes of new problems created, existing ones labeled in negative terms, irritation and resentment instead of sympathy, misleading information, and the creation or exacerbation of existing uncertainty and worry (Lazarus & Folkman, 1984). Social contacts of the best-intentioned people may have unforeseen negative consequences by reinforcing negative stereotypes of disability, and thus discourage parents from effective behavioral interventions and appropriate expectations of their children (Woolfson, 2004). When relationships are contentious, they are associated with depression and immune dysregulation (Keicolt-Glaser, et al., 1993; Keicolt-Glaser et al., 2002), and can exacerbate stressful situations (Seligman & Darling, 1997). Beresford (1994) noted that sources of formal support can be as much a stressor as a coping resource. Parent reports often confirm significant emotional and practical difficulties when working with an agency and with medical or school personnel (Affleck, Tennen, & Rowe, 1991; Gill, 1997; Hornby, 1994; Sloper, 1999; Summers et al., 1989).

But again, the key factor appears to be one's perception of support, rather than any objective definition or measurement. Those resources that a person perceives to be available are as important as those that are actually provided (Cohen et al., 2001; Hastings et al., 2002; Hastings & Taunt, 2002).

Often overlooked in social support research are certain costs involved and skills required in obtaining and maintaining social relationships. Time and reciprocity are required, with positive personality attributes and capable social skills leveraging the process (Salovey, et al., 2000). All of these requisite factors may be negatively

impacted by stress (Lazarus & Folkman, 1984), and leveraged by the attainment and maintenance of positive affect (Fredrickson, 1998). In addition, Carver & Scheier (1999) found the manner in which one engages support resources may differ. They found that those with predominantly pessimistic life orientations tended to use social support to reinforce their perceptions and “escapist” tendencies of sleeping, eating and drinking; they also tended to withdraw and to isolate in times of stress, whereas optimists were more likely to seek proactive supportive others, who would reinforce their positive outcome expectations.

Maternal employment provides both material and social resources and is associated with lower levels of stress (Sloper, 1999; Sloper et al., 1991). However this also is more complex than apparent at first glance. For it does not appear to be employment *per se* which is beneficial, as much as the degree to which the parent is pursuing her personal interests (Barnett et al., 2003; Beresford, 1994) and is engaged in multiple roles outside of care giving (Hong & Seltzer, 1995; Krauss & Seltzer, 1989). The opportunity to engage in multiple roles is for these parents often determined by the availability of quality respite (Abbeduto et al., 2004; Allen, 1999; Factor, Perry, & Freeman, 1990; Singer, Irvin, Irvine, Hawkins, & Cooley, 1989; Summers, Behr, & Turnbull, 1989), often compounded by behavioral, communication and physical care needs beyond the norm.

As with other variables, research is conflicting with regard to the contribution of socio-economic circumstances. Beresford (1994) noted the pragmatic financial impact of having a disabled child, with potential loss of earnings as well as additional

expenses for quality respite providers, medical or incontinent supplies, special dietary needs, or adaptive construction. Some socio-economic disadvantage may be a direct consequence of a child's disability, or his or her challenging behavior (Allen, 1999). Quine and Pahl (1991) noted the ability of financial resources to buffer the effects of stressful child behavior, with practical purchases such as laundry or cleaning services, other household help, and respite care (also Smith, Oliver, & Innocenti, 2001). Sloper and Turner (1993) found socio-economic disadvantage to be related to outcomes for both mothers and fathers, on a par with personality factors and life events (also Parrish et al., 2004; Sloper et al., 1991). Furthermore, limited resources may create a disruptive context in which parents are less available and less able to respond effectively or consistently to the unique needs of a child with a disability (Floyd & Saitzyk, 1992).

Although numerous studies of a wide variety of outcome factors have found that demographic factors such as gender, religion, socioeconomic status, or race were not related to specific outcome variables such as positive perceptions in mothers (Hastings et al., 2002) or maternal adjustment to a child with disabilities (Noojin & Wallander, 1997), socio-economic circumstances may impact families in less obvious ways. Poorer quality of health care received, and more negative perceptions of health care providers (Cooper-Patrick et al., 1999; Fiscella, Franks, Gold, & Clancy, 2000; Poehlman et al., 2005; Van Ryn & Burke, 2000), may further tax already stretched mental and physical resources, as may a lack of adequate transportation or safe housing (Hastings & Taunt, 2002). Level of education and socioeconomic status are

correlated, with level of education a strong predictor of psychological well-being (Ryff & Singer, 2002). Further education may also engender more effective problem solving skills and more positive coping strategies (Quine & Pahl, 1991).

Cultural factors are important to consider in this context as well. Seligman and Darling (1997) noted that cultural factors influence a parent's perception of his or her situation; however, they cautioned against the use of cultural stereotypes in formulating expectations or interventions. Cultural factors may include social class, but also religious identity, race, or other affiliations.

"Situational variables" include cultural factors, and inevitably influence an individual's perception of his or her circumstance, resources, options and outcomes: "the immense human variety of beliefs and practices seems to have an undeniably powerful influence on how a specific family interprets a specific disability" (Ferguson, 2002, p. 129). Even notions of happiness are formed in part by cultural considerations. In North America, happiness is determined chiefly by personal achievement, individual pursuit, self-esteem, and personal accountability; in East Asia, by interpersonal connectedness and social relationships, role obligation, and a sense of balance (Lu & Gilmour, 2004; Suh & Oishi, 2004; Uchida, Norasakkunkit & Kitayama, 2004). As with all cultural considerations, one must guard against the use of assumptions based on any stereotype or generalization. Cultural factors, along with numerous other individual variables, reinforce the primacy of individual differences in research with this population; how an individual *perceives* his or her situation is

paramount, both in the meaning with which he or she infuses an event, and in his or her subsequent reaction to it.

Adaptation to Caregiving: the Research

There is a long history of research involving the ability of families to adapt to (or cope with), with stressors on the family system. The classic ABCX model was originally introduced in 1958, by Reuben Hill; he described a family crisis (X) as the outcome of an initial stressor event (A), impacted by both (B) the family's resources for addressing the crisis and (C) their definition, or interpretation, of the event (Ferguson, 2002). In later formulation, Lazarus & Folkman (1984) posited the theory that the process of coping mediates the effects of stress on an individual's well-being via coping resources and coping strategies. Studies with this population have shown both of these factors to be more significant predictors of parents' well-being than factors such as degree of impairment, care needs, etc. (Beresford, 1996). The impact either of insufficient resources or of inadequate strategies may heighten vulnerability to stress and its adverse effects. It is also known that the health and welfare of the children in their care are to a large degree dependent on the ability of their parents to adapt and cope successfully (Beresford, 1996; Hauenstein, 1990; Seligman & Darling, 1997; Webster-Stratton, 1991; Kinsella, Ong, Murtagh, Prior, & Sawyer, 1999).

The new research paradigm, in contrast, does not assume that care giving inevitably impacts families in a negative fashion; it acknowledges that many parents

adapt and cope well with their situations, and views these parents as actively managing their family situations (Beresford, 1996). Nor is the goal of this research simply to counter with a limited search for purely positive outcomes, but instead the goal is to identify those factors which contribute to the successful adaptation of some families. More recent research is concurring that families of children with disabilities have more in common with their non-disability counterpart families than they have differences (Ferguson, 2002, p. 128; also Barnett, 2003; Krauss & Seltzer, 1999).

Given the negative focus and methodological design of earlier research and the more recent acknowledgement of concurrent positive impacts in the lives of these families, perhaps newscaster Paul Harvey's admonition to heed "the rest of the story" rings true here as well. For there is indeed more to the story of these families and their futures together than such negatively formulated investigations would reveal. It is important that research move from its ubiquitous focus on adverse impacts to an exploration of how these families cope, succeed, and care for themselves and their families, including the child with disabilities (Helff & Glidden, 1998).

The research of Hastings and Taunt (2002) was ultimately spurred by a father who called their attention to the lack of positively valenced queries on a questionnaire for parents of children with disabilities. Krauss and Selzer (1999) hypothesized that mothers caring for their disabled children in the long-term would exhibit some compromise of their well-being over their years of care giving, but their data was not supportive of that assumption. Similarly, the study of Scorgie and Sobsey (2000) was originally conceptualized as a study of effective management strategies used to

manage life by parents of children with disabilities, but was changed as a result of parental feedback emphasizing the positive changes they had experienced as a direct result of their unique experiences of parenting a child with a disability.

Research by Grant et al. (1998) noted rewarding experiences to be the norm rather than the exception. Positive care giving aspects included the satisfaction of preventing institutionalization, presenting well in public, overcoming difficulties, and seeing the individual reach his or her full potential, happy and well-adjusted (also Nolan, Grant, & Keady, 1996). Caregivers themselves reported beneficial intrapersonal factors of rising successfully to challenge, a sense of being needed and a sense of purpose. Greenberg et al. (1993) found that families expressed gratitude for their relationships with their adult children, citing also an increased family strength and closeness. Lehman and Roberto (1996) found that mothers of children with disabilities were more positive about their children than mothers of teenagers without disabilities. Hayden and Heller (1997) examined problem-solving skills and coping abilities in caregivers of adults with mental retardation, finding that as a group they had highly developed effective problem-solving skills, with subscale scores higher than those of the families used to set the test norms. Other researchers have noted positive effects on the marital relationships of parents (Hornby, 1995), on improved coping and management strategies (Scorgie, Wilgosh, & McDonald, 1999), on increased self-esteem and sense of competence (Krauss & Seltzer, 1999), on the ability of the child to connect with others as well as their sense of humor and insightfulness (Poehlman et al., 2005), on increased personal growth (Sandler & Mistretta, 1998), on

spiritual or philosophical growth (Scorgie & Sobsey, 2000), on expanded personal and social networks, and on positive impacts on others and on the community (Stainton & Besser, 1998). Summers, Behr, and Turnbull (1989) noted that in the experiences of many families who have children with disabilities, those children are “active and contributing members of their families, whose presence makes a real contribution to an improved quality of life” (p. 31).

The emerging view is that most families rearing children with disabilities can accommodate successfully to this life task (Cahill & Glidden, 1996; Costigan, Floyd, Harter, & McClintock, 1997; Flaherty & Glidden, 2000; Glidden & Johnson, 1999; Hong, Seltzer, & Krauss, 2001; Scott et al., 1997; Seligman & Darling, 1997; Turnbull et al., 1993), and that they have just as much in common with mainstream families as they do with each other (Singer, 1993). Antonovsky (1993) advocated replacing the historical focus on pathogenesis to what he termed a salutogenic orientation, to reflect a proactive focus on health promotion: “. . . [taking] the paradigmatic leap of asking not ‘What prevents breakdown?’ but the initial salutogenic question ‘What promotes health?’ (p. 116), moving from the concept of *risk factors* to a consideration of *salutary factors*, and their impact on the outcome of even undesirable stressors. Antonovsky (1993) observed that the problem set and perspective of a given family is “a complexity of inextricably intertwined cognitive, affective, and instrumental issues” (p. 113), not easily or accurately represented by simple generalizations.

Characteristics of individuals themselves, including their personalities, resources, and beliefs, as well as their consequent cognitions and behaviors throughout

the coping process, are believed to be among the strongest determinants of how they will fare in terms both of psychological and of physical health when faced with stressful experiences (Park, 1998). Personality characteristics of optimism, hope and general positive affect and perception were mentioned earlier, along with effective coping strategies, as personal coping resources which help to mediate the effects of stress or alter the perception of an event as stressful in the first place.

Effective problem-solving ability has been mentioned briefly as an important coping resource, to leverage one's efforts in addressing life's problems in an effective manner and to mitigate situational stress associated with these problems when effectively addressed. Studies with care giving parents have concurred that effective problem-solving strategies help them to avoid an over-reliance on less effective emotional strategies and to, indeed, reduce both the level of stress experienced (Folkman & Moskowitz, 2004; Krauss & Seltzer, 1999; Moore & Beckwitt, 2003; Sloper, 1991) as well as physical correlates of stressful experience (Folkman & Moskowitz, 2004).

Problem-Solving Ability and Family Functioning

The concept of "coping" is a rather broad construct often used to account for individual differences in response to stress, including "the cognitive and behavioral activities by which a person attempts to manage a stressful situation as well as the emotions it generates" (D'Zurilla & Chang, 1995, p. 548). Problem-solving activities

are included in the broad construct of coping and have been studied in the specific context of care giving, most often with caregivers of the physically disabled or of those with debilitating or chronic disease. With those populations, effective problem-solving skills have been linked with: increased quality of caregiving, decreased levels of perceived stress, and health care expenditures with spinal cord injury patients (Elliott, Shewchuk, & Richards, 1999); decreased perception of disability-related stress and better overall adjustment to a child's physical disability (Hauenstein, 19990; Noojin & Wallander, 1997); improved physical, role and social functioning and ability to cope in caregivers of cancer patients (Toseland, Blanchard, & McCallion, 1995; Nezu, Nezu, Felgoise, McClure, & Houts, 2003; Nezu, Nezu, Houts, Friedman, & Faddis, 1999); reduced distress and improved well-being both in caregiver and in the physically disabled patient (Kurylo, Elliott, & Shewchuk, 2001); and decreased depression and health problems in caregivers of stroke patients (Grant, Elliott, Giger, & Bartolucci, 2001; Shanmugham, Cano, Elliott, & Davis, 2009).

Mothers of children with mental retardation and severe behavior problems were less likely to experience depressive symptoms if they relied on problem-focused coping strategies (Krauss & Seltzer, 1999); the use of such strategies was positively correlated with well-being among mothers of adults with retardation, especially when care giving demands were more extensive (Seltzer, Greenberg, & Krauss, 1995). Beresford (1996) and Hayden and Heller (1997) found that parents of children with disabilities, as a group, demonstrated problem-solving skills at or above the typical parent norms. They demonstrated a wide variety of strategies and creativity in daily

solutions. Noojin and Wallander (1997) studied the adjustment of mothers of children with physical disabilities, and found a positive correlation between better psychological adjustment and (1) high levels of confidence in their problem-solving ability, (2) a tendency to approach rather than to avoid problems, and (3) a sense of being in control of their emotions and behavior during problem-solving. Mothers in their study who reported the highest levels of stress also revealed a tendency to avoid problems and to feel out of control of their emotions and behavior during problem-solving.

Problem-solving is also relevant to parenting of children in general, regardless of a cognitive or physical disability (Shure, 1996; Shure & Spivak, 1978; Vuchinich, 1999); it is also relevant in families with child behavior difficulties (Barkley, Edwards, Laneri, Fletcher, & Metevia, 2001; Sanders, Mazzucchelli, & Studman, 2004; Webster-Stratton, 1991). Problem-solving abilities can distinguish parents who maltreat their children from those who do not (Hansen, Pallotta, Christopher, Conaway, & Lundquist, 1995). Strong and cohesive families have developed effective problem-solving skills. Tallman (1993) noted a tendency among researchers to attribute a broad array of individual and collective difficulties to problem-solving deficits; these deficits are, in turn, the root cause of most family distress and disorganization. Patterson (1982) emphasized the fact that problem-solving in families becomes most evident when it is absent. "It is only when the debris of unsolved problems is everywhere that this omitted mechanism comes into focus" (p. 230, as quoted in Tallman, 1993).

In more general terms, problem-solving has been shown to affect significantly, hopelessness, suicidal ideation, depression, anxiety, and psychological distress (Cheng, 2001; Clum & Febraro, 2004; Elliott, Sherwin, Harkins, & Marmarosh, 1995; MacNair & Elliott, 1992; Nezu, Wilkins, & Nezu, 2004). Problem-solving may act as a moderator in the stress-depression and stress-hopelessness equations (Cheng, 2001). Worry is related to and predicted by deficient problem-solving orientation (Dugas, Letarte, Rheame, Freeston, & Ladouceur, 1995). Effective, self-appraised problem solvers reported fewer physical symptoms and had lower chance expectancies than did ineffective problem solvers, who experienced more negative health perceptions and higher beliefs in chance health outcomes (Elliott & Marmarosh, 1994). There has been demonstrated, consistently, a significant relationship between problem-solving deficits and psychological distress; effective problem-solving has been shown to have significant effects on mitigating the harmful stress effects of life events (D’Zurilla, Nezu, & Maudeu-Olivares, 2002).

The relationship between problem-solving deficits and psychological distress has been previously reviewed, as well as the connection between such deficits and depressive symptomatology and anxiety. It has been found repeatedly that effective problem solvers experience lower levels of stress than do ineffective problem solvers *under similar levels of high stress* (D’Zurilla & Nezu, 1999). In addition, effective problem-solving has been correlated with positive psychological well-being, such as competence, productivity, and optimism (Carver & Scheirer, 1999; Chang and D’Zurilla, 1996; Elliott, Herrick, MacNair, & Harkins, 1994), as well as with

improved self esteem (D’Zurilla, Chang, & Sanna, 2003; McCabe, Blankstein, & Mills, 1999), with the use of adaptive coping strategies (D’Zurilla & Chang, 1995; MacNair & Elliott, 1992; Noojin & Wallander, 1997), with fewer physical health complaints (Elliott, Grant, & Miller, 2004; Elliott & Marmarosh, 1994), and with improved life satisfaction (Chang, Downey, & Salata, 2004).

Social Problem-solving Model

As a general description, “problem-solving is the process by which people both understand and react to problems in living by altering the problematic nature of the situation itself, the person’s reaction to the situation, or both” (Nezu, Palmatier, & Nezu, 2004, p. 225), illustrating the reciprocal interaction between the situation itself and the person who is coping with the situation. A problem is defined as “any life situation or task (present or anticipated) that demands a response for adaptive functioning but no effective response is immediately apparent or available to the person or people confronted with the situation because of the presence of one or more obstacles” (D’Zurilla, Nezu, & Maydeu-Olivares, 2004, p. 12). Such obstacles might include novelty, ambiguity, unpredictability, conflicting stimulus demands, performance skill deficits, or lack of resources. They may be either single time-limited events, a series of similar or related events, or a chronic, ongoing situation (D’Zurilla et al., 2004).

A solution is defined as a coping response designed to impact the situation perceived as a problem, one's negative response to it, or as both responses (Nezu, Palmatier, & Nezu, 2004). An effective solution is that which "achieves the appropriate problem-solving goals while maximizing positive consequences and minimizing negative consequences" (D'Zurilla, Nezu, & Maydeu-Olivares, 2002, p. 4).

The term social problem-solving refers to the complex, "cognitive-affective-behavioral process by which a person attempts to discover, or invent effective or adaptive coping responses for specific problematic situations encountered in daily living" (D'Zurilla & Nezu, 1990, p. 156), or more simply, to "problem-solving as it occurs in the real world" (D'Zurilla & Chang, 1995, p. 548). The "social" in *social problem-solving* refers to "problem-solving that influences one's adaptive functioning in the real-life social environment" (D'Zurilla, Nezu, and Maydeu-Olivares, 2004). The social problem-solving model of D'Zurilla and Nezu (1999) posits the theory that problem-solving outcomes comprise two interdependent processes: (a) a general motivational component, or *problem orientation dimension* and (b) *problem-solving style*, the general tendencies with which individuals approach and manage their problems. The original Social Problem-Solving Inventory (SPSI) was developed by D'Zurilla and Nezu (1990) to identify, specifically, an individual's problem orientation and problem-solving skills. Subsequent research (Maydeu-Olivares and D'Zurilla, 1996) resulted in the revised version (SPSI-R), to identify problem orientation and three distinct problem-solving styles.

An individual's problem orientation may be either positive or negative in valence. *Positive* problem orientation is a constructive problem-solving attitude that includes the general tendencies to: (a) view a problem as a challenge, with potential for benefit or gain; (b) expect that life's problems are solvable (optimistic); (c) believe in one's own competency to solve problems (self-reliant); (d) believe that time and effort are integral to successful problem-solving; and (e) approach problems promptly rather than avoiding them. *Negative* problem orientation, on the other hand, is a maladaptive problem-solving approach that includes general tendencies to: (a) view a problem as threatening to one's psychological, social or economic well-being; (b) lack confidence in one's ability to solve problems successfully, and (c) experience low frustration tolerance in problematic situations (D'Zurilla, Nezu, and Maydeu-Olivares, 2004).

The major problem orientation variables are problem perception, problem attribution, problem appraisal, perceived control, and time/effort commitment.

Problem perception involves the readiness to recognize a situation as problematic, rather than denying or ignoring that fact; it sets the stage for implementing problem-solving operations in service of a solution (problem definition, information gathering and generating alternative solutions, selecting a course of action, implementing, and outcome assessment). *Problem attribution* involves the tendency to ascribe causality to a possibly ambiguous situation in a positive or negative manner. In other words, problem attribution will determine whether or not an individual views problems as a normal part of life's course, to be solved as a matter of

course, or whether or not the individual is more likely to react to perceived problems with negative affect, self-doubt, pessimism, and avoidance of problem-solving activities (D’Zurilla & Nezu, 1999).

Problem appraisal, influenced by problem attribution, involves the perceived degree of significance of a given problem and the extent to which it may represent potential harm/threat or benefit/challenge. Those who view problems as challenges with potential for personal growth tend to approach problems in a deliberate fashion, by planning, whereas those who are threatened and fearful are more likely to experience avoidance, anxiety, and poor problem-solving activities. Problem-solving appraisal has been linked in numerous instances with general psychological adjustment (Heppner & Lee, 2002). *Perceived control* is composed of an individual’s sense of self-efficacy (belief that he or she is capable of successful problem resolution) as well as his or her outcome expectancies (belief that problems are likely to be solved successfully, or avoidance behavior in absence of that belief). Self-efficacy plays a major role in a number of common psychological problems, and constitutes an important component of depression (Maddux, 2002). *Time/effort commitment* involves both (a) the likelihood that the individual will devise accurate time estimates required to resolve a given problem successfully, and (b) the likelihood that he or she will be willing to invest that time and effort to the resolution (D’Zurilla & Nezu, 1999).

The second dimension of the problem-solving model, interdependent with problem orientation, involves problem-solving *styles*. There are three possible problem-solving styles in the social problem-solving model that are used when

confronting problems: two maladaptive styles which are not conducive to effective problem-solving and may instead exacerbate the problem situation, and one effective style which is most likely to result in effective solutions.

Impulsivity/Carelessness Style is a dysfunctional problem-solving pattern characterized by active efforts to resolve problems, but with impulsive, careless, hurried and incomplete attempts to apply problem-solving techniques. An individual high in this dimension will typically consider only a few possible options before choosing an action, with little consideration of alternatives. Outcomes are poorly monitored or evaluated, further decreasing efficacy of action. The second dysfunctional pattern is the *Avoidance Style*, characterized by procrastination, passivity, and dependency. Individuals high in this dimension would rather avoid problems than confront them directly, postponing decisive action for as long as possible or waiting for the problem to resolve itself; they may shift the responsibility for solutions to their own problems onto others.

The constructive style of *Rational Problem-solving* is characterized by rational, deliberate, systematic implementation of effective problem-solving skills. Four specific tasks are involved in effective problem-solving: problem definition and formulation, the generation of alternative solutions, decision-making, and solution implementation and verification. An effective problem solver, then, is an individual who typically collects relevant data and information, clarifies potential obstacles, identifies a variety of possible options, evaluates potential outcomes, compares the alternatives, and chooses and implements a solution with careful monitoring and

evaluation of the outcome (D’Zurilla, Nezu, & Maydeu-Olivares, 2002).

Thus there are five possible problem-solving dimensions in this model: two constructive dimensions of Positive Problem Orientation and Rational Problem-solving, and three dysfunctional dimensions of Negative Problem Orientation, Impulsive/Careless Style, and Avoidance Style. Evidence is ample that an individual’s tendencies on these dimensions impact a multitude of factors. Some research studies have taken this concept a step further, and summed the two positive measures (PPO, RPS) to obtain an index of constructive problem-solving style; they have also taken the three negative measures (NPO, AS, ICS) for an index of dysfunctional problem-solving style (Berry, Elliott, & Rivera, 2007; Elliott, Brossart, Berry, & Fine, 2008; Elliott & Shewchuk, 2003; Kurylo, Elliott, DeVivo, & Dreer, 2004; Rivera, Elliott, Berry, & Grant, 2008; Rivera, Elliott, Berry, Shewchuk, & Oswald, 2006).

Specifically linking problem-solving and well-being, D’Zurilla et al. (2002) identified five problem-solving dimensions (positive and negative problem orientations, and three problem-solving styles – impulsivity/carelessness, avoidance and rational problem-solving) as significantly correlated with life satisfaction. Negative problem orientation (NPO), Impulsivity/Carelessness Style (ICS), and Avoidance Style (AS) have been associated with numerous measures of psychological distress (anxiety, depression, hopelessness, suicidality), and negatively correlated with self-esteem, life satisfaction, extraversion, social adjustment, interpersonal competence and social skills. Positive problem orientation (PPO) and Rational Problem-solving (RPS) have been correlated with those same variables, in the

opposite direction – positively with self-esteem, life satisfaction, extraversion, social adjustment, interpersonal competence and social skills, and negatively with the psychological distress measures (D’Zurilla, Nezu, & Maydeu-Olivares, 2002). To the degree that social problem-solving promotes health could be considered a *salutary*, or health-promoting, *factor*, proposed by Antonovsky as an alternate paradigm to the conventional focus on *risk factors* (Antonovsky, 1993).

Well-being: Definition and Correlates

One’s sense of well-being is not the absence of stressful situations, but an overall satisfaction with various aspects of one’s life (Diener, 2000; Keyes & Magyar-Moe, 2003; Ryff, 1989). The study of subjective well-being (SWB) was developed in part in response to the ubiquitous emphasis in psychology on negative states and traits. Myers and Diener (1995) found in their review that psychological articles with a negative state focus outnumbered those with a positive focus by 17 to 1. Alternately, SWB researchers have historically attended to the entire range of well-being, “from misery to elation” (Diener, Suh, Lucas, & Smith, 1999). Subjective well-being is defined by an individual’s perception of and evaluative responses to their life events – both on cognitive and emotional levels.

Ryan and Deci (2001) reviewed two traditional approaches to the study of well-being. The hedonic view focuses on pleasure or happiness, and dates from Greek philosophy of the fourth century B.C., when philosopher Aristippus taught that “the

goal of life is to experience the maximum amount of pleasure, and that happiness is the totality of one's hedonic moments" (pp.143-144). From this perspective grew the first approach, which considers well-being as part of the pleasure/pain continuum; it consists of three basic components: life satisfaction, the presence of positive mood, and the absence of negative mood (Diener, Suh, Lucas, & Smith, 1999). These components have been shown to be distinct and separate constructs (Diener, 2000; Diener, 1996; Diener, Lucas & Oishi, 2002; Isen, Daubman, & Nowicki, 1987; Lucas, Diener, & Suh, 1996), independent of one another, rather than mere ends of the same continuum. One can experience increased positive *and* negative affect at the same time, contrary to conventional "wisdom." Neither the presence of positive affect nor the absence of negative affect is essential for a sense of life satisfaction. The term subjective well-being (SWB) refers to people's own valuations of their lives, including both cognitive and affective components.

Conversely, the eudaimonic view held that the pursuit of pleasure could result in outcomes that would not promote wellness; it is, instead, more evident in Aristotle's teaching, that true happiness is concerned with the expression of virtue, "in doing what is worth doing" (Ryan & Deci, 2001, p. 145). The second approach includes a consideration of one's life goals (Lent et al., 2005), a sense of meaning, and the realization of one's true potential (Ryan & Deci, 2001). This view considers happiness as a by-product of a well-lived life, rather than an end in and of itself (Ryff & Singer, 1998), and includes six ideals or factors: self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth

(Ryff, C. D., 1989). Ryan and Deci (2001) concluded that it may be most useful to view well-being as a complex construct containing elements both of happiness and of meaningfulness, which “appear to represent intricately related forms of well-being that can be brought together within a common conceptual framework” (Lent, 2004, p. 486).

Peterson, Park and Seligman (2005) propose the inclusion of a third approach: the pursuit of engagement, introduced by Csikszentmihalyi’s concept of “flow:” a psychological state experienced during highly engaging pursuits in which time passes quickly, attention is highly focused, and the sense of self is transcended, all of which is invigorating and additive to one’s sense of well-being (also Csikszentmihalyi, 1990).

Lent (2004) emphasized the potential benefit of studying interrelations among the various concepts of well-being, the individual components of well-being, and the different factors (e.g., personality, situation) that may influence each of those components. This is especially pertinent, since research shows that one’s perception of well-being will generalize from one life domain to another (e.g. work to home, or vice versa), with bi-directional influence from one domain to the other, either enhancing overall well-being or exacerbating its lack thereof (Diener, Suh, Lucas, & Smith, 1999; Lent, 2004).

The World Health Organization (WHO) addresses such interrelations and components in their definition of Quality of Life as:

. . . an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. . . a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment (World Health Organization).

It is the instrument developed by the WHO, the WHOQOL-BREF (brief version), that is used to assess this broad definition of quality of life that is used in the current study.

As is by now apparent, numerous factors are correlated with subjective well-being (SWB), either in a causal fashion or with bidirectional correlation. There has been much debate regarding the roles of environment, situational variables, and personality, as well as the role of affect, both trait (stable personality aspects) and state (situational affect responses). Kozma, Stone, and Stones (2000) concluded that SWB has trait- and state-like properties, rather than being solely attributed solely to environmental and personality variables (also DeNeve & Cooper, 1998; Diener, 1996; Diener, Suh, Lucas, & Smith, 1999; Heady & Wearing, 1989; Lent, 2004; Veenhoven, 1994). Other correlated factors include optimism/pessimism and expectations (King, Scollon, Ramsey, & Williams, 2000; MacLeod & Conway, 2005); hope (Magaletta & Oliver, 1999); locus of control and self-efficacy (DeNeve & Cooper, 1998; Lent et al., 2005), self-esteem (McCabe, Blankstein, & Mills, 1999), situational resources and life events (Fujita & Diener, 2005; Heady & Wearing, 1989; Lent et al., 2005; Suh,

Diener, & Fajita, 1996); coping and problem-solving skills (Chang, Downey, & Salata, 2004; McConaghy & Caltabiano, 2005), and numerous other factors.

This study will focus specifically on the contribution of problem-solving orientation and problem-solving style to a caregiver's expression of well-being on a self-report measure.

Purpose of the Study

Overall, research has documented great complexity and variety in the lives of children with cognitive disabilities and their families. Each has a unique story, but there are areas of common focus. Although many aspects of a child's care and functioning pose a challenge, more recently there is also an appreciation of their positive contributions to their families. Many different categories of coping resources play an important part in the well-being and overall functioning of these children and their families. "Coping" is a complex construct, and families must "cope" with a variety of challenges in ordinary life. There are aspects of having a child with a disability which may pose some of those challenges, but families must be viewed in the context of their totality and not viewed exclusively as families of children with disabilities.

Problem-solving abilities have been correlated with effective coping in care giving populations in general and have been linked with better care giving and overall functioning (Kurylo, Elliott, & Shewchuk, 2001; psychological, physical and social

functioning; decreased perception of stress and improved adjustment (Elliott, Shewchuk & Richards, 1999; Grant, Elliott, Giger, & Bartolucci, 2001; Hauenstein, 1990; Noojin & Wallander, 1997). In typical populations, effective problem-solving is linked with effective parenting in general (Shure, 1996; Vuchinich, 1999), decreased incidence of and risk for depression in children of depressed parents (Chen, Johnston, Sheeber, & Leve, 2009), as well as with psychological (Cheng, 2001; Elliott, Grant, & Miller, 2004; D’Zurilla, Nezu, & Maydeu-Olivares, 2002) and physical (Elliott and Marmarosh, 1994) health, stress management (Cheng, 2001), and many other aspects of effective functioning and well-being (D’Zurilla, Nezu, & Maydeu-Olivares, 2002).

Family adjustment and well-being may be related to certain characteristics of the child him/herself. Most notably, challenging behaviors have been consistently linked with parental stress (Baker et al., 2003; Qureshi, 1993; Willoughby, & Glidden, 1995).

The current study examines the relationships between caregivers’ social problem-solving skills, child behaviors, family adjustment to childhood disability, and levels of caregiver well-being, as measured by the Social Problem-solving Index, Revised (SPSI-R:S), the Nisonger Child Behavior Rating Form (NCBRF), the Family Impact of Childhood Disability Scale (FICD), and the World Health Organization Quality of Life Measure, brief (WHOQOL-BREF).

Rationale

Effective problem-solving has been shown to impact quality of life both in physical and in psychological health arenas, as well as in quality of caregiving, adjustment to disability, decreased perception stress and improved social functioning (Elliot, Shewchuk, & Richards, 1999; Grant, Elliott, Giger, & Bartolucci, 2001; Hauenstein, 1990; Kurylo, Elliott, & Shewchuk, 2001; Noojin & Wallander, 1997).

Research has documented effective problem-solving interventions with cancer patients (Nezu, Nezu, Felgoise, McClure, & Houts, 2003; Nezu, Nezu, Houts, Friedman, & Faddis, 1999; Toseland, Blanchard, & McCallion, 1995), with parents of children with a disability (Pelchat, Bisson, Ricard, Perreault, & Bouchard, 1999), with patients with spinal cord injury (Elliott, 1999), and with caregivers: with dementia patients (Chang, D’Zurilla, & Sanna, 2002), with persons who have traumatic brain injury (Rivera, Elliott, Berry, & Grant, 2008; Wade, Carey, & Wolfe, 2006), with stroke survivors (Grant, Elliott, Weaver, Bartolucci, & Giger, 2002), and with children who have cancer (Sahler et al., 2005). Among parents of children with mental retardation, problem-solving interventions were shown to buffer the impact of caregiving stress on well-being (Seltzer, Greenberg, & Krauss, 1995), to enhance the effective use of social support (Hayden & Heller, 1997), to improve family functioning (Sanders, Mazzuchelli, & Studman, 2004), and to reduce negative parent-child interactions and child behavior problems (McIntyre, 2008), fostering caregiver

health and, by extension, that of their care recipients (Kurylo, Elliott, & Shewchuk, 2001).

Differences in caregiver problem-solving abilities may determine which individuals are more susceptible to depression, anxiety and illness; problem-solving training appears to be effective in reducing all of these (Rivera, Elliott, Berry, & Grant, 2008). A meta-analysis by Malouff, Thursteinsson, & Schutte (2007) identified problem-solving training to be most effective when the problem-orientation component was included.

The present study adds to the growing body of empirically validated research on the ability of families of children with disabilities to function *well*, rather than merely to “cope.” It highlights the complex context in which these families function, and the myriad of variables which may leverage their efforts to survive and to thrive.

Hypotheses

The following hypotheses were proposed. In all cases in which a hypothesis was confirmed, ad hoc testing was done to determine if the level of challenging behaviors presented by the child (behavior challenge variable) mediated that correlation.

Hypothesis 1. Positive Problem Orientation (PPO), as measured by the PPO scale within the SPSI-R:S, will demonstrate a significant, positive correlation with caregiver quality of life, as measured by the (a) Physical, (b) Psychological, (c) Social,

and (d) Environmental subscales of the WHOQOL-BREF scale. In other words, individuals scoring higher on positive problem orientation will score higher on the WHOQOL-BREF subscales.

Hypothesis 2. Negative Problem Orientation (NPO), as measured by the NPO scales within the SPSI-R:S, will demonstrate a significant, negative correlation with caregiver scores on the WHOQOL-BREF subscales. In other words, individuals with a negative problem orientation will score lower on the WHOQOL-BREF subscales.

Hypothesis 3. The scores of those individuals who report a Rational Problem-solving style (RPS) of the SPSI-R:S will demonstrate a significant, positive correlation with caregiver scores on the WHOQOL-BREF subscales. In other words, individuals who tend to employ a rational and systematic approach to problem-solving, i.e., the Rational Problem-solving style, will score higher on the WHOQOL-BREF subscales than those who adopt a less rational problem-solving style.

Hypothesis 4. The scores of those individuals who tend toward the Impulsive/Careless Style of problem-solving (ICS) of the SPSI-R:S will demonstrate a significant, negative correlation with caregiver scores on the WHOQOL-BREF subscales. In other words, individuals who tend to employ the Impulsive/Careless Style of problem-solving, one of the two less functional styles, will score lower on the WHOQOL-BREF subscales.

Hypothesis 5. The scores of those individuals who tend toward the Avoidant Style of problem-solving (AS) of the SPSI-R:S will demonstrate a significant, negative correlation with caregiver scores on the WHOQOL-BREF subscales.

Hypothesis 6. A Positive Problem Orientation (PPO) will be positively correlated with the endorsement of positive impact items, and negatively correlated with the endorsement of negative items on the Family Impact of Child Disability (FICD) scale.

Hypothesis 7. A Negative Problem Orientation (NPO), will be negatively correlated with the endorsement of positive impact items, and positively correlated with the endorsement of negative items on the Family Impact of Child Disability (FICD) scale.

Hypothesis 8. Scores on the Rational Problem-solving style (RPS) scale will be negatively correlated with the endorsement of positive impact items, and positively correlated with the endorsement of negative items on the Family Impact of Child Disability (FICD) scale.

Hypothesis 9. Scores on the Impulsive/Careless Style of problem-solving (ICS) will be negatively correlated with the endorsement of positive impact items, and positively correlated with the endorsement of negative items on the Family Impact of Child Disability (FICD) scale.

Hypothesis 10. Scores on the Avoidant Style of problem-solving (AS) will be negatively correlated with the endorsement of positive impact items, and positively correlated with the endorsement of negative items on the Family Impact of Child Disability (FICD) scale.

Chapter 2

Method

Participants

Participants were 111 primary caregivers of children with developmental disabilities between the ages of 5 and 23, recruited from the Mental Retardation (MR) division of a northeast regional county Mental Health/Mental Retardation (MH/MR) office. Of the agency families with eligible children between the identified ages of 5 and 21 receiving MR services, a number of demographic characteristics were identified. Ethnic makeup of this group comprised 83.1% Caucasian, 10.9% Hispanic, 4.8% African-American, and 1.2% endorsed "Other" (N=248). Biological parents account for 88.7% of the parent-child relationships; adoptive parents, 4.4%, foster parents 1.6%, grandparents 0.8%, and 4.4% are identified as "other" (e.g. living with older siblings, aunt, uncle, etc.). Single parents compose 24.2% of this population, and 75.8% partnered with another. The children receiving services are 64% boys and 36% girls, with a mean age of 14.7. A primary caregiver was defined as an individual who provided the majority of daily care of a child with a disability, and may have been a biological, foster, adoptive, or step- parent or grandparent.

Procedures

Participants were recruited from the MR division of a northeast regional county MH/MR office. They were identified from the division's mailing list as caring for a child having met the eligibility criteria to receive services. For the MR division, eligibility criteria include documentation of mental retardation before the age of 21.

A total of 200 survey packets were mailed to those addresses identified by the division's mailing list as caring for a child having met the eligibility criteria to receive MR agency services, who were within the targeted age range. The packets contained an introductory letter, a resource page, a page of general instructions, questionnaires (retyped and formatted with permission from their authors, when applicable, to allow for consistent flow), and postage-paid return envelopes.

An introductory letter (Appendix A), which addressed both the positive and potential negative aspects of participation, fronted the entire packet. It was followed by a resource list for parents of children with disabilities (Appendix B), and general instructions for the packet, including statements regarding anonymity (Appendix C). Next were placed the instruments themselves (Appendix D): the demographics questionnaire, the Family Impact of Child Disability scale (FICD), the Nisonger Child Behavior Rating Form (NCBRF), the World Health Organization Quality of Life-Brief scale (WHOQOL-BREF), and the Social Problem-solving Inventory-revised short form (SPSI-R:S). Additional space was provided mid-packet, which invited parents to share any comments they might choose to include. These anecdotal comments were

included in the Discussion section of this manuscript, as being further illustrative of the caregivers' perspectives. It was estimated that the measures would require approximately 30 – 45 minutes for participants to complete.

Mailing labels were generated from the agency's computer records, and packets were mailed via surface mail with no identifying information, permitting no method of connecting an individual response packet to a given caregiver household. Responses were opened by the researcher and all pages of a given response packet, along with scoring sheets, were assigned a tracking number which corresponded with case numbers of entries in the SPSS data spreadsheet to enable accurate checking of data as needed.

Measures

Demographic Information. Demographic information was gleaned from a compilation entitled "A Few Basic Questions," which include, for the caregiver: gender, level of education, employment status of each parent in the household, income level, type of community, relationship to the child, degree of involvement in the child's daily care, and level of regular assistance of others with the care of the child. Queries addressing the child him/herself include: gender, age, and presence or absence of siblings with a disability.

Social Problem-solving Inventory-Revised (SPSI-R:S). Social problem-solving orientation and style was assessed by the 25-item short version of the Social Problem-

solving Inventory-Revised (SPSI-R: S), which has been used in previous caregiver research (eg: Nezu, Palmatier, & Nezu, 2004). This instrument is based on five-dimensional model of problem-solving and yields five empirically-derived scales. Two of the scales measure the problem orientation dimensions: Positive Problem Orientation (PPO) and Negative Problem Orientation (NPO). The remaining scales are considered behavioral response styles and problem-solving skills scales: Rational Problem-solving (RPS); and the Impulsive/Careless Style (ICS), and Avoidance Style (AS). The 25 items are rated on a 5-point Likert-type scale, ranging from “*not at all true of me*” (0) to *extremely true of me* (4). Higher scores on each scale indicate a greater tendency toward that particular facet of problem-solving.

The Positive Problem Orientation (PPO) scale assesses a constructive problem-solving attitude that includes the general tendencies to view problems in a positive light, as challenges rather than as threats, to be optimistic that life’s problems are solvable, and to believe in one’s own competency to solve problems. Sample items from the PPO scale include “When I have a problem, I try to see it as a challenge or opportunity to benefit in some positive way from having the problem” and “Whenever I have a problem, I believe that it can be solved.” The Negative Problem Orientation (NPO) scale assesses a maladaptive problem-solving approach that includes general tendencies to view a problem as threatening, to lack confidence in one’s ability to solve problems successfully, and to experience low frustration tolerance in problematic situations. Sample items from the NPO scale include “When my first efforts to solve a problem fail, I get very upset” and “I feel threatened and afraid when

I have an important problem to solve.” (D’Zurilla, Nezu, & Maydeu-Olivares, 2004).

The Rational Problem-solving (RPS) scale assesses a tendency to engage, systematically and intentionally, in effective problem-solving techniques, which typically include attending to relevant data, potential obstacles, possible options and potential outcomes, and then implementing solutions with careful monitoring and evaluation of the outcome. Sample items from the RPS scale include “‘Before I try to solve a problem, I set a specific goal so that I know exactly what I want to accomplish” and “When I am trying to solve a problem, I think of as many options as possible until I cannot come up with any more ideas.” The Avoidance Style (AS) scale assesses a tendency to postpone problems rather than address them directly, in hopes that the problem will solve itself or that others will solve it for them. This style is characterized by procrastination, passivity, and dependency. Sample items from the AS scale include “I go out of my way to avoid having to deal with problems in my life” and “When a problem occurs in my life, I put off trying to solve it for as long as possible.” The Impulsivity/Carelessness Style (ICS) scale assesses a tendency to approach problems in a haphazard, incomplete fashion, typically considering only a few possible options before choosing an action with little consideration of alternatives. Outcomes are poorly monitored or evaluated, further decreasing effective action (D’Zurilla, Nezu, & Maydeu-Olivares, 2002). Sample items from the ICS scale include “When I have a decision to make, I do not take the time to consider the pros and cons of each option” and “When I am trying to solve a problem, I go with the first good idea that comes to mind.”

Both positive problem orientation (PPO) and rational problem-solving (RPS) are considered to be constructive approaches to problem-solving, but negative problem orientation (NPO), impulsive/careless style (ISC), and avoidance style (AS) are considered dysfunctional approaches to problem-solving. Some research studies have taken this concept a step further, and summed the two positive measures (PPO, RPS) to obtain an index of constructive problem-solving style, and in a similar manner, summed the three negative measures (NPO, AS, ICS) for an index of dysfunctional problem-solving style (Berry, Elliott, & Rivera, 2007; Elliott, Brossart, Berry, & Fine, 2008; Elliott and Shewchuk, 2003; Kurylo, Elliott, DeVivo, & Dreer, 2004; Rivera, Elliott, Berry, & Grant, 2008; Rivera, Elliott, Berry, Shewchuk, & Oswald, 2006).

The original 56-item SPSI-R (further distinguished as the SPSI-R:L, from which the SPSI-R:S was derived) has been evaluated among diverse populations for psychometric properties, and has demonstrated reliability by virtue of strong internal consistency, stability over time, and strong structural, concurrent, predictive, convergent, and discriminant validity (D’Zurilla, Nezu, & Maydeu-Olivares, 2002). It appears to be sensitive to the effects of problem-solving interventions.

The instrument used in this study, the SPSI-R:S, is derived from the SPSI-R:L. It has demonstrated good psychometric properties through re-analysis of the data from SPSI-R:L using only those items included in the SPSI-R:S, rather than to have re-administered the short form to another large sample. The SPSI-R:S is characterized by high correlations with the SPSI-R:L scales (r of .92 for RPS to 1.00 for PPO). Strong internal consistency and stability over time were demonstrated in this manner for the

SPSI-R:S. Alpha values were consistent with the parent version of the instrument: for young adults (.89), middle-aged adults (.93) and elderly adults (.88), with subtest scales ranging from .69 to .93. Temporal stability was shown by test-retest analyses, with Pearson r values adequate to high across the five SPSI-R scales of - 0.72 for PPO and ICS to 0.84 for Overall SPSI-R score. Structural validity was confirmed by factor analysis in the same manner. Predictive validity was confirmed by similar correlations, having the external measures of psychological distress and well-being as its parent version. The SPSI-R:S is estimated to take approximately 10 minutes to complete (D’Zurilla, Nezu, & Maydeu-Olivares, 2002).

The World Health Organization Quality of Life instrument (WHOQOL-BREF).

Quality of life was assessed by the brief version of the World Health Organization Quality of Life instrument (WHOQOL-BREF). This instrument was developed by the World Health Organization, with the collaboration of 15 centers around the world, from 10 years of multi-cultural research on Quality of Life (QOL). It has been used in a variety of cultural settings, and can provide valid cross-cultural comparisons. It has wide applicability and has been used in medical contexts as well as in research and policy making. The element that makes this instrument unique is its focus on the perception of the individual, rather than yet another instrument to be completed by “objective” practitioners of the medical sciences. It recognizes that illness and stressors impact an individual’s perception of his or her social relationships, working capacity, financial status, etc. (Skevington, Lotfy, & O’Connell, 2004). The 26 items

of this scale are rated on a 5-point Likert-type scale ranging from “*very poor*” (0) to “*very good/extremely*” (3). Responses are scored according to the instrument’s specific formula, with several items reverse-scored, in accordance with the instructions.

Incorporated within the first domain, Physical Health are such considerations as energy and fatigue, pain and discomfort, sleep and rest, mobility, activities of daily living, degree of dependence on medicine or medical aids, and work capacity. Sample items from this subscale include: “How satisfied are you with your sleep?” and “Do you have enough energy for everyday life?”

The second domain, Psychological Health, includes body image and appearance, negative and positive feelings, self-esteem, thinking, learning, memory and concentration, and spirituality, religion, and personal beliefs. Sample items include “How much do you enjoy life?” and “To what extent do you feel your life to be meaningful?”

The third domain, Social Relationships, taps personal relationships, social support, and sexual activity, asking “How satisfied are you with your personal relationships?” and “How satisfied are you with the support you get from your friends?”

Domain 4, Environmental, includes freedom, physical safety and security, home environment, financial resources, accessibility and quality of health and social care, opportunities for acquiring new information and skills, recreation/ leisure activity, physical environment (pollution, noise, traffic, climate) and transportation.

Sample queries include: “How safe do you feel in your daily life?” and “To what extent do you have the opportunity for leisure activities?” (The WHOQOL Group, 1998).

The psychometric properties of this instrument were analyzed, using cross-sectional data obtained from a survey of adults carried out in 23 countries ($n = 11,830$), from diverse cultures and socio-economic development levels, educational levels, and types of marital status (Skevington et al., 2004). Consistent with results from factor analyses of extensive field trials of the original WHOQOL-100, the WHOQOL-BREF was developed along four domains of quality of life (QOL): physical, psychological, social, and environmental (WHOQOL Group, 1998). It was determined that two of the original 6 factors of the WHOQOL-100 (independence and spirituality) were associated with the physical (for independence) and psychological (for spirituality) domains.

Cronbach’s alpha values for each of the four domains ranged from 0.66 for domain 3, Social Relationships, to 0.84 for domain 1, Physical Health, demonstrating good internal consistency. Test-retest reliabilities for individual domains were 0.66 for physical health, 0.72 for psychological, 0.75 for social relationships, and 0.87 for environment (The WHOQOL Group, 1998b).

The WHOQOL-100 has previously been shown to have excellent ability to discriminate between ill and well respondents, and the WHOQOL-BREF has been demonstrated as being comparable in this regard (The WHOQOL Group, 1998a). A comparison of domain scores for sick and well respondents found that discriminant validity was significant for each domain in the total population, and was best

demonstrated in the physical domain, followed by the psychological, social and environmental domains (Skevington et al.). Domain concepts demonstrated construct validity, because individual items were for the most part strongly correlated with the domain to which they were assigned, and not to any other than their intended domain. Item-domain correlations ranged from 0.48 for pain to 0.70 for activities of daily living (Domain1); from 0.50 for negative feelings to 0.65 for spirituality (Domain 2); from 0.45 for sex to 0.57 for personal relationships (Domain 3); and (Domain 4) from 0.47 for leisure to 0.56 for financial resources (Skevington et al.). This abbreviated measure takes about 5 minutes to complete.

Family Impact of Child Disability scale (FICD). A family's adjustment to the child's disability was assessed by the 20-item version of the Family Impact of Child Disability scale (FICD). Most significantly, this scale was designed to reflect both positive and negative parent appraisals of the impact of their child's disability on family life, as separate constructs (Trute & Heibert-Murphy, 2002).

Reliability of the original 15-item FICD was determined by an assessment of the internal consistency of the subscales, with alphas of .88 for the negative subscale and .71 for the positive subscale. It was found to be independent of social desirability response style bias, with evidence of discriminant validity both for negative and for positive subscales; with temporal stability over the course of a 7-year time period; and with good predictive validity for parenting stress (Trute & Heibert-Murphy, 2002; Trute, Heibert-Murphy, & Levine, 2007).

The 20-item version developed by the same authors was used in this study. Five additional items were added to the positive subscale to better balance its weighting in the total score. The items of both positive and negative subscales are rated on a 4-point Likert-type scale ranging from “*not at all*” (1) to “*to a great degree*” (4). The totals for each item in a given subscale are added to arrive at the total score for each subscale. Sample items from the positive subscale include, “The experience has made us come to terms with what should be valued in life” and “The child’s disability has led to positive personal growth, or more strength as a person, in mother and/or father.” Sample items from the negative subscale include “There have been extraordinary time demands created in looking after the needs of the disabled child” and “It has led to limitations in social contacts outside the home.”

High internal consistency was demonstrated by alphas of .89 for the negative subscale; .81 (mothers) and .85 (fathers) for the positive subscale. Test-retest reliability suggested stability over time. It was also determined that this FICD differed conceptually and empirically from a measure of overall family functioning (Trute et al., 2007). It takes about 5 minutes to complete.

The Nisonger Child Behavior Rating Form (NCBRF). The level of a child’s challenging behaviors was assessed by Nisonger Child Behavior Rating Form (NCBRF). The NCBRF was developed as an instrument for the assessment of behavioral and emotional problems, specifically in children with mental retardation (Aman, Tassé, Rojahn, & Hammer, 1996; Tassé, Aman, Hammer, & Rojahn, 1996;

Tassé & Lecavalier, 2000). The parent report version of the scale was used for this study (there is also a teacher report version). This instrument is somewhat unique because it focuses not solely on negative or problematic behavior, but also includes a measure of positive social behavior. These are not combined as valent parts of the same construct, but are separate constructs – positive social behavior as one, and behavior considered to be problematic and stressful for a parent as the other.

The 10 items of the Positive Social scale are rated on a 4-point Likert-type scale ranging from “*not true*” (0) to “*completely or always true*” (3). Possible sub-scale scores are Compliant/Calm and Adaptive/Social, the total from the two subscales composing the Positive Social scale. Sample items from the Positive Social scale include “Was cheerful or happy,” and “Shared or helped others,” and “Accepted redirection.” The 66 items on the companion Problem Behavior scale are also rated on a 4-point Likert-type scale, but ranging from “*if the behavior did not occur, or was not a problem*” (0) to “*if the behavior occurred a lot, or was a severe problem*” (3). The six subscales composing the Problem Behavior scale include: Conduct Problem, Insecure/Anxious, Hyperactive, Self-Injury/Stereotypic, Self-Isolated/Ritualistic, and Overly Sensitive. Sample items from this scale include “crying, tearful episodes” and “fidgets, wiggles, or squirms” and “physically attacks people.” Higher scores for both the Positive Social and Problem Behavior scales constitute greater degrees of the so-named behavior constellations. Because they are separate constructs, the disparate number of items (10 for Positive Social and 66 for Problem Behavior) is not a factor in scoring.

Although the NCBRF yields scores at three levels: two total behavior scales (one of social competence and one of problem behavior), eight subscales of behavior types, and the individual items available for scrutiny, the focus of this study was limited to the total behavior scales. Psychometrically, the Nisonger CBRF has been determined a sound instrument for assessing emotional and behavioral problems in children and adolescents with MR. It has been determined (Aman, Tassé, Rojahn, & Hammer, 1996) to have sound internal consistency reliability, as demonstrated by a median alpha value of .85 for parent ratings on Problem Behavior subscales (ranging from .77 for Self-isolated/Ritualistic to .93 for Conduct Problem) and a median alpha value of .78 for parent ratings on Social Competence subscales (ranging from .73 for Adaptive Social to .82 for Compliant/Calm).

The Aberrant Behavior Checklist (ABC) was used by Aman, et al. (1996) to assess concurrent validity of the problem behavior subscales of the Nisonger CBRF. The ABC is a behavior rating scale which was developed to assess treatment effects in individuals with mental retardation, and has been used extensively to study problem behavior in children and adults with mental retardation. Median correlations of .72 between parent versions of the NCBRF and ABC (ranging from .49 for Self-Isolated/Ritualistic to .80 for Hyperactive); 369 participants indicated that the subscales which appeared to be clinically related did indeed seem to tap similar constructs. Potential age and gender effects were assessed by Tassé, Aman, Hammer, and Rojahn (1996). In addition to good face validity with the population, coverage of a wide range of internalizing and externalizing problems, good internal consistency, and

strong concurrent validity with similar subscales on the ABC (Aman and Singh, 1986), they found no statistically significant main effects as a function of gender. The instrument was completed easily by parents in 7-8 minutes.

The Research Design

The research design is a cross-sectional correlational design. Variables were operationalized as the sub-scale scores on the Social Problem-solving Inventory-Revised, short form (SPSI-R:S). The SPSI-R:S measured an individual's problem-solving orientation both on Positive Problem Orientation and on Negative Problem Orientation sub-scales, and also identified a style (Rational Problem-solving, Impulsive/Careless, or Avoidant) that best described the individual's approach to problem-solving.

The variables for this study included: two problem-solving orientations, Positive (PPO) and Negative (NPO), operationalized as scores on the Problem Orientation subscales of the respective valences, and three problem-solving styles, operationalized as scores on the respective problem-solving style subscales (Impulsive/Careless, Avoidant, and Rational Problem-Solving) of the Social Problem-solving Inventory, Revised, short form (SPSI-R:S).

Additional variables were operationalized as scores on the Family Impact of Childhood Disability Scale (FICD), a measure of the caregiver's perception of the

impact of the child's disability on the family, and the World Health Organization Quality of Life Measure, brief (WHOQOL-BREF), a measure of global quality of life.

The level of challenging behaviors on the part of the child was considered as a possible mediating variable, which might mediate, or might alter, the strength of any correlations between variables. In other words, when there is a significant correlation between the problem-solving variables and the quality of life or family impact variables, additional tests were to be run to determine if the level of a child's problem behaviors would alter that correlation. This level of challenging behavior was measured by scores on the Nisonger Child Behavior Rating Form (NCBRF).

Descriptive Statistics were analyzed on the participant demographics, including ethnic characteristics, parent-child relationship (biological, adoptive, foster, etc.), educational level and marital status of caregiver, employment status, income, level of caregiving assistance, age and gender of the child with a disability, and whether or not there were any siblings with a disability in the family.

Descriptive Analysis of Continuous Variables. Correlational research analysis is a statistical tool used to measure and describe a relationship between two observed variables, with no attempt to control or manipulate the variables. In this study, correlational analyses were used to evaluate the hypothesized relationships between problem-solving ability (problem orientation and problem-solving style), perceived

quality of life, and caregiver's perception of family adjustment, as measured by scores on the respective self-report measures.

All data were entered into the Statistical Program for the Social Sciences 15.0 for Windows (SPSS). The accuracy of data entry was reviewed to ensure that values entered were identical to those on the individual measures; that there were no omitted values; that the range of scores entered was correct, and did not exceed or go lower than the determined possible range of responses. Minimum and maximum values, means, and standard deviations were calculated for continuous variables, with the data sheets reviewed for accuracy. Skew and kurtosis of data were calculated to assess the extent to which the data distributions approximated expectations of normal distributions. Measures of *skewness* (the skewness statistic) describe the extent to which the distribution of a given variable compares with the distribution on the standard normal curve, also known as the "Bell curve." *Kurtosis* is a measure of how flat the top of a distribution curve is, in comparison with a normal distribution of the same variance.

Pearson Correlations were obtained to evaluate the relationship between the variables of each hypothesis. Pearson Correlations (*Pearson r*), are used to determine the extent to which the values of a given two variables are proportional, or related to each other, including the "strength" of that correlation

Additional Analyses: Mediation. On those hypotheses for which correlations of statistical significance were found, further tests were used to determine if there was

a mediating effect of child behavior, as measured by scores on the Nisonger Child Behavior Rating Form (NCBRF). The consideration of a potential mediating effect was born from research linking the level of a child's challenging behaviors to parental stress (e.g. Baker et al., 2003; Hodapp, Ricci, Ly, & Fidler, 2003), depression (Hong & Seltzer, 1995), the limiting of social relationships (Cohen, Gottlieb, & Underwood, 2001), and the use of avoidant coping (Baker, Blacher, Crnic, & Edelbrock, 2002).

Unsolicited Anecdotal Comments. Some caregivers opted to share comments in the space available, and several are used in discussion to illustrate pertinent aspects of the study.

Chapter 3

Results

Demographic Data

Demographic data were collected on gender, age, ethnicity, nature of parenting relationship, education level, marital status, employment and level of outside assistance available to assist the family with care of the child with a disability.

A total of 111 valid surveys were completed. One survey was disqualified by a very clear response set and many items left blank. This response rate of 55% is not atypical with this population of parents who are accustomed to completing county and other surveys on their children, and who express appreciation for the opportunity to contribute their input.

Gender. Female respondents composed the bulk of participants: 81.1 % ($n = 90$); there were 18.0 % male respondents ($n = 20$), and 1 participant (.9%) omitted the item.

Age. The age of the 111 participants ranged from 24 to 69 years of age. The average age of all respondents was 46.52, SD 7.647. Table 1 summarizes the age distribution of respondents.

Table 1

Age Distribution of Respondents

	Age	Frequency	Percent
Valid	20-29	1	.9
	30-39	19	17.3
	40-49	52	47.3
	50-59	33	33
	60-69	5	4.5
Missing		1	.9
	Total	111	100

Ethnic characteristics. Table 2 summarizes the ethnic characteristics of respondents. According to agency data, the population from which this sample was drawn is composed of 83% Caucasian, 4.8% African-American, 10.9% Hispanic; 1.2% endorsed Other.

Table 2

Ethnic Distribution of participants

	Relationship	Frequency	Percent	Agency percent
Valid	Caucasian	101	91.0	83.0
	African-American	3	2.7	4.8
	Hispanic	5	4.5	10.9
	Other	1	.9	1.2
Missing		1	.9	
	Total	111	100	

Parent-child relationship. Biological parents composed the bulk of the sample, with representations of grandparents, adoptive, and foster parents as well. In one case, the respondent endorsed both biological and adoptive parent. Table 3 summarizes the distribution of this relationship among participants.

Table 3

Distribution of Parent-Child Relationship

	Relationship	Frequency	Percent
Valid	Biological parent	95	85.6
	Adoptive parent	4	3.6
	Foster parent	1	.9
	Grandparent	6	5.4
	Other	2	1.8
	Both biological and adoptive	1	.9
Missing		2	1.8
	Total	111	100

Educational levels. The education levels of participants ranged from fewer than 12 years of school (11.7%) through the completion of post-graduate education (3.6%). College graduates composed the bulk of the sample (36.9%). The educational levels of participants are summarized in Table 4.

Table 4

Education Levels of Participants

	Education	Frequency	Percent
Valid	Less than High School	13	11.7
	High School Graduate	40	36.0
	Technical School Graduate	6	5.4
	High School "Plus"	6	5.4
	College Graduate	41	36.9
	College Graduate "Plus"	4	3.6
Missing		1	.9
	Total	111	100.0

Marital status: These were largely two-parent households (78.4 %), composed both of married parents and of parents with a Significant Other / Partner ($n = 87$). Single-parent households composed 20.7 % of the total ($n = 23$), including never married, separated or divorced parents.

Employment. Of total respondents (90% of whom were female caregivers), 41.4 % were employed on a full-time basis, and 26.1 % on a part-time basis. Of spouses of the respondents, 61.3 % were employed on a full-time basis. Table 5 provides the details of caregiver employment data.

Table 5

Employment Status of Participants: Respondent			
Employment of Respondent		Frequency	Percent
Valid	Full Time	46	41.4
	Part Time	29	26.1
	Retired	6	5.4
	Unemployed, seeking	8	7.2
	Unemployed, not seeking	19	17.1
Missing		3	2.7
	Total	111	100.0

Employment Status of Participants: Spouse			
Spouse of Respondent, Employment			
Valid	Full Time	69	62.2
	Part Time	2	1.8
	Retired	2	1.8
	Unemployed, Seeking	8	7.2
	Unemployed, Not Seeking	5	4.5
Missing	“Not Applicable” (e.g. single parent households)	21	18.9
	Omitted	4	3.6
	Total	111	100.0

Limiting Employment. Of caregiver respondents, 36.9 % were limiting employment as a result of concerns or care needs pertaining to their children, and would increase their hours of employment if suitable childcare were available. This item was omitted by 30 respondents (27%), and in 3 instances (2.7%) it was marked “not applicable.”

Household Income. Distribution of household income ranged from less than \$20,000 (15.3%) to over \$100,000 (10.8%). A summary of the household income categories is provided in Table 6.

Table 6

Household Income of Participants			
	Household Income	Frequency	Percent
Valid	Less than \$20,000	17	15.3
	\$20,001 - \$40,000	24	21.6
	\$40,001 - \$60,000	24	21.6
	\$60,001 - \$80,000	18	16.2
	\$80,001 - \$100,000	9	8.1
	Over \$100,000	12	10.8
	Total	104	93.7
Missing		7	6.3
	Total	111	100.0

Community Distribution. The bulk of respondents considered their residence to be in suburban communities (56.8%); 16.2% considered themselves to be rural, and 21.6 identified with urban / city. Urban, for the geographic area of this study, references a city of eastern Pennsylvania with a population of 72,531 in July of 2007, or another of 26,094 at that time (City-data.com, 2009). The community distribution of the participants is summarized in Table 7.

Table 7

Community Distribution of Participants			
	Community	Frequency	Percent
Valid	Suburban	63	56.8
	Rural/Country	18	16.2
	Urban/City	24	21.6
Missing		6	5.4
	Total	111	100.0

Assistance with caregiving. Of responding households, 4.5 % reported receiving no outside assistance with care giving, and 20.7 % had the assistance of another parent/caregiver only. The assistance of the child's sibling only was reported in 10.8 % of households, and in 14.4 % the assistance of another caregiver and a sibling (13.5 % reported another caregiver, sibling and additional help). "Other"

additional assistance was reported in 19.8 % of households. Table 8 details the sources of care giving assistance.

Table 8

Sources of Care giving Assistance

		Frequency	Percent
Valid	No outside help at all	5	4.5
	Other parent/partner	23	20.7
	Sibling	12	10.8
	Other	22	19.8
	Other parent/partner and sibling	16	14.4
	Other parent/partner and Other	11	9.9
	Sibling and Other	4	3.6
	Other parent/partner, Sibling and Other	15	13.5
Missing		3	2.7
	Total	111	100.0

Caregiving Assistance from Agencies. Of responding families, 35.1 % reported receiving some level of assistance from outside agencies (23.4 % “a little” and 11.7 % “a lot”); 62.2 % reported none. The number of care hours received weekly ranged

from 0 to 91 hours. Of the families receiving assistance from outside agencies ($n = 39$), the hours of care received ranged from 2 to 91 per week, with a mean of 25.03 and standard deviation of 21.35.

Gender of child. In 62% of households, the child with a disability was male, and was female in 36% of households.

Age of child. The average of the child with a disability was 13.33 ($SD = 4.29$), with a range of 4 to 23 years old.

Siblings with a disability. Eighteen percent of the respondents reported that, in addition to the child about whom they were responding, there was another child in the household with a disability as well.

Descriptive Analyses of the Continuous Variables

For continuous variables to be used in the analysis, skew and kurtosis of data were calculated to assess the extent to which the data distributions approximate expectations of normal distributions. Of the 111 participants, not all responded to each item of the packet; therefore, some degree of variance will be noted between totals of items recorded.

Problem Orientation. Scores on the SPSI-R:S, a self-administered measure of problem-solving orientation- positive and negative, were also found to be within the limits of normal distribution. Standard scores on the Positive Problem Orientation (PPO) ranged from 59 (Very Much Below Norm Group Average) to 131 (Very Much

Above Norm Group Average), with Mean of 97.82 (within Norm Group Average), Standard Deviation of 14.5. High standard scores on the PPO indicate positive or adaptive ways of viewing problems in daily living, and low scores the converse (D’Zurilla, Nezu, & Maydeu-Olivares, 2002). Negative Problem Orientation (NPO) was similarly varied. Standard scores ranged from 74 (Below Norm Group Average) to 141 (Extremely Above Norm Group Average), which references the range of Negative Problem Orientation, independent of the Positive Orientation score. High scores on the NPO indicate dysfunctional problem-solving orientation, and low scores indicate a more functional orientation. The Mean score was 98.67 (within Norm Group Average). Standard Deviation was 14.65. The descriptive data for scores on the Problem-Solving Orientation subscales of the SPSI-R:S are summarized in Table 9.

Table 9

Problem Orientation Scores

	PPO (Standard Score)	NPO (Standard Score)
N	105	105
Minimum	59	74
Maximum	131	141
Mean	97.82	98.67
Standard Deviation	14.5	14.65

Problem-solving Style. Scores on the SPSI-R:S also determine one of three problem-solving *styles* – RPS (Rational Problem-solving), ICS (Impulsive/Careless Style), and AS (Avoidant Style). Responses on the problem-solving style scales were found to be within the normal distribution in all cases. Standard scores on the RPS scale ranged from 60 (Very Much Below Norm Group Average, meaning very low “good” ability) to 128 (Above Norm Group Average, meaning better than average “good” ability), with Mean 98.22, (within Norm Group Average), Standard Deviation 14.15. ICS scores indicate high or low levels of “poor” or deficient problem-solving ability, and ICS standard scores ranged from 73 (Below Norm Group Average) to 145 (Extremely Above Norm Group Average). The Mean was 95.62 (within Norm Group Average), Standard Deviation 14.23. Standard scores on the AS scale (also a “deficient” indicator) ranged from 76 (Below Norm Group Average) to 145 (Extremely Above Norm Group Average), Mean 96.74, Standard Deviation 14.36. The descriptive data for scores on the Problem-solving Style subscales of the SPSI-R:S are summarized in Table 10.

Table 10.

Problem-Solving Style Scores

	RPS (Standard Score)	ICS (Standard Score)	AS (Standard Score)
N	105	105	105
Minimum	60	73	76
Maximum	128	145	145
Mean	98.22	95.62	96.74
Standard Deviation	14.15	14.23	14.36

Quality of Life. Scores on the WHOQOL-BREF, a brief self-administered measure of an individual's perception of his or her quality of life, were examined for characteristics of distribution. Scores were computed for each of the four domains -- physical, psychological, social and environmental. Scores on all four domains were normally distributed. All items of this scale are rated on a 5-point Likert-type scale ranging from "very poor" (0) to "very good/extremely" (3).

Respondents' scores on *Domain 1 (physical)* ranged from a minimum of 8 to a maximum of 35, with a Mean of 26.04, Standard Deviation was 5.35. Scores on *Domain 2 (psychological)* ranged from 8 to 29, Mean of 21.67, Standard Deviation 4.434. *Domain 3 (social)* scores ranged from 3 to 29, with a Mean 9.99, and Standard Deviation 2.54. Respondents' scores on *Domain 4 (environmental)* ranged from 16 to 39, Mean 28.65, Standard Deviation 5.36.

The descriptive data for scores on the Quality of Life measure (WHOQOL-BREF) are summarized in Tables 11.

Table 11

Quality of Life (WHOQOL-BREF) Scores					
	Domain 1 (physical)	Domain 2 (psychological)	Domain 3 (social)	Domain 4 (environmental)	TOTAL
N	106	108	106	108	104
Minimum	8	8	3	16	42
Maximum	35	29	15	39	121
Mean	26.04	21.67	9.99	28.65	93.75
Standard Deviation	5.35	4.43	2.54	5.36	15.28

Family Impact of Childhood Disability. The minimum Family Impact of Childhood Disability (FICD) Positive score was 13; the maximum was 40; Mean was 28.57, Standard Deviation 5.93. All items both of positive and of negative subscales are rated on a 4-point Likert-type scale ranging from “*not at all*” (1) to “*to a great degree*” (4). The descriptive data on FICD scores, both Positive and Negative, are summarized in Table 12

Table 12

Family Impact (FICD) Scores

	FICD Positive	FICD Negative
N	109	109
Minimum	13	10
Maximum	40	40
Mean	28.57	27.29
Standard Deviation	5.93	7.65

Child Behavior. Scores on the Nisonger CBRF, a parent-administered measure of positive social and challenging (problem) behaviors, were examined for characteristics of distribution and were found to be within the normal limits. Positive scale scores ranged from 0 to 27, with Mean, 14.62, Standard Deviation, 6.11. Problem scale scores ranged from 0 to 130, Mean, 38.64, Standard Deviation, 28.67. The descriptive data for scores on the Nisonger CBRF are summarized in Table 13.

Table 13

Nisonger CBRF Scores

	NCBRF Positive	NCBRF Problem
N	108	109
Minimum	0	0
Maximum	27	130
Mean	14.62	38.64
Standard Deviation	6.11	28.67

Statistical Analysis of the Research Hypotheses

Hypothesis 1: Hypothesis 1 stated that there would be a positive correlation between individuals' scores on the Positive Problem Orientation (PPO) scale of the SPSI-R:S and quality of life scores (QOL) on the WHOQOL-BREF. This hypothesis was supported across all four domains of the WHOQOL-BREF. The correlations ranged from $r = .21$ ($p < .04$) of Domain 1 (physical) to $r = .41$ ($p < .00$), of Domain 2 (psychological). The Pearson Correlations between PPO and QOL scores are shown in Table 14.

Table 14

Pearson Correlations Between PPO and QOL Scores

		Domain 1 (Physical)	Domain 2 (Psychol.)	Domain 3 (Social)	Domain 4 (Environ.)
PPO (Std. Score)	Pearson Correlation	.21(*)	.42(**)	.25(*)	.22(*)
	Sig. (2-tailed)	.04	.00	.01	.67
	N	103	104	102	104

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Hypothesis 2: Hypothesis 2 stated that there would be a negative correlation between individuals' scores on the Negative Problem Orientation (NPO) scale of the SPSI-R:S and quality of life scores (QOL) on the WHOQOL-BREF. This hypothesis was also supported across all four domains of the WHOQOL-BREF. The correlations ranged from $r = -.26$ ($p < .01$) of Domain 3 (social) to $r = -.54$ ($p < .00$), of Domain 2 (psychological). The Pearson Correlations between NPO and QOL scores are shown in Table 15.

Table 15

Pearson Correlations Between NPO and QOL Scores

		Domain 1 (Physical)	Domain 2 (Psychol.)	Domain 3 (Social)	Domain 4 (Environ.)
NPO (Std. Score)	Pearson Correlation	-.46(**)	-.54(**)	-.26(*)	-.27(**)
	Sig. (2-tailed)	.00	.00	.01	.01
	N	103	104	102	104

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Hypothesis 3: Hypothesis 3 stated that there would be a positive correlation between individuals' scores on the Rational Problem-solving (RPS) scale of the SPSSI-R:S and quality of life scores (QOL) on the WHOQOL-BREF. This hypothesis was supported only in Domain 2 (psychological). Pearson $r = .24$ ($p < .02$). There were no significant correlations with the other 3 scales. The Pearson Correlations between RPS and QOL scores are shown in Table 16.

Table 16

Pearson Correlations Between RPS and QOL Scores

		Domain 1 (Physical)	Domain 2 (Psychol.)	Domain 3 (Social)	Domain 4 (Environ.)
RPS (Std. Score)	Pearson Correlation	.06	.24(*)	.05	.11
	Sig. (2-tailed)	.57	.02	.60	.27
	N	103	104	102	104

* Correlation is significant at the 0.05 level (2-tailed).

Hypothesis 4: Hypothesis 4 stated that there would be a negative correlation between individuals' scores on the Impulsive/Careless (ICS) scale of the SPSI-R:S and quality of life scores (QOL) on the WHOQOL-BREF. This hypothesis was supported only in Domain 2 (psychological). Pearson $r = -.212$ ($p < .03$). There were no significant correlations with the other 4 scales. The Pearson Correlations between ICS and QOL scores are shown in Table 17.

Table 17

Pearson Correlations Between ICS and QOL Scores

		Domain 1 (Physical)	Domain 2 (Psychol.)	Domain 3 (Social)	Domain 4 (Environ.)
ICS (Std. Score)	Pearson Correlation	-.13	-.21(*)	-.05	.01
	Sig. (2-tailed)	.19	.03	.63	.92
	N	103	104	102	104

* Correlation is significant at the 0.05 level (2-tailed).

Hypothesis 5: Hypothesis 5 stated that there would be a negative correlation between individuals' scores on the Avoidant Style (AS) scale of the SPSI-R:S and their quality of life scores (QOL) on the WHOQOL-BREF. This hypothesis was supported in all domains except Domain 3 (social). The physical domain (1) showed the most robust correlation ($r = -.31$, $p < .00$). The Pearson Correlations between AS and QOL scores are shown in Table 18.

Table 18

Pearson Correlations Between AS and QOL Scores

		Domain 1 (Physical)	Domain 2 (Psychol.)	Domain 3 (Social)	Domain 4 (Environ.)
AS (Std. Score)	Pearson Correlation	-.31(**)	-.30(**)	-.03	-.20(*)
	Sig. (2-tailed)	.00	.00	.75	.05
	N	103	104	102	104

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Hypothesis 6: Hypothesis 6 stated that there would be a positive correlation between individuals' scores on the Positive Problem Orientation (PPO) scale of the SPSI-R:S and scores on the FICD scale, with participants endorsing (a) more positive and (b) fewer negative items. This hypothesis was not supported. There was no significant correlation in participants endorsing either more positive items ($r = .05$, $p < .61$, 2-tailed, $N = 101$), or fewer negative items ($r = .09$, $p < .35$, 2-tailed, $N = 101$).

Hypothesis 7. Hypothesis 7 stated that there would be a negative correlation between individuals' scores on the Negative Problem Orientation (NPO) scale of the SPSI-R:S and scores on the FICD scale, with participants endorsing (a) fewer positive and (b) more negative items. This hypothesis was not supported. There was no significant correlation in participants endorsing either fewer positive items ($r = .01$, $p < .92$, 2-tailed, $N = 104$), or more negative items ($r = .11$, $p < .27$, 2-tailed, $N = 104$).

Hypothesis 8. Hypothesis 8 stated that there would be a positive correlation between individuals' scores on the Rational Problem-solving (RPS) scale of the SPSI-R:S and scores on the FICD scale, with participants endorsing (a) more positive and (b) fewer negative items. This hypothesis was not supported. There was no significant correlation in participants endorsing either more positive items ($r = -.00, p < .99$, 2-tailed, $N = 104$), or fewer negative items ($r = .19, p < .06$, 2-tailed, $N = 104$).

Hypothesis 9. Hypothesis 9 stated that there would be a negative correlation between individuals' scores on the Impulsive/Careless problem-solving (ICS) scale of the SPSI-R:S and scores on the FICD scale, with participants endorsing (a) fewer positive and (b) more negative items. A small negative correlation was supported between (a) ICS and FICD in the positive direction ($r = .22, p < .02, N = 104$), but none was supported between (b) ICS and FICD in the negative direction ($r = .04, p < .71, N = 104$).

Hypothesis 10. Hypothesis 10 stated that there would be a negative correlation scores on the FICD scale, with participants endorsing (a) fewer positive and (b) more negative items. This hypothesis was not supported. There was no significant correlation in participants endorsing either fewer positive items ($r = .10, p < .89$, 2-tailed, $N = 104$), or more negative items ($r = .02, p < .86$, 2-tailed, $N = 104$).

Additional Analyses

Tests of Mediation. Because a child's behavior has been shown to impact a family or caregiver in myriad ways, from positive, supportive behavior (e.g. Hastings & Taunt, 2002; Heller, Miller, & Factor, 1997) to challenging behaviors, positively correlated with depression in mothers (Hong & Seltzer, 1995), and stress from embarrassment and social isolation (e.g. Cohen, Gottlieb, & Underwood, 2001; Qureshi, 1990), it was considered that this might impact parents' perception of their quality of life, independent of their levels of problem solving abilities. In other words, if both problem solving variables and quality of life are correlated with child behavior, the possibility that child behavior might mediate the relationship with problem solving skills and quality of life was to be tested. Perhaps even those caregivers with good problem solving skills perceive quality of life diminished by their child's behaviors, or those with poor skills and helpful children perceive an enhanced quality.

Likewise, however, the correlation between child behaviors and quality of life might be mediated by a parents' problem solving skills because, in the first place, those skills impacts a child's behavior significantly (e.g. Beresford, 1994; Baker et al., 2003; Vuccinich, 1999).

The first step was to identify correlations between initial and outcome variables. Both positive and negative problem orientations were significantly correlated with all four domains of perceived quality of life (Hypotheses 1 and 2). Of the problem solving styles, Avoidant style (Hypothesis 5) was correlated with three

QOL domains, and both rational Problem Solving and Avoidant styles were correlated only with the psychological domain (Hypotheses 3 and 4). A small negative correlation was found between Impulsive/Careless style and the positive FICD subscale (Hypothesis 9a).

The second step was to determine if a correlation existed between the study variables and the proposed mediating variable. The only significant correlation between any of the variables and the mediating variable is that of Quality of life (all four domains). Only small correlations which bordered on significance were noted between the problem behavior subscale and both NPO and ICS. Had there been significant correlations found at this point, the third step would have been to perform a regression analysis, entering those initial variables which did correlate with the proposed mediating variable.

However, lacking the correlations, step three was not completed. Although scores on the problem behavior subscale are negatively correlated with quality of life scores, they are not significantly correlated with any of the initial (problem solving) variables. Thus, there would be no mediation in any of the four cases. Although the initial variable and the NCBRF-problem are correlated with QOL, they do so independently of each other, and do not rely on each other in any way. The Pearson Correlations between the other variables and NCBRF Problem scale scores are shown in table 19.

Table 19

Pearson Correlation Between NCBRF and Variables of Study		
		NCBRF Problem
PPO (Standard Score)	Pearson Correlation	.02
	Sig. (2-tailed)	.81
	N	104
NPO (Standard Score)	Pearson Correlation	.17
	Sig. (2-tailed)	.08
	N	104
ICS (Standard Score)	Pearson Correlation	.17
	Sig. (2-tailed)	.09
	N	104
AS (Standard Score)	Pearson Correlation	.04
	Sig. (2-tailed)	.72
	N	104
FICD Positive Total	Pearson Correlation	-.06
	Sig. (2-tailed)	.55
	N	108
QOL – Domain 1 (Physical)	Pearson Correlation	-.29(**)
	Sig. (2-tailed)	.00
	N	105
QOL – Domain 2 (Psychological)	Pearson Correlation	-.25(**)

Table 19, Cont'd.

Pearson Correlation Between NCBRF and Variables of Study		
	Sig. (2-tailed)	
	N	107
QOL – Domain 3 (Social)	Pearson Correlation	-.36(**)
	Sig. (2-tailed)	.000
	N	105
QOL – Domain 4 (Environmental)	Pearson Correlation	-.24(**)
	Sig. (2-tailed)	.014
	N	107

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

Chapter 4

Discussion

Care giving literature is replete with associations between the stress of ongoing care giving and a myriad of negative outcomes; these occur on the individual caregiver and, by extension, on the care recipient, and on the entire family of which they are a part. Historical models of care giving are often predicated on assumptions of stress, or burden-bearing, and as such, employed instruments which equated stress with pathology as a matter of course.(???) This indeed is a very real part of the care giving picture. The current study in no respect seeks to deny the existence of, in some cases, extreme hardships endured as a consequence of unrelenting vigilance and skills (behavioral, medical, custodial) required on a daily basis with limited, or no outside assistance or support, and occurring often in single-parent families with other severe stressors. These situations do exist, in spite of the best efforts of legislation, agencies and private organizations to improve the lot of family care givers in this country.

There is wide variety along continuums of severity on a number of factors pertaining to these children with disabilities – continuums of behavioral difficulties, both internalizing and externalizing, and sometimes extreme; continuums of the severity of medical care needed, including portable life-support monitoring and equipment; continuums of seizure frequency and intensity, even 100 in a single day; medical conditions which include long periods of sleeplessness, even for days; continuums of frequency and duration of hospital stays, long-distance medical

treatments, diagnostics and consultation; continuums of available resources, including financial, environmental, and respite; of available support – emotional, practical, social; of degrees of physical health; and even continuums of difficulty with regard to accessing and interacting with service agencies, school systems and other bureaucracies involved in the child's care. One father wrote: "I have profound respect for my wife and her ability to negotiate the system in seeking and finding services for our son, and being able to retain, collate and disseminate the vast amount of information that one encounters." Frustrations abound with "the time [required] to call and speak with caseworkers, behavior specialists, communicate with teachers, file insurance claims, re-authorize Medical Assistance cards, submit FSS (reimbursement program) documentation, doctor visits, etc." Adequately summed, "balancing time, energy and finances often feels like walking a tightrope."

Other parents articulated hardship:

"People do not realize how hard it is to have a child with a disability. I take my son to four therapies a week. My husband works 11 hours a day so that I can work part-time to care for my son. . ."

". . . I have to lock refrigerator and cupboards, and to sleep on the downstairs sofa to prevent damage, or his escape."

One mother noted that her son had "broken my washer, lawnmower, computer, and tried to burn my house down." Another detailed all manner of violence perpetrated on family members, property and those in the community.

A single mother wrote: “It’s hard. To find a better place to live. It’s hard to look forward to a year when your child won’t spend several days or weeks in a hospital . . . it’s hard to hold a job, because there are days when your child gets sick in school and you have to pick him up. You can’t ever go out unless the weather is perfect . . . never when it’s raining.”

Over 20 years of experience in this field with these families has afforded this researcher the opportunity to interact with a wide variety of caregivers of children with physical, emotional and cognitive disabilities, and to observe firsthand the range of possible situations and responses. Extreme obstacles in some instances are faced with composure and courage. Yet in others, relatively minor intrusions spark extreme responses. A preponderance of research studies have confirmed the pervasive influence of an individual’s perception, as well as a host of personality, resource and coping skill factors, in mediating their vulnerability to the cumulative impact of stressors in their lives. Although earlier research was designed with assumptions of care giving experiences as burdensome and stressful, more recent explorations have acknowledged positive experiences and outcomes, even concurrent with the negative, as separate and independent constructs. Family responses articulated this as well:

“Having a disabled child has been a God-sent blessing...I wouldn’t change her, she’s perfect the way she is!”

“He is the most lovable child you’d ever want to meet. He does not have one mean bone in his body. He smiles all the time.”

“We consider our son a gift from God and feel privileged to be his parents . . . we do not feel that he is a burden. He is our joy in life!”

“She makes strangers smile; she loves most people and is an amazing person.”

Vulnerability to the cumulative impact of stressors in one’s life is mediated by a host of variables – physical health and health behaviors, degrees of social support, financial status, socioeconomic factors, personal beliefs and ideologies, personality factors, cognitive factors, and by the coping strategies they typically employ. These factors also influence coping style and success, as do an individual’s beliefs about locus of control, previous coping experience, parenting skills, and problem-solving skills.

Antonovsky (1993) advocated replacing the historical focus on pathogenesis with a salutogenic orientation, moving from the concept of risk factors to a consideration of salutary factors and the impact of these on the outcome of challenging events. In addition to the idiosyncracies of their individual situations, it is important to emphasize the fact that many of these families have just as much in common with mainstream families as with each other, and that they are concurrently managing the vagaries of typical family life (Ferguson, 2002).

Problem-solving has emerged as a consistent factor in the mitigation or exacerbation of difficult situations, and this is no less true in the lives of parents who manage the challenges of raising a child with a disability. Problem-solving deficits have been linked with numerous physical, psychological and situational outcomes of negative quality and increased distress. Conversely, effective problem solvers have

demonstrated enhanced physical, psychological, and general well-being.

The present study was designed to examine the association between problem-solving orientation, problem-solving style, quality of life, perception of impact on the family of the child's disability, and the potential of the child's behavior to mediate any correlations found.

Consistent with prior research, problem solving variables were indeed correlated with a higher quality of life perceived by the responding caregiver, as evidenced by higher scores on subscales of the self-report quality of life measure. This was true both for positive and for negative problem *orientations* across all of the domains, for all three of the problem solving *styles* on the psychological domain, and for the Avoidant Style (AS) across three of the four domains (physical, psychological and environmental – excepting only the social domain).

Hypothesis 1. The first hypothesis was developed to operationalize the association between Positive Problem Orientation (PPO) and quality of life, as expressed by scores on self-report inventories. This hypothesis was supported. Caregivers with higher scores on the PPO measure scored higher on all four domains of the quality of life measure, and conversely those with lower scores on the PPO measure scored lower on all four domains of the quality of life measure. This correlation was most robust with the psychological domain ($r = .42$) and less so with the social ($r = .25$), environmental ($r = .22$), and physical ($r = .21$) domains. This is consistent with prior research. Higher positive orientation has been associated with lower depression scores among caregivers of women with physical disabilities

(Rivera, et al., 2006), with better adjustment over time in families of children having suffered traumatic brain injury (Rivara, et al., 1996), and with more adaptive wellness and accident prevention behaviors (Dreer, Elliott, and Tucker, 2004). The correlations were positive as predicted and all were of significance.

Hypothesis 2. The second hypothesis assessed the correlation between negative Problem Orientation (NPO) and quality of life, as expressed by scores on the self-report inventory. This hypothesis was also supported. Care givers with higher scores on the NPO measure scored lower on all four domains of the quality of life measure, and those with lower scores on the NPO measure scored higher on all four domains of the quality of life measure. The correlations were most robust with the psychological ($r = -.54$) and physical ($r = -.46$) domains, and less so with the environmental ($r = -.27$) and social ($r = -.26$) domains. All of the correlations were negative as predicted, and were significant. Thus, negative problem orientation, as shown by extant research and confirmed by this study, is negatively correlated with a caregiver's expressed quality of life (all domains) on a self-report measure. A study by Grant, et al. (2006) was able to distinguish between variables of the problem-solving process (PPO, RPS, NPO, IS, ICS) in order to identify negative orientation as being primarily responsible for the association between problem-solving and depression and well-being in caregivers of stroke survivors.

Grant, Elliott, Weaver, Bartolucci and Giger (2002) associated a greater negative orientation with a low sense of preparation for care giving roles in family members; this is also true with stroke survivors. Rivera, Elliott, Berry and Grant

(2008) noted specifically that decreases in caregiver depression and health complaints were associated with decreases in dysfunctional problem-solving styles; however, for constructive problem-solving styles, there were no significant effects.

Positive and negative problem orientations, by definition, are not two opposites of the same continuum, but separate and independent constructs. Interestingly enough, the correlations between NPO and QOL domains were much more robust than those between PPO and quality of life domains. A number of studies have found the absence of the negative to be more significant than the presence of the positive in this regard: on caregiver depression rates; (Dreer, Elliott, Shewchuk, Berry and Rivera, 2007; Elliott, Shewchuk, and Richards, 2001; Rivera, Elliott, Berry, Grant and Oswald, 2007); on caregiver life satisfaction and depression (Kurylo, Elliott, DeVivo and Dreer, 2004; Rivera, Elliott, Berry, Shewchuk and Oswald, 2006); on caregiver depression, anxiety and health complaints (Elliott, Shewchuk, Richards, 2001; Rivera, Elliott, Berry, and Grant, 2008); and on caregiver physical and mental health, social functioning and vitality (Elliott and Shewchuk, 2003). Although Rivera, et al. (2006) determined that higher PPO (and RPS) scores were significantly associated with lower depression scores among caregivers of women with physical disabilities, only higher NPO scores were associated with lower mental/social functioning and life satisfaction scores.

All problem solving variables (both orientations and styles) were most strongly correlated with the psychological domain than with any other. This is consistent with

problem solving research, in which problem solving variables are correlated with psychological distress by various measures (depression, hopelessness, anxiety, suicidal ideation, self-control, self esteem, etc.) and also by numerous researchers (Carver & Scheirer, 1999; Chang & D’Zurilla, 1996, D’Zurilla, Chang & Sanna, 2003, etc.).

It is suggested that an elevated negative orientation may override the beneficial aspects of more adaptive problem-solving abilities, confirming the influence of NPO in the overall constellation (Elliott, Shewchuk, Miller and Richards, 2001). Individuals with dysfunctional problem-solving scores benefited to a more significant degree than did those with more constructive problem-solving profiles in problem-solving intervention studies, with a decrease in NPO attributable to improved outcomes more so than to improvement in PPO (Grant, Elliott, Weaver, Bartolucci, and Giger, 2002; Rivera, Elliott, Berry and Grant, 2008; Sahler, et al., 2005).

Hypothesis 3. The third hypothesis assessed whether or not there was a correlation between a Rational Problem-solving (RPS) style and caregiver quality of life. This hypothesis was marginally supported, with a small correlation with the psychological domain ($r = .24$). It has been noted that problem orientation, in particular negative problem orientation, is the factor of primacy in determining outcomes related to problem-solving skills. RPS, as the most functional of the problem-solving styles, was expected to be significantly correlated with quality of life in all domains. Research results are inconsistent in this regard. Although this lack of correlation was also found in other studies (Kurylo, Elliott, DeVivo, and Dreer, 2004;

Elliott and Shewchuk, 2003; Elliott, Shewchuk, and Richards, 2001), these others did identify positive contributions of the RPS style, but not with regard to well-being or quality of life. For instance, Rivera, et al., (2006) identified RPS with lower depression scores among caregivers, but not with mental/social functioning or life satisfaction scores. It should be noted that this study did not distinguish between those individuals with RPS (style) and NPO (negative orientation), as opposed to those with RPS and PPO (positive orientation). It is possible that a more negative orientation and expectation will override the more beneficial qualities of more adaptive constructive problem-solving skills (Elliott, Shewchuk, Miller, and Richaards, 2001).

Hypothesis 4. The fourth hypothesis assessed whether or not there was a correlation between an Impulsive/careless style (ICS) of problem-solving and caregiver quality of life. This hypothesis was also supported in only the psychological domain ($r = -.21$). Here also, inconsistencies are evident in the research. A number of studies have found no correlation with any problem-solving style on study variables such as caregiver depressive behavior, anxiety, and health complaints (Elliott and Shewchuk, 2003; Elliott, Shewchuk, and Richards, 2001), yet others have found correlations between this less functional styles and poorer outcomes, including poorer quality of care for the recipient in care giving situations (Elliott, Shewchuk, and Richards, 1999; Kurylo, Elliott, DeVivo, and Dreer, 2004). This is the second of the three problem solving styles to be correlated only in the domain of psychological health,

Hypothesis 5. The fifth hypothesis assessed whether or not there was a correlation between an Avoidant style (AS) of problem-solving and caregiver quality of life. This hypothesis was supported in three of the four domains – physical ($r = -.31$), psychological ($r = -.30$) and environmental ($r = -.20$). It joins the other two problem solving styles in being correlated with the psychological domain, in addition to correlations with the physical and environmental domains – the sole problem solving *style* to do so.

Several previous studies have found a lack of contribution by problem-solving styles to outcome variables (Elliott and Shewchuk, 2003; Elliott, Shewchuk, and Richards, 2001). In general, the problem-solving styles have been shown to be of less import in influencing outcomes than their orientation counterparts, as the cited studies have deduced. However, in the case of AS, some researchers found it specifically correlated (along with NPO) in negative outcomes such as caregiver depression (Dreer, Elliott, Shewchuk, Berry, and Rivera, 2007); however, others found it specifically correlated (also along with NPO) with *higher* caregiver life satisfaction (Rivera, et al., 2006). Perhaps individuals with negative orientation find more relief in avoiding problems than in approaching them with the haste and carelessness hallmark of the ICS style, addressed above. With the entire set of problem solving styles, however, correlations were found with the psychological domain of the quality of life measure, which illustrates the contribution of the cognitive components inherent in problem solving theory and measurement, and reinforces the correlations between problem solving abilities and psychological attributes reviewed in Chapter 1.

Problem solving skills are an important component of the cognitive behavioral skill package with which an individual approaches and lives his or her everyday life, and chooses courses of action which, subsequently, will impact his or her future and quality of life. How individuals perceive a problem situation, the attributions and assumptions through which they appraise the situation, the degree of perceived control and competence, and their willingness to invest time and effort into the work of successful resolution and outcome assessment, are influenced by their problem solving orientation, as well as, to some degree, their problem solving styles. Most especially, the psychological domain of the QOL measure is correlated with all five of the problem solving variables.

Much has been said, both in this manuscript and elsewhere, of the pervasive influence of perception on the experience, actions, and subsequent outcomes of individuals and their problem-solving contexts. The first 5 hypotheses have indicated, an agreement with the majority of reviewed research, indicating that an individual's problem-solving *orientation* is of paramount importance in influencing his or her perception of quality of life, with the absence of the negative demonstrating stronger correlation than the presence of the positive. Shewchuk, Johnson, and Elliott (2000) posited the theory that the information processing aspects of problem orientation may render individuals with negative appraisals less able to encode new information, or less flexible in times of stress and challenge.

Hypotheses 6 through 10 examined the relationships between problem-solving

components (orientations and styles) and a caregiver's perception of the impact of the child's disability on the family.

Hypothesis 6. The sixth hypothesis of this study sought to ascertain whether or not a correlation existed between PPO and caregiver perception of family adjustment to the child's disability, by virtue of positively and negatively valenced items on a self-report measure (FICD). This hypothesis was not supported. There was no correlation found, either with (a) the positively valenced scale or (b) with the negatively valenced scale.

Hypothesis 7. The seventh hypothesis assessed whether or not there was a correlation between an NPO and FICD. This hypothesis was not supported; there was no significant correlation, either with (a) the positively valenced scale or (b) with the negatively valenced scale.

Hypothesis 8. Hypothesis 8 assessed potential correlations between RPS style of problem-solving and FICD. This hypothesis was not supported; there was no significant correlation, either (a) with the positively valenced scale or (b) with the negatively valenced scale.

Hypothesis 9. Hypothesis 9 assessed potential correlations between ICS style of problem-solving and FICD. In relation to the positively valenced scale of the FICD, a small correlation was found between (a) ICS and FICD, *in the positive direction*. No correlation was found between ICS and FICD in the negative direction. It is possible that the consequences of an impulsive, careless style of problem-solving behaviors predispose individuals to cumulative outcomes of hasty decision making in a fashion

which uniquely impacts their perceptions of the positive impact of the child with a disability on the family.

Hypothesis 10. Hypothesis 10 assessed potential correlations between AS style of problem-solving and FICD. This hypothesis was not supported; there was no significant correlation, either (a) with the positively valenced scale or (b) with the negatively valenced scale.

Hypotheses 6 through 10 examined the relationships between problem-solving components (orientations and styles) and a caregiver's perception of the impact of the child's disability on the family, as measured by the FICD. With the exception of those scoring higher on the ICS scale of the problem-solving measure, scores on no other components of this problem-solving model (orientations or styles) correlated with scores either on positive or on negative scales of the FICD. Perhaps the factors impacting a caregiver's perception of the impact of his or her child's disability on the family are even more complex than anticipated, or the particular items of the FICD measure tap constructs which are not as readily impacted by problem-solving variables. All caregivers, regardless of problem-solving orientation and skills, may perceive both hardship and blessing in the responses of the family to their children's disabilities; perhaps in different ways, means, or degree, which may not be reflected in this particular instrument.

Additional Analyses

In the cases of the four hypotheses in which correlations between study variables were found, further correlations determined that there was no mediating effect of child behavior, as reflected on the Nisonger CBRF measure. Although there was a correlation between child behavior scores and caregiver quality of life scores, this was independent of the cases in which study variables (PPO, NPO, AS) were also correlated with quality of life scores. Child behaviors were not correlated with FICD scores, and thus would not mediate the sole correlation (hypothesis 9a) between a problem-solving variable (ICS) and scores on the positively valenced scale of the FICD. Prior research validates the correlation between the degree and valence of a child's behavior on the quality of life of a caregiver and indeed of the entire family (Baker et al., 2003; Hodapp, Ricci, Ly, and Fidler, 2003; Ricci and Hodapp, 2003). Although this study also concurs with that correlation, it was nonetheless not found to mediate any of the correlations between problem-solving and quality of life, or between problem-solving and family impact, the variables of this study.

Clinical Implications

Problem orientation consistently emerges as a primary factor in care giving research. Of the aspects of social problem-solving theory, problem orientation, or the cognitive-emotional set determining how an individual perceives presenting problems,

has been significantly correlated with a number of factors influencing caregiver health, as well as the quality of care that the individual renders. The presence of a negative orientation, even more so than the presence of positive orientation, has been implicated in most of those studies, illustrating the adage of the absence of negative trumping the presence of positive. It has also been demonstrated to be responsive to treatment models aimed at improving problem orientation in this manner (Malouff, Thorsteinsson, and Schutte, 2005). Reducing negative orientation in particular is important in caregiver populations because of the impact on care recipients (Kurylo, Elliott, DeVivo, and Dreer, 2004; Kurylo, Elliott, and Shewchuk, 2001), and because it will leverage the ability of the caregiver to provide that care over time.

Problem-solving training has been effective in decreasing caregiver depression, health complaints, and dysfunctional problem-solving styles (Kurylo, Elliott, and Shewchuk, 2001; Rivera, Elliott, Berry, and Grant, 2008; Sahler, Fairclough, Phipps, Mulhern, Dolgin, Noll, et al., 2005), and in reducing mental and physical health problems in the general population (Malouff, Thorsteinsson, and Schutte, 2007). It has been shown to be effective in varied settings as well, including interventions by telephone (Grant, Elliott, Weaver, Bartolucci, Giger, and Newman, 2002), by video-conferencing (Elliott, Brossart, Berry, and Fine, 2008), and by online problem-solving intervention (Wade, Carey, and Wolfe, 2006). It is effective across ethnic groups, with one study reporting even greater benefits to Spanish-speaking mothers than to their English-speaking counterparts (Sahler, et al., 2005).

The success of problem-solving interventions further documents the usefulness of cognitive-behavioral strategies and beliefs that leverage adjustment both in routine and in stressful situations. Because the Problem Solving Inventory used in this study was originally designed in keeping with the more recent focus on positive psychology (or the study of what *works*), so also might the approach to interventions with caregivers focus on the improvement of quality of life by strengthening positive skills in conjunction with the decrease in negative habits and outlooks.

Problem-solving interventions hold promise for increasing quality of life for caregivers and, by extension, for their care recipients, perhaps most dramatically in the case of decreasing negative orientation, but in addition by enhancing positive orientation for the psychological benefits of a more positive, hopeful approach.

Limitations

This research was limited to caregivers of children with developmental disabilities, without distinction between the myriad of care giving variables, such as the presence or absence of severe medical conditions and medical monitoring needs, the degree of family support and respite time afforded a caregiver, or the degree of perceived support from professional staff (school, medical, case management), all of which present in this population. Medical conditions of caregivers, financial or employment stressors, marital problems, or other family crises were not factored into

the results and could, of course, impact perceptions of one's quality of life; another family member's disability could also become an impacting factor.

The limitation inherent in the use of correlational research is that causal assumptions cannot be made; there are only determinations of strength and directionality of correlations.

Participants were self-selected, by the definition of a survey process. Thus, individuals who cannot read, or who are burdened to the point of being unable to participate are under-represented. Responses were limited to one caregiver per household. To have mailed two survey packets per household may have been more insightful, and perhaps encouraged the participation of more fathers.

Future Research

Future research will hopefully contribute to the current level of understanding of the clinical relevance of the style components of the social problem-solving model, and also to the preponderance of evidence in support of the relevance of orientation components; this research will also hopefully contribute to enhance understanding of the mechanisms by which the various aspects of problem solving interact, and the relationship of these various components to the therapeutic process of successful intervention. Research is necessary with caregiver groups determined by age of the cared-for child, and separately, over time, because the child's diagnosis could provide glimpses into the trajectory through which families move over time. Additionally,

focus on the type of diagnosis given the child would further distinguish between categories which were of necessity considered together in this study (e.g. autism, mental retardation, physical disabilities, etc.).

Working directly with this caregiver population, future research could promote proactive interventions with proven efficacy, to leverage the health and well-being of caregivers in the variety of situations in which they are found, as well as to inform policy to maximize the ability of caregivers to function well over time. Longitudinal studies with families receiving such intervention could document its impact on future service needs and the quality of life for caregivers, recipients, and family members (e.g. siblings) over time. Any changes in efficacy pertaining to the timeliness of intervention (i.e. from time of birth or diagnosis, or at a later point in the child's and family's processes of adjustment) could be noted as well. Research into potential correlations between early intervention with caregivers and the degree of service utilization over time may perhaps determine whether or not an impact has been had on the amount of services needed in families with carrying competence (???) in the problem solving arena and if that quality of life for caregivers, recipients, and family members over time might translate into proactive resource allocation to minimize later institutional (or group home) placements and other service expenditures.

Perhaps most importantly, research may continue with renewed focus on the *positive* – on positive aspects of change and adjustment, on those who function *well* amid critical situations and in recurrent medical crises. Positive problem orientation and effective problem solving skills may be an important part of this distinction;

nurturing the development of effective problem solving skills may prevent hardship and distress on the part of those grappling with deficiencies in these areas. But there will be other distinctions which come to light as well, and this population of caregivers is a perfect example of the power of perception to flavor outcomes and efforts in situations regarded by many as inherently problematic.

The outcome of successful adjustment to the caregiving for a loved one is adequately summed by a parent responder:

“We feel our exceptional child is a gift. He has changed our family for the better in our capacity to love, accept and in tolerance. The limitations that accompany a disabled child have changed our views on many levels in life, such as society, success, progress, rejection, abilities, creativity, and problem-solving.”

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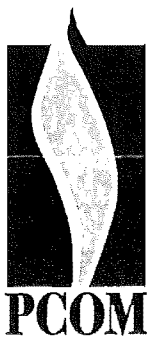
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APPENDICES

Appendix A

Introductory Letter to Participants



PHILADELPHIA · COLLEGE · OF · OSTEOPATHIC · MEDICINE

DEPARTMENT OF PSYCHOLOGY
215-871-6442
215-871-6458 FAX
psyd@pcom.edu E-MAIL

Dear Parent/Caregiver:

We are currently conducting a study on the experience of parenting a child with developmental disabilities, and the impact on family and caregiver quality of life. As a parent/caregiver of such a child, your input will be helpful in addressing concerns of families and caregivers of children with disabilities. **If you choose to participate, please complete the enclosed survey items, and return them in the enclosed envelope within two weeks.** Completion time for the survey material will be at most, 30 minutes.

Packets are being mailed to random families with children involved with the MR Children's Unit of Northampton County, with a return process that is entirely anonymous. Your participation in this study is voluntary and you may decide not to participate or to stop your participation at any point in time with no consequences to you. Some items in the enclosed questionnaires ask about feelings, thoughts, beliefs, and behaviors – very personal information. Some individuals may experience this as upsetting or uncomfortable. In addition, you may find that you are reminded of something, which could be experienced as upsetting or uncomfortable. Should either of these conditions occur, please refer to the attached list of resources and contacts, or feel free to contact either of the researchers for a list of referrals in your area. While several of the questions may appear unrelated to our study topic, these surveys were developed outside the researchers' control and cannot be altered by us.

If you are interested in the results of our study as a whole, you may contact the investigators for a synopsis of the results at completion. With any questions or concerns, please feel free to contact the researcher, Bonita Fisher or principal investigator, Dr. Stuart Badner, at the numbers below.

Thank you in advance for your willingness to participate in this important study. Your participation will not only contribute to the fund of knowledge regarding the complexities of raising a child with developmental disabilities, but may be useful in further research and program development.

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PCOM, Department of Psychology
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Philadelphia, Pa. 19131

Stuart Badner, Psy. D.
Clinical Assistant Professor, Dissertation Chair
PCOM, Department of Psychology
(570.856.1875)

Appendix B

List of Resources for Parents of Children with Developmental Disabilities

RESOURCE LIST

For mental health emergencies (when someone feels like harming themselves or another):

NORTHAMPTON COUNTY Crisis: 610.252.9060

LEHIGH COUNTY Crisis: 610.782.3127

For times when it's not quite a crisis, but you want to talk to someone, 24 hours/day, 7 days/week

WARM LINE: 610.820.8549/8451

Really good online resource directory – for county crisis and other services, as well as some helpful links for basic service needs:

<http://hopehouse-rhd.org/LehighValleyResourceDirectory/CrisisResponse1.html>

Additional online resources:

The ARC (Advocacy and Resources for Citizens) – an organization dedicated to Supporting families of individuals with a disability: <http://www.thearca.org>
(Lehigh-Northampton chapter, direct = <http://www.arcofl-n.org/who/index.html>)
Special note: The ARC hosts a Family Resource Center with free internet access–
610.849.8076.

SEAS (Support and Education for Asperger's Syndrome, Lehigh Valley) -
<http://www.seas-pa.org/seas-content.html>

Parent-to-Parent of Pennsylvania – created “by families for families” of children and adults with special needs” – including a parent-to-parent support option:
<http://www.parenttoparent.org>

Links specific to Autism: <http://www.autismlink.com/locations/view/39>
<http://www.autism-society.org/site/PageServer>
<http://www.aboard.org/aboard/default.asp?id=57&menu=sub11>

<http://www.elc-pa.org/disabilities/disabilities.html>

Starfish Advocacy Association – an internet community for families of children with neurological disorders: <http://www.starfishadvocacy.org/>

And finally, a priceless little book of encouragement specific to parenting a child with a disability: Changed by a Child. Barbara Gill, 1997. A small Broadway Books paperback, ISBN 0-385-48243-4, available on Amazon.com for \$10.36 (new).

Appendix C

Instructions to Participants



DEPARTMENT OF PSYCHOLOGY
215-871-6442
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psyd@pcom.edu E-MAIL

Instructions for Participants:

Enclosed you will find:

- Demographic Information
- Family Impact of Childhood Disability Scale
- Nisonger Child Behavior Rating Form
- World Health Organization Quality of Life Scale –Brief scale
- Social Problem-Solving Inventory-Revised, Short form

Please follow the directions at the top of each survey. Please print legibly. Remember that ***your responses are completely anonymous.*** To protect your confidentiality, please do not write any identifying information on any of the materials. Identifying information includes items such as your name, address, social security number, etc. ***Please place your completed surveys into the envelope provided, seal and return the envelope to the researcher within the next two weeks.***

Again, *thank you* for your participation.

Appendix D

Questionnaire Packet

DEMOGRAPHIC INFORMATION

Please place a check mark beside the item which best describes your current situation, or fill in the space where indicated.

ABOUT YOU, THE CAREGIVER:

1. Gender: ☐ Male ☐ Female

2. Age: _____

3. Race/Ethnic Background:

☐ Caucasian

☐ African American

☐ Hispanic

☐ Asian/Pacific Islander

☐ Native American/American Indian

☐ Other (Please Specify) _____

4. Marital Status:

☐ Married

☐ Significant Other/Partner

☐ Single/Never Married

☐ Separated

☐ Divorced

☐ Widowed

5. Formal Education:

☐ High School Graduate

☐ College Graduate

☐ Technical School Graduate

☐ Other

6. Employment Status (of YOU - parent/caregiver completing this survey):

☐ Full Time (occupation: _____)

☐ Part Time (occupation: _____)

☐ Retired

☐ Unemployed, looking for work

☐ Unemployed, not looking

7. Employment Status of 2nd parent/caregiver (if applicable):

☐ Full Time (occupation: _____)

☐ Part Time (occupation: _____)

- ☐ Retired
☐ Unemployed, looking for work
☐ Unemployed, not looking

8. If one of you (parents/caregivers) are not working or are working part-time, would you be working more if you could find additional qualified help with your child's care?

☐ yes ☐ no

9. Income level:

- | | |
|--|---|
| <input type="checkbox"/> Less than \$20,000 | <input type="checkbox"/> \$60,001 - \$80,000 |
| <input type="checkbox"/> \$20,001 - \$40,000 | <input type="checkbox"/> \$80,001 - \$100,000 |
| <input type="checkbox"/> \$40,001 - \$60,000 | <input type="checkbox"/> Over \$100,000 |

10. Type of community you live in:

☐ Urban/ City ☐ Suburban ☐ Rural/ Country

11. My relationship to the child with a disability is:

- | | |
|--|---|
| <input type="checkbox"/> Biological Parent | <input type="checkbox"/> Foster Parent |
| <input type="checkbox"/> Adoptive Parent | <input type="checkbox"/> Grandparent |
| <input type="checkbox"/> Step parent | <input type="checkbox"/> Other (please specify) _____ |

12. Does anyone else within the family or friends help you, when needed, with this child's care?

- ☐ Other parent/Caregiver
- ☐ A sibling (brother or sister of child with disability)
- ☐ Other (please specify): _____

13. How much help do you have from outside agencies, in the form of in-home care?

- ☐ None -- I am responsible for all of this child's care
- ☐ I receive a little outside help from others

(Approx. number of hours per week: _____)

____ I receive a lot of outside help from others

(Approx. number of hours per week: _____)

ABOUT YOUR CHILD WITH A DISABILITY:

14. Gender: ____ Boy ____ Girl

15. Age: _____

16. Is there another child in the household with a disability?

____ Yes (Please specify type of disability): _____

____ No

FAMILY IMPACT OF CHILDHOOD DISABILITY SCALE

Used with permission of Dr. Barry Trute

Directions

Please choose answers to the following statements which answer the question "In your view, what consequences have resulted from having a child with a disability in your family?" Rate each item from 1 – 4, as follows:

(1) Not at all (2) To a mild degree (3) To a moderate degree (4) To a great degree

____ 1. There have been extraordinary time demands created in looking after the needs of the disabled child.

____ 2. There has been unwelcome disruption to "normal" family routines.

____ 3. The experience has made us more spiritual.

____ 4. It has led to financial costs.

____ 5. Family members do more for each other than they do for themselves.

____ 6. Having a disabled child has led to an improved relationship with spouse.

(1) Not at all (2) To a mild degree (3) To a moderate degree (4) To a great degree

- ___ 7. It has led to limitations in social contacts outside the home.
- ___ 8. The experience has made us come to terms with what should be valued in life.
- ___ 9. Chronic stress in the family has been a consequence.
- ___ 10. This experience has helped me appreciate how every child has a unique personality and special talents.
- ___ 11. We have had to postpone or cancel major holidays.
- ___ 12. Family members have become more tolerant of differences in other people and generally more accepting of physical or mental differences between people.
- ___ 13. It has led to a reduction in time parents could spend with friends.
- ___ 14. The child's disability has led to positive personal growth, or more strength as a person, in mother and/or father.
- ___ 15. Because of the situation, parents have hesitated to phone friends and acquaintances.
- ___ 16. The experience has made family members more aware of other people's needs and struggles which are based on a disability.
- ___ 17. The situation has led to tension with spouse.
- ___ 18. The experience has taught me that there are many special pleasures from a child with disabilities.
- ___ 19. Because of the circumstances of the child's disability, there has been a postponement of major purchases.
- ___ 20. Raising a disabled child has made life more meaningful for family members.

THE NISONGER CHILD BEHAVIOR RATING FORM

Used with permission of Dr. Michael G. Aman and Dr. Marc J. Tassé

Directions:

Please circle the number of the response that best describes your child's behavior over the last month. If you are not sure of a response, choose the one that is the most true.

POSITIVE SOCIAL. Please describe the child's behavior as it was at home over the last month.

	Not True 0	Somewhat/Sometimes True 1	Very or Often True 2	Completely or Always True 3
IN THE LAST MONTH, THIS CHILD HAS:				
1. Accepted redirection	0	1	2	3
2. Expressed ideas clearly	0	1	2	3
3. Followed rules	0	1	2	3
4. Initiated positive interactions	0	1	2	3
5. Participated in group activities	0	1	2	3
6. Resisted provocation, was tolerant	0	1	2	3
7. Shared or helped others	0	1	2	3
8. Stayed on task	0	1	2	3
9. Was cheerful or happy	0	1	2	3
10. Was patient, able to delay	0	1	2	3

PROBLEM BEHAVIOR. For each item that describes the child's behavior as it was over the last month, circle the:

- 0 – if the behavior **did not** occur, or was **not a problem**.
- 1 – if the behavior occurred **occasionally**, or was a **mild problem**.
- 2 – if the behavior occurred **quite often**, or was a **moderate problem**.
- 3 – if the behavior occurred **a lot**, or was a **severe problem**.

PLEASE DO NOT SKIP ANY QUESTIONS. IF YOU DO NOT KNOW THE ANSWER OR HAVE NOT HAD A CHANCE TO OBSERVE THE CHILD FOR A GIVEN TIME, CIRCLE THE ZERO.

1. Apathetic or unmotivated.	0	1	2	3
2. Argues with parents, teachers, or other adults.	0	1	2	3
3. Clings to adults, too dependent.	0	1	2	3
4. Cruelty or meanness to others.	0	1	2	3
5. Crying, tearful episodes.	0	1	2	3

- 0 – if the behavior did not occur, or was not a problem.
 1 – if the behavior occurred occasionally, or was a mild problem.
 2 – if the behavior occurred quite often, or was a moderate problem.
 3 – if the behavior occurred a lot, or was a severe problem.

6. Hits or slaps own head, neck, hands.	0	1	2	3
7. Defiant, challenges adult authority.	0	1	2	3
8. Knowingly destroys property.	0	1	2	3
9. Difficulty concentrating.	0	1	2	3
10. Disobedient.	0	1	2	3
11. Rocks body or head back and forth repetitively.	0	1	2	3
12. Doesn't feel guilty after misbehaving.	0	1	2	3
13. Easily distracted.	0	1	2	3
14. Easily frustrated.	0	1	2	3
15. Overly sensitive; feelings easily hurt.	0	1	2	3
16. Exaggerates abilities or achievements.	0	1	2	3
17. Explosive, easily angered.	0	1	2	3
18. Has rituals such as head rolling or floor pacing.	0	1	2	3
19. Fails to finish things he/she starts.	0	1	2	3
20. Feelings are easily hurt.	0	1	2	3
21. Feels others are against him/her.	0	1	2	3
22. Harms self by scratching skin or pulling hair.	0	1	2	3
23. Feels worthless or inferior.	0	1	2	3
24. Fidgets, wiggles, or squirms.	0	1	2	3
25. Shy around others; bashful.	0	1	2	3
26. Gets in physical fights.	0	1	2	3
27. Irritable.	0	1	2	3
28. Repeatedly flaps or waves hands, fingers or objects (such as pieces of string).	0	1	2	3
29. Isolates self from others	0	1	2	3
30. Lying or cheating.	0	1	2	3
31. Nervous or tense.	0	1	2	3
32. Gouges self, puts things in ears, nose, etc., or eats inedible things.	0	1	2	3
33. Overactive, doesn't sit still.	0	1	2	3
34. Overly anxious to please others.	0	1	2	3
35. Overly excited, exuberant.	0	1	2	3
36. Physically attacks people.	0	1	2	3
37. Refuses to talk.	0	1	2	3
38. Repeats the same sound, word, or phrase over and over.	0	1	2	3
39. Restless, high energy level.	0	1	2	3
40. Runs away from adults, teachers, or other authority figures.	0	1	2	3
41. Says no one likes him/her.	0	1	2	3
42. Secretive, keeps things to self.	0	1	2	3
43. Repeatedly bites self hard enough to leave tooth marks or break skin.	0	1	2	3

- 0 – if the behavior did not occur, or was not a problem.
 1 – if the behavior occurred occasionally, or was a mild problem.
 2 – if the behavior occurred quite often, or was a moderate problem.
 3 – if the behavior occurred a lot, or was a severe problem.

44. Self-conscious or easily embarrassed.	0	1	2	3
45. Shifts rapidly from topic to topic.	0	1	2	3
46. Short attention span.	0	1	2	3
47. Shy or timid behavior.	0	1	2	3
48. Steals.	0	1	2	3
49. Odd repetitive behaviors (e.g., stares, grimaces, rigid postures).	0	1	2	3
50. Stubborn, has to do things own way.	0	1	2	3
51. Sudden changes in mood.	0	1	2	3
52. Sulks, is silent and moody.	0	1	2	3
53. Physically harms or hurts self on purpose.	0	1	2	3
54. Talks back to teacher, parents, or other adults.	0	1	2	3
55. Talks too much or too loud.	0	1	2	3
56. Temper tantrums.	0	1	2	3
57. Threatens people.	0	1	2	3
58. Threatens to harm self.	0	1	2	3
59. Engages in meaningless, repetitive body movements.	0	1	2	3
60. Too fearful or anxious.	0	1	2	3
61. Underactive, slow.	0	1	2	3
62. Unhappy or sad.	0	1	2	3
63. Violates rules.	0	1	2	3
64. Withdrawn, uninvolved with others.	0	1	2	3
65. Worrying.	0	1	2	3
66. Argues with other children or peers.	0	1	2	3

**Thank you for participating thus far – Please proceed to the
 WHOQOL-BREF and the SPSI.**

Please feel free to use this space to tell us anything you think we should know about you and/or your family and/or your child with a disability:

WHOQOL-BREF

This questionnaire asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question.

	Very poor	Poor	Neither poor nor good	Good	Very Good
1. How would you rate your quality of life?	1	2	3	4	5
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2. How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two weeks.

	Not at all	A little	A moderate amount	Very much	An extreme amount
3. To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4. How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5. How much do you enjoy life?	1	2	3	4	5
6. To what extent do you feel your life to be meaningful?	1	2	3	4	5

	Not at all	Slightly	A Moderate amount	Very much	Extremely
7. How well are you able to concentrate?	1	2	3	4	5
8. How safe do you feel in your daily life?	1	2	3	4	5
9. How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

	Not at all	A little	Moderately	Mostly	Completely
10. Do you have enough energy for everyday life?	1	2	3	4	5
11. Are you able to accept your bodily appearance?	1	2	3	4	5
12. Have you enough money to meet your needs?	1	2	3	4	5

	Not at all	A little	Moderately	Mostly	Completely
13. How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14. To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
	Very poor	Poor	Neither poor nor well	Well	Very well
15. How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16. How satisfied are you with your sleep?	1	2	3	4	5
17. How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18. How satisfied are you with your capacity for work?	1	2	3	4	5
19. How satisfied are you with your abilities?	1	2	3	4	5
20. How satisfied are you with your personal relationships?	1	2	3	4	5
21. How satisfied are you with your sex life?	1	2	3	4	5
22. How satisfied are you with the support you get from your friends?	1	2	3	4	5
23. How satisfied are you with the conditions of your living place?	1	2	3	4	5
24. How satisfied are you with your access to health services?	1	2	3	4	5
25. How satisfied are you with your mode of transportation?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last two weeks.

	Never	Seldom	Quite often	Very often	Always
26. How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

SPSI-R:S

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Instructions: Below are some ways that you might think, feel, and act when faced with problems in everyday living. We are not talking about the ordinary hassles and pressures that you handle successfully every day. In this questionnaire, a problem is something important in your life that bothers you a lot, but you don't immediately know how to make it better or stop it from bothering you so much. The problem could be something about yourself (such as your thoughts, feelings, behavior, health, or appearance), your relationships with other people (such as your family, friends, teachers, or boss), or your environment and the things you own (such as your house, car, property, or money). Please read each statement carefully and choose one of the numbers below that best shows how much the statement is true of you. See yourself as you usually think, feel, and act when you are faced with important problems in your life these days. Circle the number that is the most true of you. Do not erase if you want to change an answer, instead put an "X" through the answer you wish to change. Try to answer all of the questions.

	Not at All True of Me	Slightly True of Me	Moderately True of Me	Very True of Me	Extremely True of Me
	0	1	2	3	4
1. I feel threatened and afraid when I have an important problem to solve.	0	1	2	3	4
2. When making decisions, I do not evaluate all my options carefully enough.	0	1	2	3	4
3. I feel nervous and unsure of myself when I have an important decision to make.	0	1	2	3	4
4. When my first efforts to solve a problem fail, I know if I persist and do not give up too easily, I will be able to eventually find a good solution.	0	1	2	3	4
5. When I have a problem, I try to see it as a challenge, or opportunity to benefit in some positive way from having the problem.	0	1	2	3	4
6. I wait to see if a problem will resolve itself first, before trying to solve it myself.	0	1	2	3	4
7. When my first efforts to solve a problem fail, I get very frustrated.	0	1	2	3	4
8. When I am faced with a difficult problem, I doubt that I will be able to solve it on my own no matter how hard I try.	0	1	2	3	4
9. Whenever I have a problem, I believe that it can be solved.	0	1	2	3	4
10. I go out of my way to avoid having to deal with problems in my life.	0	1	2	3	4
11. Difficult problems make me very upset.	0	1	2	3	4
12. When I have a decision to make, I try to predict the positive and negative consequences of each option.	0	1	2	3	4
13. When problems occur in my life, I like to deal with them as soon as possible.	0	1	2	3	4
14. When I am trying to solve a problem, I go with the first good idea that comes to mind.	0	1	2	3	4
15. When I am faced with a difficult problem, I believe that I will be able to solve it on my own if I try hard enough.	0	1	2	3	4
16. When I have a problem to solve, one of the first things I do is get as many facts about the problem as possible.	0	1	2	3	4
17. When a problem occurs in my life, I put off trying to solve it for as long as possible.	0	1	2	3	4
18. I spend more time avoiding my problems than solving them.	0	1	2	3	4
19. Before I try to solve a problem, I set a specific goal so that I know exactly what I want to accomplish.	0	1	2	3	4
20. When I have a decision to make, I do not take the time to consider the pros and cons of each option.	0	1	2	3	4
21. After carrying out a solution to a problem, I try to evaluate as carefully as possible how much the situation has changed for the better.	0	1	2	3	4
22. I put off solving problems until it is too late to do anything about them.	0	1	2	3	4
23. When I am trying to solve a problem, I think of as many options as possible until I cannot come up with any more ideas.	0	1	2	3	4
24. When making decisions, I go with my "gut feeling" without thinking too much about the consequences of each option.	0	1	2	3	4
25. I am too impulsive when it comes to making decisions.	0	1	2	3	4