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Heather F. Lundy
Georgia State University

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The Dissertation Advisory Committee and the student's Department Chair, as representatives of the faculty, certify that this dissertation has met all standards of excellence and scholarship as determined by the faculty. The Dean of the College of Education concurs.

_____   _____
Kristen Varjas, Psy.D.   Joanna White, Ed.D.
Committee Chair   Committee Member

_____   _____
Jeff Ashby, Ph.D.   Elizabeth Steed, Ph.D.
Committee Member   Committee Member

_____
Date

_____
Joanna White, Ed.D.
Chair, Department of Counseling and Psychological Services

_____
R. W. Kamphaus, Ph.D.
Dean and Distinguished Research Professor
College of Education

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Heather F. Lundy
1291 Julian Drive
Watkinsville, GA 30677

The director of this dissertation is:

Dr. Kristen Varjas
Department of Counseling and Psychological Services
College of Education
Georgia State University
Atlanta, GA 30303-3083

VITA

Heather F. Lundy

ADDRESS: 1291 Julian Drive
                  Watkinsville, GA 30677

EDUCATION:
          Ph.D. 2011   Georgia State University
                        School Psychology
          Ed.S. 2001   Georgia Southern University
                        School Psychology
          M.Ed. 1999   Georgia Southern University
                        School Psychology
          B.A.   1998   University of Georgia
                        Psychology

PROFESSIONAL EXPERIENCE:
          2001-Present School Psychologist
                        Barrow County School System, Winder, GA

PROFESSIONAL ORGANIZATIONS:
          2001-Present Professional Association of Georgia Educators
          1999-Present Georgia Association of School Psychologists

ABSTRACT

PARENTAL STRESS, SOCIOECONOMIC STATUS, SATISFACTION WITH
SERVICES, AND FAMILY QUALITY OF LIFE AMONG PARENTS
OF CHIDREN RECEIVING SPECIAL EDUCATION SERVICES
by
Heather F. Lundy

Family quality of life (FQOL) refers to the degree to which families of individuals

with disabilities are able to meet their basic needs, enjoy time together, and pursue leisure

interests and activities (Park et al., 2003). Researchers have identified barriers that

families of individuals with disabilities encounter as they pursue a life of quality

including elevated parental stress (Hauser-Cram, Warfield, Shonkoff, & Kraus, 2001),

low socioeconomic status (SES) (Park, Turnbull, & Turnbull, 2002) and inadequate

social service support (Soresi, Nota, & Ferrari, 2007). This study utilized data collected

from a sample of parents ($N =$ 389) of children receiving special education services from

preschool through fifth grade to determine parental stress levels, satisfaction with social

service supports and FQOL. Instruments included a demographic questionnaire, Parental

Stress Scale (PSS; Berry & Jones, 1995), Client Satisfaction Questionnaire-8 (CSQ-8;

Larsen, Attkisson, Hargreaves, & Nguyen, 1979) and Family Quality of Life Survey

(FQOLS; Turnbull et al., 2004). A MANCOVA analysis failed to reflect significant

differences between parental stress levels and FQOL based on child disability type. Point

biserial correlations did not reveal significant relationships between children's free or

reduced lunch (FRL) status, parental stress, satisfaction with social services, and FQOL.

Initial linear regression analysis indicated that parental stress was a significant predictor

of FQOL ($p < .001$) while satisfaction with social services approached significance ($p =$

.057). However, a subsequent linear regression analysis that included the interaction

between satisfaction with social services and parental stress failed to support a

moderation effect between satisfaction with social services and parental stress in the prediction of FQOL ($p = .142$). The examination of parental stress and FQOL within a school-based setting was a unique contribution to the literature that focuses primarily on FQOL and families of children with disabilities within clinical, medical and mental health settings. Limitations of this study, future research directions, and implications for school-based mental health providers are presented.

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ABBREVIATIONS

FQOL	Family Quality of Life
QOL	Quality of Life
SES	Socioeconomic Status
CDC	Centers for Disease Control and Prevention
NHIS-D	National Health Interview Surveys on Disability
FRL	Free or Reduced Lunch
TIN	Testing Identification Number
PSS	Parental Stress Scale
CSQ-8	Client Satisfaction Questionnaire – 8
FQOLS	Family Quality of Life Survey
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, 4th Edition – Text Revision

CHAPTER 1

ADVOCATING FOR FAMILIES OF CHILDREN WITH DISABILITIES AND

FAMILY QUALITY OF LIFE: AN ECOLOGICAL SYSTEMS APPROACH

Over the past several decades, researchers have acknowledged the importance of

examining the quality of life (QOL) of individuals with disabilities and their families.

Family quality of life (FQOL; Park et al., 2003) refers to the degree to which families of

individuals with disabilities are able to meet their basic needs, enjoy time together, and

pursue interests and activities that are important to them. Today, it is a commonly held

belief that all individuals and their families, regardless of disability status, have a right to

a life of quality. Parents of children with disabilities have reported positive contributions

that their child has on their QOL such as fostering the development of patience, love,

compassion, and tolerance (Kausar, Jevne, & Sobsey, 2003), improved relations with

family members (Kausar et al., 2003), and positive changes in spiritual values (Trute,

Heibert-Murphy, & Levine, 2007).

Researchers also have suggested that the responsibilities of caring for a child with

a disability may negatively impact parents' mental health (Dellve, Samuelsson, Tallborn,

Fasth, & Hallberg, 2006; Glenn, Cunningham, Poole, Reeves, & Weindling, 2009; Pisula,

2007) and FQOL (Wodehouse & McGill, 2009). There have been numerous demographic

factors (e.g., poverty, minority status, single-parent status) that have been identified as

possible risk factors for families as they strive to achieve lives of quality (Brandon &

Hogan, 2004; Honberg, Kogan, Allen, Strickland, & Newacheck, 2009; Rosenberg,

Zhang, & Robinson, 2008; Welterlin & LaRue, 2007). Mental health service providers

are in a unique position to understand the needs of families raising children with

disabilities and advocate for them as they strive to achieve lives of quality. This article will first review demographic factors that may negatively impact FQOL for families of children with disabilities. Second, parental mental health and protective factors that parents of children with disabilities utilized to enhance FQOL will be presented. Third, this article will examine the supports and barriers to FQOL within various ecological systems (i.e., family, informal social, school, spiritual, and social service support) systems and offer recommendations and practical suggestions mental health service providers may utilize as they work to enhance FQOL for families of children with disabilities.

Demographic Factors Impacting FQOL

Poverty

The impact of poverty on families of children with disabilities has received considerable attention in the literature (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2005; Oppenheim & Harker, 1996; Rosenberg et al., 2008). The number of children with disabilities living in poverty in the U.S. is disproportionate to the number of typically developing children with recent data approximating that 28% of children with disabilities were being raised in poverty whereas only 16% of children without disabilities live in poverty (U.S. Census Bureau, 2006). The relationship between poverty status and childhood disability was examined in Rosenberg and colleagues' (2008) study of 19,150 parents which indicated that by two years of age, children residing in families below the poverty level were more likely to present with developmental delays than children whose families were above the poverty level.

A potential contribution to the relationship between poverty status and disability is the increased financial strain placed on families as they care for their child's needs (Hanvey, 2002). Oppenheim & Harker (1996) identified that children with disabilities may require adapted modes of transportation, modifications made to the home, special diets, child care, supplies, individualized health care, and adaptive equipment (e.g., communication and mobility devices) which are oftentimes expensive to acquire (Oppenheim & Harker, 1996; Roeher Institute, 2000). In a recent survey of Canadian children with disabilities (e.g., sensory, communication, physical, learning) ($N = 90$, 480), researchers found that less than half of all children's needs for assistive technology were met completely (45.3%), while approximately one-third had some but not all of the equipment they required (30.1%), and almost one quarter did not have any of the assistive technology (24.6%). Parents of these children with disabilities cited the cost to obtain the aids as the primary reason why they were unable to meet their child's assistive technology needs (Bélair et al., 2008).

Unfortunately, researchers also have suggested that children with disabilities in low socioeconomic status (SES) families may be less likely to receive early intervention services than children with disabilities in higher SES families (e.g., Bailey et al., 2004; Denney, Itkonen & Okamoto, 2007; McManus, McCormick, Acevedo-Garcia, Ganz, & Hauser-Cram, 2009). Bailey and colleagues (2004) found that families of lower SES ($N = 2,974$) were less likely to access early intervention services than families of higher SES. They attributed this lack of access to later identification of their child's disability resulting from a lack of resources and a delay in seeking out early intervention services. McManus and colleagues (2009) utilized data from the 2005-2006 National Survey of

Children with Special Healthcare Needs. In their sample of children younger than three

that had been diagnosed with developmental disabilities, they found that children residing

in low SES families were less likely to receive early intervention services than children

residing in higher SES households. The authors attributed differences in access to

services to family demographics and state programming procedures.

Poverty status and health insurance. Poverty status also has been found to

increase the likelihood that families of a child with disabilities will not possess adequate

health insurance, thereby reducing the family's access to adequate medical services for

their child (Porterfield & McBride, 2007; Rondero Hernandez, Montana, & Clarke,

2010). Honberg and colleagues (2009) reviewed data collected from a national survey of

parents of children with health care needs ($N = 40,465$) and found that despite expansions

to the Medicaid and Children's Health Insurance Programs, families living in poverty

were less likely to have health insurance coverage when compared to families of higher

SES. In addition, they found that when compared to families of higher SES, low SES

families who had health insurance coverage for their child with a disability were less

likely to have benefits that enabled them to receive services from needed health care

providers (Honberg et al., 2009). Porterfield and McBride reviewed data collected from

the 2001 National Survey of Children with Special Health Care Needs ($N = 38,866$).

They discovered that not only were children from families of lower SES less likely to

have health insurance coverage than children residing in families of higher SES, parents

of lower SES often failed to recognize their child's needs for specialized health care

services.

Minority Status

The Centers for Disease Control and Prevention (CDC; Keppel, Pearcy, &
Wagener, 2002) identified risk factors that potentially increased the likelihood of
childhood disability faced by minority families (e.g., limited access to prenatal care,
increased risk for low birth weight babies). Keppel and colleagues (2002) found that
minority families were more likely to live in poverty than non-minority families. Poverty
status has been linked to a family's ability to obtain health insurance. As such, families of
minority status have been found to lack health insurance (Honberg et al., 2009; Bailey et
al., 2005; Welterlin & LaRue, 2007)which impedes their ability to access to early
intervention services (Bailey et al., 2004; Rosenberg et al., 2008.

    Minority status and health insurance. Minority families have been found less
likely to have health insurance than their non-minority counterparts (Honberg et al.,
2009; Bailey et al., 2005). In their conceptual paper, Welterlin & LaRue (2007)
hypothesized this lack of health insurance among minority families may be attributed to
social, cultural, and economic barriers (Welterlin & LaRue, 2007). Freedman and
Capobianco Boyer (2000) reported that the minority parents of children with disabilities
($n = 8$) in their study identified inadequate information or misinformation about various
support options which the authors attributed to social service providers' lack of outreach
to ethnic minority families. Honberg and colleagues' (2009) found that Hispanic children
with disabilities were less likely to have health insurance coverage than other ethnic
groups (i.e., White, Black, Other). Minority families with limited English language
proficiency were less likely to have health insurance coverage for their child with a
disability than parents fluent in the English language while Hispanic non-English

speaking families were least likely to have health insurance coverage than the other ethnic groups included in the study (Honberg et al., 2009).

Minority status and access to early intervention services. Researchers (Bailey et al., 2004; Rosenberg et al., 2008) have found that minority families experienced more difficulty accessing early intervention services than their non-minority counterparts. Bailey and colleagues (2004) interviewed a large sample of parents ($N = 3,338$) whose children were receiving early intervention services. They found that minority families were more likely to report difficulty finding out about early intervention services than White families. In a longitudinal study of children receiving early intervention services (i.e., Babies Can't Wait) ($N = 8,950$), African-American children ($n = 1226$) were least likely to have access to early intervention services, and were half as likely to receive the needed services as white children (Rosenberg et al., 2008). African American parents that accessed early intervention services for their child with a disability reported being less satisfied with the services than White families (Rosenberg et al., 2008). The researchers hypothesized that this discrepancy in accessing services may imply that Part C of the Individuals with Disabilities Education Improvement Act which allows for community and governmental agencies to coordinate efforts to address the needs of children with developmental delays from birth until their third birthday may meet the needs of White families more successfully than for African American families.

Single Parent Status

Hogan and colleagues (2000) obtained data from the 1994 and 1995 National Health Interview Surveys on Disability (NHIS-D) ($N = 41,300$) and the Year 2000 Health Supplement to the 1994 and 1995 NHIS-D ($N = 9,530$). Their findings suggested that

families of children with disabilities were more likely to be headed by a single parent.

Unfortunately, being a single parent may further increase the challenges faced by parents

raising a child with a disability, particularly in regards to employment, income, and

utilization of social service supports. For example, Lukemeyer and colleagues (2000)

reported that single parents of children with disabilities were less likely to be employed

and experienced more financial difficulties than single mothers of typically developing

children. A child with a disability often requires specialized care that most child care

providers are unable to give, which may explain single parents' difficulty obtaining work

(Brandon & Hogan, 2001). High care-taking demands and lack of employment

opportunities appear related to single parents of children with disabilities reporting more

difficulty accessing and utilizing social service supports (Lukemeyer et al., 2000) than

their married counterparts.

Age of Child with Disability

Researchers have suggested that parents of younger children with disabilities may

experience lower FQOL than parents of children with disabilities who were older (Mash

& Johnston, 1983; Rogers, 2007). Rogers (2007) reviewed interviews and personal

narratives obtained from 24 parents of children with disabilities (i.e., autism spectrum

disorders, emotional/behavioral disorders, medical conditions, speech delays, birth

defects) to explore emotional difficulties experienced by these parents and found that the

emotional stress experienced by families of children with disabilities may be more

intense for parents of young children. Rogers also determined that parental stress levels

may be higher when the child is younger because diagnoses typically occur when the

child is young. Mash and Johnston (1983) compared parents of children diagnosed with

hyperactivity ($n = 40$) to parents of age-matched typically developing children ($n = 51$) and found that parents of younger children (age = 5) with hyperactivity reported the higher levels of stress than parents of older children (age = 8) with hyperactivity. These elevated stress levels were related to the frequency and magnitude of the child's behavior challenges and parents' attempts to learn effective ways to manage their child's behaviors.

Families Raising Multiple Children with Disabilities

Families raising children with disabilities, especially those of genetic etiology, may have more than one child with a disability. Rogers' (2007) study of families raising children with disabilities ($N = 24$) included families raising more than one child with a disability and found that when a second child in the family began exhibiting similar difficulties as their first child with a disability. Findings suggested that parents experienced more intense reactions associated with the need to adapt to the anticipated demands of their newly diagnosed child's needs, concern about the child and family's future, and feelings of sadness related to not having a typically developing child (Rogers, 2007). Orsmond and colleagues (2007) examined maternal well-being of mothers of adolescents and adults with autism ($n = 325$) to mothers raising a child with autism and an additional child with a disability (i.e., medical conditions, learning disabilities, and psychiatric disorders) ($n = 59$). Results showed that mothers raising more than one child with a disability reported lower personal well-being and lower family functioning than mothers raising only one child with a disability (Orsmond, Lin, & Mailick Seltzer, 2007). These researchers posited that lower personal well-being among mothers raising more than one child with a disability may have been a result of the increased caretaking

demands, feelings of anxiety, and other emotional difficulties related to meeting their children's needs (Orsmond et al., 2007).

Rural and Urban Communities

The geographic location (rural, urban) of families of a child with a disability may influence the availability and quality of social service supports families of children with disabilities utilize to enhance FQOL. While there have been significant advances in social service supports for families of children with disabilities, social services in rural communities remain relatively unchanged due to poverty (Brown, 2008) and a lack of financial resources to fund social services. Barriers to social service supports in rural communities, such as limited services available (Applequist, 2009; Brasfield, 2008; Darling and Gallagher, 2004), poor quality of services (Brasfield, 2008), and distance required to access services (Applequist, 2009; Brasfield, 2008) have been reported in the literature. Darling and Gallagher (2004) examined the needs (e.g., financial, shelter, food, transportation) and supports (assistance from various sources) of families of young children with disabilities residing in rural and urban communities and found that families living in rural communities reported less access to support services than families residing in urban areas. Applequist (2009) found that parents ($n = 30$) of children with disabilities (ages one through 18) residing in rural areas compared to those families living in urban areas reported having fewer choices of early intervention services for their young children and fewer special educators resulting in limited special education placements. Brasfield (2008) conducted a qualitative study of mothers of children with disabilities ($N = 10$) residing in a rural community to identify stressors, coping resources, and resilience. The mothers reported an overall lack of available social service supports, poor quality of

available services, lengthy travel to and from urban areas for treatments, and a lack of parental support groups (Brasfield, 2008).

Parental Stress and Childhood Disability

The impact of raising a child with a disability on parental stress levels has received extensive attention in the literature and numerous studies have documented that both mothers and fathers reported more stress related to raising their child with a disability than parents of typically developing children (e.g., Dellve et al., 2006; Fidler, Hodapp, & Dykens, 2000; Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008). These increased stress levels have been directly related to childrearing responsibilities (Fidler et al., 2000), concern for their child's future (Pisula, 2007), and feelings of isolation from other parents raising children without a disability. In their work with mothers of children with cerebral palsy, Glenn and colleagues (2009) found considerably higher levels of maternal stress when compared to mothers of typically developing children, with the highest levels of stress determined by factors such as role restriction, feelings of isolation, insufficient support from their spouse, and demandingness of their child. In addition, Pisula (2007) compared stress levels of mothers of children with autism ($n = 25$) and Down syndrome (n = 25) and found that mothers of children with autism reported elevated levels of stress due to their concern about child's dependence on others, concern for their child's future, and concern about the permanency of the disability.

The current literature suggests the presence and intensity of child behavior problems may have the most impact on parental stress levels (Hassall, Rose, & McDonald, 2005; Tomanik, Harris, & Hawkins, 2004; Baker et al., 2003). For example, in Hauser-Cram's and colleagues' (2001) study of 183 parents of children with Down

syndrome, motor impairment, and developmental delays, child behavior problems better predicted elevated parental stress levels than child intellectual disability, physical disability, and developmental delays. Hassall and colleagues (2005) conducted a study of mothers of children with an intellectual disability and severe behavior difficulties ($N =$ 46), and results suggested maternal stress levels were more related to the frequency and intensity of their child's inappropriate behavior than their intellectual limitations. In another study of mothers of children diagnosed as having pervasive developmental disorder ($N = 60$), the behavioral difficulties associated with autism spectrum behaviors were found to contribute significantly to higher levels of parental stress (Tomanik et al., 2004).

Although maternal stress associated with raising a child with a disability has received the most attention in the literature, there is evidence to suggest that paternal stress levels are impacted in similar ways. In their study comparing families of preschool children with developmental disabilities (49 mothers and 39 fathers) to families of typically developing children (40 mothers and 30 fathers), Oelofsen and Richardson (2006) found that both mothers and fathers of children with disabilities reported higher levels of parental stress than parents of typically developing children. Gore (2010) interviewed fathers of children with a learning disability ($N = 21$) from a wide range of social, economic, and cultural backgrounds and found that two-thirds of the fathers experienced emotional difficulties related to parenting, some reported being under constant stress, and others experienced health problems.

Despite some similarities between mothers and fathers raising children with disabilities, the literature also identifies differences. Olsson & Hwang's (2008) study of

mothers ($n = 62$) and fathers ($n = 49$) of children recently diagnosed with a disability (aged 0 to 5), found that mothers reported higher levels of distress and lower levels of overall well-being than fathers. Veisson (1999) compared depression and stress levels among 208 parents (151 mothers and 57 fathers) of children with disabilities with 156 parents (101 mothers and 55 fathers) of typically developing children. Results indicated that fathers of children with disabilities reported lower levels of depression than was reported by mothers of children with disabilities. Differences also have been observed between mothers' and fathers' stress and anxiety levels with mothers reporting higher levels of stress than fathers (Keller, Sterling Honig, 2004). Similarly, in Hastings (2003) study of couples of children with autism (ranging in age from 8-17 years) ($N = 18$) the mothers reported significantly more problems related to anxiety than was reported by the fathers. Baker-Ericzen and colleagues (2005) compared parental stress levels of parents with toddlers diagnosed with autism spectrum disorder ($n = 37$) to that of parents of typically developing children ($n = 32$) and found that child's level of social skills was significant predictor of child-related maternal stress but did not impact child-related stress of fathers.

Aside from differences in mental health functioning of mothers and fathers of children with disabilities, differences also existed in mothers' and fathers' employment opportunities outside of the home (Dowling & Dolan, 2001; Willoughby & Glidden, 1995). Research has shown that maternal employment outside the home serves as a protective factor for FQOL in that it increases family material resources, her opportunity to engage in social interactions (Dowling & Dolan, 2001). However, mothers of children with disabilities often lacked the opportunity to work outside the home more so than

mothers of typically developing children, despite their desire to do so (Dowling & Dolan, 2001). Willoughby and Glidden (1995) proposed that fathers of children with disabilities tended to feel the need to increase the family's finances to meet their child's needs, which they accomplished by working longer hours outside of the home. As a result, mothers assumed the role of primary caregiver for their child that interfered with their ability to gain employment outside of the home.

Freedman and colleagues (1995) collected qualitative data from a focus groups comprised of 31 parents of children with developmental disabilities (i.e., autism spectrum disorders, mental retardation, cerebral palsy, and medical conditions). Mothers often reported they were unable to work outside of the home due to the overwhelming exhaustion they felt as a result of the increased child care demands (McConachie, 1986). Another barrier to mothers' ability to work outside the home was the need to find a job that corresponds with the hours their child attends school since after-school care options are limited (Todd & Shearn, 1996). For example, the typical hours of state mandated and federally funded early intervention services (e.g., Head Start and school–based services) did not always coincide with the working hours for many mothers, which further hindered their ability to gain employment due to lack of childcare while they work (Todd & Shearn, 1996).

Intrinsic Parental Protective Factors for FQOL

Researchers have identified intrinsic protective factors that appear to increase the likelihood that parents of a child with a disability will successfully adapt to and maintain lives of quality for themselves and members of their family (e.g., Crnic & Low, 2002;

Einam & Cuskelly, 2002; Kersch, Hedvat, Huaser-Cram, & Warfield, 2006; Skok,

Harvey, & Reddihough, 2006).

Personality traits intrinsic to parents, such as their perception of self-efficacy

(Good, 2001; Harty Alant, & Uys, 2006; Mash & Johnston, 1983; Raikes & Thompson,

2005) and utilization of cognitive coping strategies, such as reframing (Hastings & Taunt,

2002) and problem-focused coping (Carver, Sheier, & Weintraub, 1989; Abedutto,

Mailick Seltzer, & Shattuck, 2004), have been identified in the literature as protective

factors for FQOL among parents of children with disabilities. This section will review

these intrinsic factors.

Parental self-efficacy is a cognitive factor that has been associated with parental

competence. Parental self-efficacy refers to parents' perceptions that they are capable of

competently and effectively parenting their children (Teti & Gelfand, 1991). Donovan

and colleagues (1990) posited that parents with high self-efficacy will likely interpret

difficulties related to their child as challenges and exert increased effort to meet their

child's needs. Raikes and Thompson (2005) administered self-report surveys to low SES

mothers of children identified as at-risk for developmental delays ($N = 65$). Results

suggested that when mothers reported higher levels of self-efficacy they were more

confident in their ability to effectively manage more demanding child care

responsibilities. Mash and Johnston (1983) utilized the Parenting Self-Esteem Index and

Parenting Stress Index to compare parents of children with hyperactivity ($n = 40)$ to

parents of typically developing children ($n = 51$). They found that mothers with high

parental self-efficacy were more likely to remain engaged with their child when faced

with increasingly difficult demands of parenting than mothers with lower self-efficacy.

Harty and colleagues (2006) utilized the Self-Efficacy for Parenting Tasks Index to assess

self-efficacy of 25 mothers of children with developmental disabilities (e.g. birth defect,

language delays, autism spectrum disorder). High self-efficacy was reported by all

parents in the study, particularly in regard to nurturing and emotional availability. The

authors speculated that parents with high parental self-efficacy are "regularly available

for the protection, nurturance, and care of their children" (Harty et al., 2006, p. 148).

Parents that effectively adapt to and cope with the demands of caring for their

child with a disability also utilize cognitive coping techniques, which have been defined

as "a shift in the way a situation is assessed and cognitively processed so it is rendered

more acceptable" (Grant, Ramcharan, & Flynn, 2007, p. 566). Reframing and problem-

focused strategies are two of these cognitive coping techniques. Hastings and Taunt

(2002) reviewed existing literature on positive perceptions and experiences reported by

families of children with disabilities and concluded that when parents positively reframed

their attitudes and thoughts about raising a child with a disability they adapted better to

the increased demands of raising their child, and were better able to meet their child's

needs.

Problem-focused coping, which is comprised of active coping, planning, and

positive reinterpretation and growth (Carver et al., 1989), has been proven to be helpful

for parents as they meet the demands of raising their child with a disability. Folkman and

Moskowitz (2000) hypothesized that utilization of problem-focused coping creates a

sense of control and mastery that increases parents' ability to effectively meet the

demands associated with raising their child with a disability. This was evident in

Abbeduto and colleagues' (2004) comparative analysis of self-report survey data

collected from 235 mothers of children with disabilities (genetic disorders and autism spectrum disorders) indicating that mothers who utilized problem-focused coping skills were less pessimistic about their child's future than those who failed to utilize problem-focused coping strategies. Stoneman and Gavidia-Payne (2006) conducted a study of married couples of children with disabilities ($N = 67$) and found that fathers who employed problem-focused approaches were more positive about their marriages. In addition, when fathers utilized problem-focused approaches, mothers reported feeling more positively about their relationship with their husbands (Stoneman & Gavidia-Payne, 2006).

FQOL and Ecological Systems

Families of children with disabilities do not function as isolated units; rather, they interact among numerous ecological systems within our society. Given the challenges families of children with disabilities may face as they strive to obtain FQOL, researchers are increasingly assuming an ecological perspective of disability to identify ways in which ecological factors both hinder and improve FQOL. Numerous barriers have been identified within various ecological systems that parents of children with disabilities encounter as they pursue a life of quality (e.g., Olsson & Hwang, 2002; Risdal & Singer, 2004; Park, Turnbull, & Turnbull, 2002; Wodehouse & McGill, 2009; Soresi, Nota, & Ferrari, 2007). By assuming an ecological perspective, FQOL proponents consider the families' challenges that result from the disability as a societal problem (Brown, 2008; Brown, Schalock, & Brown, 2009). Consequently, the FQOL construct has initiated the development of community programs and services to support families of individuals with disabilities and enhance their ability to access and participate in all aspects of community

life. In all, the assumption is that if an individual and their family has adequate and appropriate supports, their FQOL will be greatly enhanced (Turnbull, Turnbull, Brown, & Turnbull, 2004).

Interestingly, operational definitions of the various types of support that parents utilize as they care for their child with a disability tend to be absent in the literature (Guralnick, Hammond, Neville, & Connor, 2008). For the purpose of this article, practical support refers to the assistance given by others such as childcare and help with everyday tasks. Informal social support refers to assistance given to families of a child with a disability by their friends. Social service support encompasses the numerous services available in communities to assist parents in meeting the needs of their child and family. In the following sections, the supports and barriers within the family, social, school, employment, spiritual, and formal support systems will be examined. Recommendations for ways in which mental health service providers may advocate for families of children with disabilities as they strive to decrease barriers that exist within the various systems will also be discussed. A summary of recommendations as well as practical suggestions for mental health service providers are presented in Table 1.

Family System

Parents of children with disabilities often rely on each other and other family members for support as they care for their child with a disability. This section will focus on the supports and barriers to achieving FQOL within the family system (i.e., spouses/partners and extended family members).

Parental relationships. Parents often look to each other for support as they meet the daily demands of caring for their child with a disability. Kersch and colleagues (2006)

analyzed data collected from families participating in a longitudinal study of the

development of children with disabilities and family adaptation ($N = 67$) and found that

higher marital quality, characterized by shared activities and agreement between partners

on household tasks, decision making, and recreation, buffered parents from experiencing

elevated levels of stress. Skok and colleagues (2006) utilized structured interviews and

self-report surveys with mothers of children with cerebral palsy to examine relationships

among severity of childhood disability, parental stress, levels, and support from family

and friends. Results indicated that when parents perceived their partners as supporting

them in their parenting role they were less likely to view situations as stressful and they

felt more able to effectively manage the demands of stressful situations (Shok, Harvey, &

Reddihough, 2006). Positive relationships between parents of children with disabilities

also have been found to improve mothers' and fathers' mental health. Kersch and

colleagues' (2006) found that the marriage quality of parents of children with disabilities

predicted overall parental mental health functioning regardless of family socioeconomic

status, child characteristics, and amount of social support the family received.

Unfortunately, it has been documented in the literature that raising a child with a

disability may negatively impact the relationship between the child's parents (Kersch et

al., 2006; Risdal & Singer, 2004; Urbano, Hodapp, & Floyd, 2007). Kersch and

colleagues' (2006) found that parents reported lower-quality marriages than couples of

children without disabilities, with approximately 25% of parents in the study describing

their marital relationship as strained. Risdal and Singer (2004) conducted a meta-analysis

of studies involving families of children with developmental disabilities and chronic

illness and found that while marriage difficulties of parents of a child with a disability

may not be as common as once believed, these parents did experience more marriage difficulties than parents of typically developing children. Urbano and colleagues (2007) compared divorce rates of parents of children with birth defects ($n = 10,283$) and typically developing children ($n = 361,154$) and found that marriages of parents raising children with birth defects were more likely to end in divorce than marriages of parents of typically developing children.

Enhancing parental relationships and preventing discord has been proposed as some of the most effective means of promoting overall well-being of parents of children with disabilities (Sloper, 1999). Therefore, mental health service providers need to be aware of the potential for parents of children with disabilities to experience difficulties in their relationships with each other and provide support as appropriate. This support could take the form of encouraging parents of children with disabilities to consider private counseling services and sharing knowledge with parents regarding practitioners in the area available to provide family counseling (see Table 1).

Extended Family. Parents often rely on extended family members for support when caring for a child with a disability (Brown, Anand, Alan Fung, Isaacs, & Baum, 2003). In a study of parents of children with intellectual disabilities ($N = 34$) mothers reported receiving practical help from extended family members, particularly in the sharing of child care responsibilities (Pal, Das, Chaudhury, & Sengupta, 2005). Grandparents have been noted to play an important role in supporting parents of a child with a disability. In a study of mothers ($n = 22$) and fathers ($n = 3$) of children with disabilities (e.g., genetic disorders, birth defects, medical disorders), Hornby and Ashworth (1994) found that grandparents, particularly maternal grandparents, assisted

with childcare and transportation of their grandchild with a disability. Harris and

colleagues (1985) conducted a study involving mothers, fathers, grandmothers, and

grandfathers of 19 children with autism and reported that maternal grandmothers are

empathetic toward their daughter's difficulties raising their child with a disability.

Maternal grandmothers provided the most support of all grandparents, which was helpful

in buffering maternal stress levels (Harris, Handleman, & Palmer, 1985). In a qualitative

study of grandparents of children diagnosed with autism spectrum disorder ($N = 6$), semi-

structured interviews revealed that grandparents of children with disabilities were

particularly helpful in supporting parents as they advocated for their child (Margetts,

Lecourteur, & Croom, 2006).

    However, many parents have reported that the amount and type of support they

received from extended family members was not enough to assist them in effectively

managing their child's disabilities (Brown et al., 2003). For example, while parents of

children with a range of disabilities (e.g., genetic disorders, medical disorders) ($N = 34$)

reported they received emotional support from extended family members they did not

receive adequate practical support (Brown et al., 2003). Brown and colleagues

hypothesized this lack of practical support may be related to a lack of "knowledge or

comfort level" (Brown et al., 2003, p. 226) that extended family members may possess

about caring for individuals with disabilities. The authors also hypothesized that a lack of

involvement from extended family members may be attributed to geographical barriers

(Brown et al., 2003).

    Additional factors (e.g., disagreement regarding treatment, emotional distance

between family members) may explain the lack of support parents of children with

disabilities may receive from extended family members. Upon reviewing empirical studies of grandparents of children with autism, Hillman (2007) posited that parents of children with disabilities may disagree with their parents over treatment for the child's disability and discipline practices. In a longitudinal study of 64 families of children with developmental disabilities (i.e., mental retardation, autism spectrum disorder, developmental delay, cerebral palsy) elevated parental stress levels were related to increased emotional distance between the relationships with in-laws (Trute, 2003).

Recommendations for mental health service providers within the family system. Mental health service providers might alleviate family discord brought on by disagreement regarding child rearing of the child with a disability by educating family members in communication and conflict resolution skills (Hillman, 2007) (see Table 1). It also may be beneficial for mental health service providers to assist family members in defining their individual roles and responsibilities and related to the child with a disability (Kazak & Marvin, 1984) (see Table 1). By ensuring family members understand the child's disability and their respective roles and responsibilities discord between family members regarding child rearing and discipline may be alleviated.

Informal Social System

Informal social support refers to assistance given to families of a child with a disability by their friends. Parents of a child with a disability have reported they often rely heavily on support from friends (Dillenburger, Keenan, Doherty, Alvin, & Tony, 2010) for childcare, assistance with daily tasks, and for emotional support. Crnic and Low (2002) cited social support in the form of friendships as particularly helpful in protecting parents of children with disabilities from experiencing elevated levels of stress.

Duvdevany and Abboud (2003) conducted a study of Israeli mothers ($N = 100$) to examine the influence of informal social support on maternal stress levels. Results indicated that mothers who received the most assistance from friends were less likely to suffer from elevated levels of stress and were more likely to report feelings of well-being (Duvdevany & Abboud, 2003). Britner and colleagues (2003) analyzed data from self-report surveys completed by 87 mothers of young children with disabilities and found that parents who reported adequate support from friends also reported higher levels of overall well-being. Rogers (2007) reviewed interviews and personal narratives of parents raising children with disabilities and discerned that when parents perceived themselves as having adequate informal social support they felt more empowered, experienced fewer marriage difficulties, utilized more effective coping strategies, reported feeling more emotionally secure, and had a greater sense of autonomy (Rogers, 2007).

Having a child with a disability also may have a negative impact on parents' informal social system, including their ability to establish friendships and participate in leisure activities they find enjoyable (Redmond & Richardson, 2003; Wodehouse & McGill, 2009). Kerr and McIntosh (2000) conducted interviews of families of children born with congenital upper limb deficiency ($N = 63$). They found that parents reported a lack of friend support in accepting the new baby, oftentimes because the friends were also grieving over the baby's disability. In addition, mothers of children born with congenital upper limb deficiency tended to avoid interacting with other new mothers because they viewed their child as being very different from a typical newborn (Kerr & McIntosh, 2000). Kazak and Marvin (1984) compared families ($N = 100$) of children with spina bifida to families of typically developing children and found that the parents of a

child with a disability lacked opportunities to establish long-term friendships. The authors

hypothesized these results were possibly due to the increased amount of time mothers of

children with disabilities spent caring for their child and the amount of time fathers work

to maintain financial stability (Kazak & Marvin, 1984) which decreased their ability to

establish friendships, pursue leisure activities, and follow through with family plans.

Recommendations for mental health service providers within the informal

social system. Mental health service providers are in a unique position to enhance

informal social support among families of children with disabilities by encouraging

parents to join community support groups for families of children with disabilities (Kerr

& McIntosh, 2001). These support groups would provide parents an opportunity to meet

other parents of children with similar needs, share their experiences, identify shared

interests, and develop friendships based on empathy and understanding for each other's

needs as they strive to raise their child with a disability. As mental health service

providers address the needs of parents, they should not lose sight of the fact that parents

wish to increase the friendship network of their child with a disability (Freedman &

Capobianco Boyer, 2000; Siklos & Kerns, 2006). In order to provide children with

disabilities the opportunity to establish friendships, mental health service providers could

research the extracurricular activities (e.g., recreational sports, Girl Scout, Boy Scouts,

etc.) that are appropriate for children with disabilities in the community and encourage

parents to enroll their child in those activities (see Table 1).

School System

Children with disabilities often receive special education support within public

school systems to address their individual education needs. Parents have reported

satisfaction with support they receive from school, as evidenced in Applequist's (2009)

work study of parents of children with disabilities ($N = 32$) that attended public school.

Those parents reported being pleased when they learned that their child could receive

school services at no cost. In addition, the parents were satisfied that the transportation

services provided by the school were provided at no cost, which was particularly helpful

for those parents who lacked reliable transportation (Applequist, 2009).

Even though research has shown benefits of parents of children with disabilities

participation in their child's education (Shelden, Angell, Stone, & Roseland, 2010) there

is evidence that this is not commonly practiced (Hess, Molina, & Kozleski, 2006).

Unfortunately, federal, state, and local-level interpretations of parental empowerment and

involvement most often reflect the minimal amount required by law and as a result,

parents are not recognized as equal partners in their child's education. At the local level,

school administrators and professionals often define how and to what extent parents are

involved. In their conceptual paper regarding equity and advocacy expectations as well as

parental participation in special education decision-making within legal mandates

Kaylanpur and colleagues (2000) contend an imbalance in power certainly exists, and it is

even more pronounced between culturally and linguistically diverse parents and school

personnel. In their focus groups of parents of children with disabilities (e.g., learning

disabilities, cognitive disabilities, emotional disorders) ($N = 27$) Hess and colleagues

(2006) found that parents felt as though they were allowed very little input in the

educational decisions made for their child. Particular concern was expressed regarding

level of communication between parents and teachers, including information regarding

their child's needs, academic progress, and behavior. The United States Department of

Education (2003) reported that African American and Hispanic parents of children with disabilities are less likely to engage with the local school system than White parents. Keyes (2000) proposed that the lack of school involvement of minority parents of children with disabilities may be due to cultural differences between the family and the school system, such as the belief that educators, not parents, are authority figures in regard to their child's education. Additional barriers may exist for minority parents, as evident in Cassidy's (1988) study of 24 African American parents raising children with disabilities. Parents in this study cited scheduling difficulties, transportation issues, and lack of understanding of the process involved in the development of their child's Individual Education Plan (IEP) as contributors to their lack of involvement with their child's school.

Al-Hassan and Gardner (2002) identified additional barriers that limit school participation by immigrant parents of students with disabilities, such as lack of familiarity with and understanding of the American public education system, differences in communication styles, and limited English proficiency. In addition, Turney and Kao analyzed data collected from the Early Childhood Longitudinal Study – Kindergarten Cohort (National Center for Education Statistics, 2001) and found that Hispanic and Asian immigrant parents did not feel welcome in their child's school, they struggled with language barriers, and were more likely to lack transportation than native-born parents, each of which deterred them from participating in their child's school.

Recommendations for mental health service providers to increase parental empowerment within the school system. Mental health service providers within schools (e.g., school counselor, school psychologist, school social worker) are in a unique

position to empower parents of children with disabilities to advocate for their children.

Hess and colleagues (2006) suggested this could be accomplished through utilization of

parent education opportunities and parent mentors. School-based mental health service

providers could foster families' needs to have their hopes and concerns for their children

heard by school personnel (Hess, Molina, & Kozleski, 2006) by creating opportunities for

parents to meet with school personnel to voice their concerns openly. In order to increase

communication between parents of children with disabilities and the school, mental

health service providers may wish to encourage school administrators to utilize a variety

of communication means, such as written notes, newsletters, email, bulletin boards, and

teacher conferences that can be conducted via phone and/or face to face (Ratcliff & Hunt,

2009) (see Table 1).

   Recommendations to increase participation of fathers within the school system.

To increase fathers' participation, school-based mental health service providers may wish

to provide parental programs at times (e.g., evenings, weekends) convenient for fathers

whose work schedules prohibit their ability to participate during the typical school day

(Palm & Fagan, 2008). School-based mental health providers should also be aware that

making home visits has been found to increase the participation of fathers of children

with disabilities (Raikes & Thompson, 2005) and as such they may wish to consider

scheduling meetings in the student's home. Mental health service providers within

schools may also want to consider creating "father-only activities" (Palm & Fagain, 2008,

p. 755), such as designating a day for fathers to eat lunch with their children or

organizing a sports activity on the weekend for fathers to participate in with their children

(see Table 1).

Recommendations to meet the needs of minority families of children with

disabilities within the school system. To effectively support minority families of children

with disabilities it is important that school-based mental health providers utilize family

supports that are flexible, sensitive to family beliefs, and incorporate families' cultural

values (Freedman & Capobianco Boyer, 2000). Such supports may include programs that

focus on parental empowerment and outreach, which has been helpful in increasing

parental empowerment and outreach for minority families (Abdul-Adil & Farmer, 2006).

Mental health service providers in the school should ensure interpreter services are

provided for parents who are not proficient in the English language (Sohn & Wang,

2006) and work with school administrators to ensure that all school information and

correspondence is provided through oral or written means in the family's native language

(Freedman & Capobianco Boyer, 2000). In order to further support minority families of

children with disabilities, school-based mental health providers may wish to develop

parental education opportunities (e.g., English language skills, cultural adaptation,

parenting skills, public school system policies) (Sohn & Wang, 2006) (see Table 1).

Church/Religious System

Parents of children with disabilities may be involved with a church or other

religious organization. In a study of 30 parents of children or adults with developmental

disabilities attending evangelical Christian churches, the parents reported their religious

affiliation was particularly helpful in providing opportunities for social interactions with

others and fostering growth of spiritual beliefs (Treloar, 2002). In their study of 34

parents of children with disabilities, (i.e., intellectual disability and genetic disorders,

attention-deficit/hyperactivity disorder, medical disorder), Brown and colleagues' (2003)

found that parents' religious beliefs and involvement with their church or religious

organization contributed to their ability to achieve and maintain a life of quality. In

addition, these parents reported having the opportunity to join in religious practices, such

as church activities, perceived emotional support, and strength derived from their

spiritual beliefs (Brown et al., 2003).

Although some parents of a child with a disability felt they were able to access

various aspects of their church or religious organization (e.g., Brown et al., 2003; Treloar,

2002), other parents reported barriers encountered as they attempted to engage in a

spiritual life of their church (e.g., Smith, 2010). Smith (2010) cited physical barriers

within the church building as problematic for children and individuals with disabilities

who have motor impairments. These physical barriers may impede families of children

with disabilities from ambulating around the building or participating in various

activities, such as classes and services (Smith, 2010). Aside from physical barriers,

children with disabilities often require specialized care that extends beyond that required

for typically developing children. In a study of parents of children and adults with

disabilities, Treloar found that parents of children with disabilities ($N = 30$) felt as though

their child was not integrated into the church due to a lack of understanding by church

leaders regarding how to include their child in church activities (Treloar, 2002). The

parents also reported feeling dissatisfied with their child's acceptance into the church

community, and felt as though their child with a disability was perceived as a burden on

the church's financial resources (Treloar, 2002). Speraw (2006) conducted a study of

parents of children with disabilities ($N = 26$) from 15 different denominations and found

that parents reported their church or other religious organization failed to recognize the importance of developing their child's spiritual life.

Recommendations for mental health service providers within the spiritual system. Mental health service providers may consider determining whether or not families of children with disabilities wish to be involved with a church or religious affiliation. This could be accomplished during the initial in-take interview with the family. It might be helpful for mental health service providers to establish open communication with local religious affiliations in order to advocate for inclusion of these families within the church/religious community. Church and religious leaders may lack knowledge about the child's disability, and mental health service providers could provide information regarding the child's disability and specific needs the child and family may require (e.g., specialized audio-visual equipment, installation of ramps or elevators, wider pews, seating arrangements to accommodate walkers and wheelchairs) (Smith, 2010) as they integrate themselves into the religious establishment (see Table 1).

Social Service Support System

Aside from relying on family members, friends, and the church for support, many parents of a child with a disability also utilized social service supports in order to improve their quality of life. The following section will review several of the main types of social service supports utilized by parents (i.e., financial assistance, medical care, community programs) designed specifically for individuals and families of children with a disability.

Financial assistance. Many families of children with disabilities receive financial assistance from government agencies and programs in order to assist them with the

increased financial burden of raising a child with a disability. This type of support has

been cited by families of a disabled child as one of the most helpful types of support they

receive (Herman, 1994), particularly by reducing the amount of out-of-pocket expenses

(Caldwell, 2007) and providing a means to employ caretakers for their child with a

disability (Caldwell & Heller, 2003). In their theoretical article, Parish and Cloud (2006)

identified many needs associated with raising a child with a disability (e.g., private

therapy, adaptive equipment, and medication) that often lead to financial strain for the

family. This increased financial burden is particularly problematic for families of low

SES and as a result, these families will require additional monetary assistance (Park et al.,

2002) and support than low-income parents of typically developing children. Marcenko

and Meyers (1994) interviewed 81 families of children with disabilities prior to receiving

their monthly subsidy ($225) and again one year later. The parents of lower SES reported

that the financial subsidy was helpful in meeting their child's and family's needs. Allard

and colleagues (1993) conducted a study of the Family Cash Assistance Project three

years after it was initiated and found that the additional financial support improved

families' feelings of empowerment, they had more work opportunities, they were less

stressed, functioned more independently, and were more successful at integrating their

child with a disability into the community.

Unfortunately, parents of a child with a disability do not always receive adequate

financial support (Freedman & Capobianco Boyer, 2000; Parish & Cloud, 2006).

Braddock (2007) identified inequities in financial support that existed throughout our

society for families of children with disabilities despite growing from 2.3 billion in 1955

to 82.6 billion in 2004. In their conceptual article, Parish and Cloud (2006) reported that

the financial assistance received by families of a child with a disability does not always cover all their child's expenses. Freedman and Capobianco Boyer (2000) utilized focus group interviews and discussion to examine the perspectives of parents of children with disabilities ($N = 31$) regarding their experiences with and impact of family supports and found that the availability of and timely reimbursement of funds was problematic for parents of children with disabilities, many parents were required to pay out of pocket for services, and the amount of time to receive reimbursement from governmental agencies was excessive. In addition, these parents felt disrespect for their time, privacy, and dignity due to excessive record keeping requirements mandated by the government agencies prior to reimbursement of funds paid out of pocket.

Recommendations for mental health service providers regarding financial assistance. Mental health service providers are in a position to advocate for policy changes that would increase the financial assistance provided to families of children with disabilities. The Federal Poverty Level (FPL; 2002) does not consider the additional costs of raising a child with a disability and as a result, many families did not receive the financial assistance that they desperately needed (Parish et al., 2008). It may be helpful for mental health service providers to encourage policy makers to examine the eligibility requirements for financial assistance to ensure more families of children with disabilities receive the financial support they need (Parish et al., 2008). Specific areas mental health service providers could address include increasing the asset amount of government sponsored health insurance (i.e., Medicaid) provided to families of children with disabilities, increasing the amount of financial assistance provided by Social Security Supplemental Income (SSI), and raising the family income limit so more families of

children with disabilities receive SSI and housing subsidies (Parish et al., 2008) (see

Table 1). In addition, mental health service providers may wish to support policy reform

proposed by the Children's Defense Fund (1999). The proposals include allowing

exemptions from welfare-aid cutoffs for families who meet state define hardship criteria,

encouraging states to utilize their own funding to support families of children with

disabilities, and increasing efforts to identify families eligible to receive Medicaid and

food stamps.

Mental health service providers will need to remain cognizant of the unique needs

of single mothers of children with disabilities (Parish, Rose, Grinstein-Weiss, Richman,

& Andrews, 2008) and work to identify those families within the community. Single

mothers of children with disabilities may lack the opportunity to gain employment or

attend school due to caretaking responsibilities and inability to afford childcare. Mental

health service providers could address this by advocating for the development of low-cost

childcare programs that will allow single mothers the opportunity to work or further their

education (see Table 1).

Medical care. Many children with disabilities have medical needs surpassing that

of typically developing children. Healthcare professionals not only share information

with parents of children with disabilities regarding their specialized needs, they are also

in a unique position to allay parents' fears and anxieties about their child's disability

(Sallfors & Hallberg, 2003). Cavallo and colleagues (2009) examined coping

mechanisms of parents of children receiving therapy due to physical disabilities ($N =$

150) and discovered that communication with healthcare professionals was especially

helpful to parents, especially those with younger children. The authors speculated that the

time of diagnosis is particularly difficult for parents, which may result in their seeking answers from the healthcare professionals more so than after the diagnosis is no longer new.

However, obtaining adequate information from healthcare professionals regarding their child's diagnosis is oftentimes difficult for parents. For example, Carraccio and colleagues (1998) surveyed parents and caregivers of children with disabilities ($N = 49$) who accompanied their child to appointments with specialists and found that only half were able to adequately describe their child's disability. Kenny and McGilloway (2007) conducted a study of 32 parents of children with low cognitive abilities and found that many parents did not receive adequate information regarding their child's disability at the time of diagnosis or thereafter.

Recommendations for mental health service providers within the medical care system. Mental health service providers may wish to communicate with local medical professionals to explain the importance of providing families of children with disabilities information regarding the etiology of the disability, treatment, and prognosis in a manner that is easy to understand. Additionally, mental health care providers may wish to encourage health care professionals to listen to parents' experiences with their child, trust in parents' intuition regarding their child's needs, and respect the personal knowledge parents have obtained about their child with a disability (Grant, Ramcharan, & Flynn, 2007) (see Table 1).

Community support services. Families of children with disabilities often utilize community support services, such as governmental agencies, private practitioners, and community organizations to address their child and family's needs (Schalock et al.,

2007). The goals of these services range from addressing the specific needs of the child

with a disability to providing in-home support to families as they meet their family's

needs. In a study of 30 families utilizing community services, Greeff and colleagues

(2006) found the families who accessed the most community services had lower levels of

stress and were better able to adapt to the challenges they faced in their lives more than

families who accessed fewer services. Cavallo's study of parents of children with

physical disabilities ($N = 150$) indicated that parents with only a high school diploma

found that community support services helped them cope with meeting their child with a

physical disability's needs which they speculated was related to a lack of financial

resources which led to their seeking out social services for financial support. In addition,

working parents also reported community support services as useful in helping them meet

their child's needs, which they posited may be because working parents rely on

community services for child care during the day.

However, parents have reported difficulty obtaining information about and

gaining access to community support services. This was evident in Freedman and

Capobianco Boyer's study of 31 parents of children with developmental disabilities in

which parents reported difficulty discerning how to enter the system and it was also

difficult for them to determine the specific types of community support they needed and

were eligible to receive, they expressed dissatisfaction due to inflexibility and the lack of

choice when selecting a provider. Strict and rigid eligibility criteria were specifically

cited as a barrier to accessing community services and many parents reported the lack of

coordination between agencies negatively impacted their ability to access all services that

might be beneficial for improving FQOL. Brown and colleagues (2003) interviewed

parents of children and adults with developmental disabilities and discovered that parents felt the quality of community services they received were inadequate and did not effectively meet their needs.

Aside from the formal supports available through community support services, parents also reported the need for community services to provide means through which their child's social life could be enhanced (Brown, 2008). Siklos and Kerns (2006) assessed the needs of families of children with Down syndrome ($n = 56$) and autism ($n = 32$) and found that parents of children with Down syndrome reported the need for community programs to provide their children with opportunities to develop friendships with other children. A similar need was evident in Freedman's and Capobianco Boyer's work (2000) in which many parents expressed the desire for community programs to provide weekend activities for children with disabilities as well more opportunities for their child to establish friendships.

Recommendations for mental health service providers within community support systems. In order to address the parental needs related to understanding their child's disability mental health service providers should ensure the information they provide to families of children with disabilities is current and easy to understand (Freedman & Capobianco Boyer, 2000). In addition, mental health service providers should be willing to provide specialized information targeted for specific types of families (e.g., medically fragile children, minorities) to address their unique needs (Freedman & Capobianco Boyer, 2000). Mental health services providers may be able to identify community resources that can be combined to reduce the amount of time and travel for families of children with disabilities. In addition, mental health service

providers may be able to provide better support for the entire family by identifying supports required within various systems and coordinating those services. This could be accomplished as part of the intake process by simply asking about the family's involvement with other services (see Table 1). A final recommendation is for mental health service providers remember that some families of children with disabilities may struggle with reading and understanding the information they receive and they may not have access to computers to research support options (Darrah et al., 2002). Therefore, mental health service providers should share information via other methods of communication, such as a telephone hotline and community television (see Table 1).

Respite care. A specific community service available to some families of children with disabilities is respite care. Initially, respite care was conceptualized as a means for providing parents and families a break from the responsibilities of caring for their child with a disability (Stalker & Robinson, 1994) in an attempt "to enable families to regrow their ability to function at home as individuals and as a family" (Brown, 2008, p.8). In a study of 14 mothers of children with disabilities who utilized respite care, mothers reported that during the time their child with a disability was placed in respite care, they engaged in more social and leisure activities, felt less depressed, and experienced a great sense of overall well-being (Botuck & Winsberg, 1991). Today, the conceptualization of respite care has evolved and not only includes the component of providing a break for parents and families it also includes a means to benefit the child with a disability while they are there (Cotterill, Hayes, Flynn, & Sloper, 1997)., Interestingly, little attention has been given in the literature of the impact of respite care on child-related characteristics. One longitudinal study was identified that examined the

impact of respite care on school achievement. Based upon data collected from 13,176 students receiving special education services who had also been placed in respite care, results revealed a significant, positive, and moderate relationship between respite care and academic achievement across time (Barnard-Brak & Thomson, 2009).

Oftentimes, respite care centers are not located in the community in which the child lives which reduces the likelihood that some families are able to utilize them for their child. Dowling and Dolan (2001) conducted interviews with parents of children with disabilities, consumers of respite care, and providers of respite care services. They found that many parents were required to commute approximately 50 miles each way to reach a respite care facility and parents did not feel the benefits of respite care outweighed the inconvenience of the amount of time spent transporting their child to and from the respite care facility. In addition, parents who were unable to drive or lacked transportation, experienced difficulties arranging transportation to a facility so far from home and as a result were not able to utilize respite care services for their family (Dowling & Dolan, 2001). Additional barriers that may interfere with a family's utilization of respite care have been reported by respite care services providers. In a study of 90 respite service providers, availability of appropriate funding, availability of respite services in rural areas, and availability of trained staff were identified as barriers families may encounter when attempting to utilize respite services (Chan, 2008).

Recommendations for mental health service providers regarding respite care. Mental health service providers should advocate that providing parents a break from the overwhelming caretaking demands of raising a child with a disability and providing services that benefit the child as well remain at the forefront of respite service. By doing

this the focus remains on what is best for the parents and their child rather than what is best for the health care professionals (Dowling & Dolan, 2001). Service providers might eliminate these transportation barriers by working with other agencies within the community as well as those in other communities to provide transportation by social services. Another way to decrease the inconvenience of lengthy commutes to respite centers is to develop local inter-disciplinary facilities that incorporate both out-patient treatment centers and respite care into one facility (Chan, 2008; Cigno & Gore, 1999) (see Table 1).

Advocacy

Perhaps one of the most important ways in which mental health service providers can assist families in achieving FQOL is to join with them to advocate for the needs of their family and their child with a disability across all ecological systems. The primary focus of advocacy outcomes is improving services and supports for individuals with disabilities and their families (Wang, Mannan, Poston, Turnbull, & Summers, 2004). As a result, three core principles of family advocacy have emerged: respecting families' priorities and decisions, helping families achieve their goals, and implementing social service supports that increase the family's capacity to function within their communities (Wang et al., 2004).

Parents of children with disabilities often find they have to advocate for services within ecological systems, such as in school to receive an appropriate individualized education plan, with physicians to ensure optimal medical treatment, and with service providers to ensure their family receives services for which they are eligible. Research suggests that parents that advocate for their children displayed higher coping skills while

they also experienced higher levels of stress and decreased quality of life as a result of the struggles they face while advocating for their family's needs (Wang et al., 2004; Nachslen, 2000). FQOL researchers working withini an ecological framework have embraced the notion of joining with families as they advocate for their ability to function within all aspects of society. Wang et al. (2004) suggested mental health service providers across systems may be able to reduce parental stress levels and improve family quality of life by joining with them as active partners in advocating with the family for the best services possible. Van Harem and Fiedler (2008) suggested school personnel should strive to be empathetic toward all families and their needs, allow for individualization of family participation, acknowledge families are experts about their needs, and build on the strengths of each family member. These suggestions seem appropriate for all mental health service providers when advocating for families of children with disabilities across all ecological systems.

Conclusion

Numerous barriers to establishing and maintaining lives of quality continue to exist for many families of children with disabilities across the systems. Mental health service providers are in a unique position to advocate for families and assist them in decreasing the barriers they encounter by increasing the family's supports. As mental health service providers advocate for families across systems it is important that they remain aware that a life of quality means different things to different people, depending on their culture, age, socio-economic status, individual personalities, and family dynamics. Therefore, a final recommendation to practitioners is to above all involve the family in each and every stage the service planning process, empower them as they make

decisions for themselves, and respect their decisions. In this way, mental health service

providers can assist families of children with disabilities in achieving the lives they strive

to possess for each and every member of their family.

Table 1

Recommendations and Practical Suggestions for Mental Health Service Providers

	Recommendations for Mental Health Service Providers	Practical Suggestions for Mental Health Service Providers
Family System	Be aware of the potential for parents to experience difficulties in their relationships with each other and provide support as appropriate (Kersch et al., 2006; Risdal & Singer, 2004; Urbano, Hodapp, & Floyd, 2007).	•Inform parents it is not uncommon to experience relationship difficulties. •Ask parents to describe their relationship with each other. •Encourage parents to consider private counseling services should they begin experiencing difficulties in their relationship. •Provide a list of family/marital counselors in the community.
	Educate family members in communication and conflict resolution skills (Hillman, 2007).	•Encourage family members to openly communicate with each other on a regular basis. •When conflicts arise, encourage families to remain calm, communicate assertively, and work to find a solution everyone agrees upon.
	Help family members define their roles and responsibilities within the family (Kazak & Marvin, 1984).	•Encourage family members to discuss their needs related to the child with a disability and with each other. •Facilitate a discussion of roles and responsibilities each family member could assume to meet those needs.

Informal Social System	Provide parents of children with disabilities information about support groups in the community (Kerr & McIntosh, 2001).	• Create a pamphlet for parents that lists, describes, and gives contact information for support groups.
	Facilitate family's engagement with support groups.	• Obtain information regarding date, time, and location of support groups. Share this information with parents. • Volunteer to attend a support group meeting with parents if they are uncomfortable with meeting with others they do not know.
	Encourage the development of support groups within the community.	• Encourage parents to begin meeting to provide support to each other. Facilitate initial meetings if necessary.
	Share information regarding extracurricular activities in the community with the family, emphasizing those appropriate for children with disabilities (Freedman & Capobianco Boyer, 2000; Siklos & Kerns, 2006).	• Identify extracurricular activities in the community. Contact the directors and ask about appropriateness of the activity for children with disabilities. • Create a pamphlet to share with parents that lists, describes, and provides contact information for extracurricular activities.
School System	Provide parent education opportunities to address parents' needs and interests. These educational opportunities could include instruction in the English language, cultural adaptation, parenting skills, specific disabilities, and information regarding public school system (Hess, Molina, & Kozleski, 2006).	• Conduct a needs assessment to determine parents' wants and needs/interests. • Once needs/interests are identified, contact experts in the community and ask if they would be willing to facilitate a class to share their knowledge/expertise with parents. • Consider holding classes on Saturdays in the school building. This will allow for numerous classes to occur at one time and increase the likelihood that parents will be able to attend.

Use parent mentors to help parents feel empowered and encourage them to advocate for their children.	• Identify parents of children with disabilities that are knowledgeable about public school services for children with disabilities and who are actively involved in the school. Ask if they would be willing to serve as a liaison between other families of children with disabilities and the school.
Foster open communication with parents to ensure they feel as though their thoughts and concerns are important and being heard (Hess, Molina, & Kozleski, 2006).	• Utilize a variety of communication means, such as written notes, newsletters, email, bulletin boards, and teacher conference conducted via telephone and/or face to face (Ratcliff & Hunt, 2009). • Provide opportunities for parental feedback and for parents to share opinions and ideas regarding school. Could be accomplished at a PTA meeting or open forum.
Ensure parental activities and education opportunities are accessible to all parents, including fathers (Palm & Fagan, 2008).	• Consider holding meetings in the evenings to increase the likelihood that parents will be able to attend. • Schedule school activities for evenings or weekends to increase the likelihood that parents will be able to attend. • Consider holding meetings at the student's home at a time convenient for parents (Raikes & Thompson, 2005).
Create "father-only" activities for fathers to attend with their child (Palm & Fagain, 2008, p. 755).	• Such activities might include a father-student lunch, sports activity held on the weekend, or a father-daughter dance.
Be sensitive to families' cultural beliefs, particularly minority families, as they relate to education, family involvement in their child's school, disability etiology, child-rearing, etc (Freedman & Capobianco Boyer,	• Research cultural beliefs and practices of the various ethnicities represented in the school. • Hold meetings with parents to learn about their specific beliefs and experiences. Ensure they do no feel as though they are being judged but

	2000).	instead are helping the school better understand how to serve/support their family and child.
	Encourage parents to be involved in all aspects of the school. Ensure they understand they are a welcomed and valued member of the school community.	• Welcome parents when they visit the school. Provide opportunities for them to become involved (e.g., helping in the media center, reading to classes, helping plan class activities, chaperoning on field trips). • Ask parents of children with disabilities for ideas and suggestions regarding fund raisers and school-wide activities (e.g. field day, award ceremonies). • Be sure to ask parents about special needs their child has to ensure they are able to fully participate in all school activities.
	Provide interpreter services. Ensure all oral and written information and correspondence is provided in family's native language (Sohn & Wang, 2006).	• Utilize interpreters employed by the school system. If none are available utilize means such as language lines. • Identify leaders of minority churches and religious affiliations who are willing to attend meetings to interpret for parents and school personnel.
Spiritual	Determine if family is involved with or wishes to be involved with a church or other religious organization.	• Upon initial family in-take meeting, ask about the family's involvement and/or interest in being involved with a church or other religious organization.

	Foster and maintain open communication with church and other religious affiliations in the community.	• Hold a meeting with community religious leaders. Share with them the positive impacts spirituality has on the lives of families of children with disabilities. • Stress the importance of inclusion of children with disabilities into activities with typically developing peers. • Provide religious leaders with ways in which to contact you should they need information regarding disabilities or resources available in the community.
	Provide church and religious leaders with information about the child's disability. Facilitate a meeting between the family and church leaders to communicate their wants, needs, and expectations from the church (Smith, 2010).	• Develop handouts that explain the child's disability. Distribute the handouts to religious leaders in the community. • Share with families the importance of communicating their wants, needs, and expectations from their church or other religious affiliation. • Encourage families of children with disabilities to meet with their religious leader. Offer to attend the meeting with them if they so desire.
Social Service System - Financial Assistance	Advocate for policy changes to increase financial assistance provided to families (Parish et al., 2008).	• Encourage policy makers to examine eligibility requirements for financial assistance to ensure more families of children with disabilities receive the financial support they need. • Lobby for an increase in asset amount allowed to families from government sponsored health insurance (Medicaid). • Lobby for an increase in financial assistance provided by Social Security Income benefits (SSI). • Lobby for an increase in the family income limit so more children with disabilities receive SSI.

Social Service Support – Medical Care	Be aware of vulnerability to poverty of certain families (e.g., single mothers). Actively work to identify those families to ensure they are receiving all the financial support they are eligible for (Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008).	• Ask parents to share information regarding their income and the financial supports they receive, if any. • Provide parents with information regarding the financial assistance they are eligible to receive. • Facilitate families' initial contact with financial assistance programs and continue to monitor their involvement over time.
	Communicate with medical professionals to ensure they understand the value parents of children with disabilities place on information provided by medical professionals.	• Initiate contact with medical professionals by writing a letter introducing yourself and your involvement with families of children with disabilities. • Share information with medical professionals about parents' reliance on them for support and reassurance for their child with a disability.
Social Service Support – Community Services	Ensure medical professionals understand the importance of providing parents of children with disabilities specific and clear information regarding their child's disability, prognosis, and medical needs (Freedman & Capobianco Boyer, 2000).	• Stress to medical professionals the importance of taking the time to talk with parents of children with disabilities, particularly at the time of diagnosis, to share information regarding the disability, prognosis, medical needs, and answer any questions the parents may have.
	Service providers should ensure the information that they provide to families of children with disabilities is clear and up to date (Freedman & Capobianco Boyer, 2000). Information provided should include information targeted for specific types of families (e.g., medically fragile, minorities) to address their unique needs (Freedman & Capobianco Boyer, 2000).	• Actively work to maintain up-to-date knowledge of various types of services, eligibility criteria, and service benefits for those services accessed by families of children with disabilities. • Be sure to obtain information specific to all types of families served. Share this information with families and encourage them to access all services they are eligible to receive.

	Methods of communication regarding support options should encompass various means to ensure all families have access to that information (Darrah et al., 2002).	• Provide families with various means to access information regarding community support services (e.g., internet, telephone hotline, community television, correspondence in the mail).
	Identify areas in which families are functioning adequately as well as those in which they require additional support.	• Upon initial in-take meeting with a family, utilize a comprehensive questionnaire that incorporates questions regarding the family's functioning across a range of areas (e.g., spouse/partner relationship, income, health of all family members, transportation, etc.).
		• Identify areas in which families are weak and explore immediate supports to address those needs.
Social Service Support – Respite Care	Advocate that respite care keep parental breaks and child benefits at the forefront of their mission (Cotterill, Hayes, Flynn, & Sloper, 1997; Stalker & Robinson, 1994).	• Initiate a professional working relationship with personnel of respite centers. Openly communicate the family's needs and expectations regarding respite care.
	Provide transportation to and from respite centers to alleviate families' length of time traveling or difficulties arising from lack of transportation (Cigno & Gore, 1999).	• Work with other community agencies to pool resources to provide transportation to respite services by social services.

References

Abbeduto, L., Mailick Seltzer, M., & Shattuck, P. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation, 109*(3), 237-254. doi: 10.1352/0895-8017(2004)109<237:PWACIM>2.0.CO;2

Abdul-Adil, J. K., & Farmer, A. D. (2006). Inner-city African American parental involvement in elementary schools: Getting beyond urban legends of apathy. *School Psychology Quarterly*, *21*(1), 1-12. doi: 10.1521/scpq.2006.21.1.1

Al-Hassan, S., & Gardner, R. (2002). Involving immigrant parents of students with disabilities in the education process. *Teaching Exceptional Children, 34*(5), 52-59.

Allard, M. A., Gottlieb, A., & Hart, D. (1993). *Impact study of the family cash assistance project: Year three results*. Waltham, MA: Shriver Center, Department of Social Science, Ethics and Law.

Applequist, K. L. (2009). Parent perspectives of special education: Framing of experiences for prospective special educators. *Rural Special Education Quarterly, 28*(2), 3-16.

Bailey, C. B., Hebbeler, K., Scarborough, A., Spiker, D., Mallik, S. & Nelson, L. (2005). Thirty-six-month outcomes for families of children who have disabilities and participated in early intervention. *Pediatrics, 116*, 1346-1352. doi: 10.1542/peds.2004-1239

Baker, B. L., McIntyre, L. L., Blacher, K., Crnic, C., Edelbrock, C., & Low, C. (2003). Preschool children with and without developmental delay: Behavioural problems

and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4-5), 217-230. doi: 10.1046/j.1365-2788.2003.00484.x

Baker-Ericzen, M. J., Brookman-Frazze, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities, 30*(4), 194-204. doi: 10.2511/rpsd.30.4.194

Barnard-Brak, L., & Thomson, D. (2009). How is taking care of caregivers of children with disabilities related to academic achievement? *Child Youth Care Forum, 38*, 91-102.doi: 10.1007/s10566-009-9070-1

Bélair, S., Foisy, M., Fortin, F., Foucreault, J., Fournier-Savard, P., Guo, S., . . . Theriault, D. (2008). *Participation and activity limitation survey, 2001: Children with disabilities and their families*. Ottawa, Canada: Statistics Canada. Retrieved March 1, 2011 from http://www.statcan.ca/english/freepub/89-628-XIE/89-628-XIE2008004.pdf

Botuck, S., & Winsberg, B. G. (1991). Effects of respite on mothers of school-aged and adult children with severe disabilities. *Mental Retardation, 29*, 43-47.

Braddock, D. (2007). Washington rises: Public financial support for intellectual disability in the United States, 1955-2004. *Mental Retardation & Developmental Disabilities Research Reviews, 13*(2), 169-177. doi: 10.1002/mrdd.20150; (*AN 25425765*)

Brandon, P. D., & Hogan, D. P. (2004). Impediments to mothers leaving welfare: The role of maternal and child disability. *Population Research and Policy Review, 23*, 419-436. doi: 10.1023/B:POPU.0000040021.82948.4d

Brasfield, C, D. (2008) *An Exploration of the Stressors, Coping Resources, and Resiliency of Rural Mothers of Children with Special Needs* (Doctoral dissertation). Retrieved from http://digitalarchive.gsu.edu/cps_diss/17

Britner, P. A., Morog, M. C., Pianta, R. C., & Marvin, R. S. (2003). Stress and coping: A comparison of self-report measures of functioning of families of young children with cerebral palsy or no medical diagnosis. *Journal of Child & Family Studies, 12*, 335-348. doi: 10.1023/A:1023943928358

Brown, I., Anand, S., Alan Fung, W. L., Isaacs, B., & Baum, N. (2003). Family quality of life: Canadian results from an international study. *Journal of Developmental and PhysicalDisabilities, 15*(3), 207-230. doi: 10.1023/A:1024931022773

Brown, I., & Brown, R. I. (2003). *Quality of life and disability: An approach for community practitioners.* London: Jessica Kingsley Publishers.

Brown, R. I. (2008). Reappraisal of challenges and supports where there is a child with a complex disability. *Inspire!, 2*(2), 4-8.

Brown, R. I., Schalock, R. L., & Brown, I. (2009). The concept of quality of life and its application to persons with intellectual disabilities and their families: Introduction and overview. *Journal of Policy and Practice in Intellectual Disabilities, 6*, 1-5.

Caldwell, J. (2007). Experiences of families with relatives with intellectual and developmental disabilities in a consumer-directed support program. *Disability and Society, 22*, 549-562. doi: 10.1080/09687590701560139

Caldwell, J., & Heller, T. (2003). Management of respite and personal assistance services in a consumer-directed family support programme. *Journal of Intellectual Disability Research, 47*, 352-366. doi: 10.1046/j.1365-2788.2003.00496.x

Carraccio, C. L., Dettmer, K. S., duPont, M. L., & Sachetti, A. D. (1998). Family member knowledge of children's medical problems: The need for universal application of an emergency data set. *Pediatrics, 102*, 367-370.

Carver, C. S., Sheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*, 267-283. doi: 10.1037/0022-3514.56.2.267

Cassidy, E. (1988). *Reaching and involving Black parents of handicapped children in their child's education program*. Lansing, MI: CAUSE Inc.

Cavallo, S., Feldman, D. E., Swaine, B., & Meshefedjian, G. (2009). Is parental coping associated with the level of function in children with physical disabilities? *Child: care, health and development, 35*, 33-40. doi: 10.1111/j.1365.2008.00884.x

Chan, J. B. (2008). A profile of respite service providers in New South Wales. *International Journal of Disability, Development, and Education, 55*(4) 289-302. doi: 10.1080/10349120802489448

Chan, J. B., & Sigafoos, J. (2001). Does respite care reduce parental stress in families with developmentally disabled children? *Child and Youth Care Forum, 30*(5), 253-263. doi: 10.1023/A:1014467226528

Children's Defense Fund. (1999). *The state of America's children yearbook*. Washington, D. C.: Children's Defense Fund.

Cigno, K., & Gore, J. (1999). A seamless service: Meeting the needs of children with disabilities through a multi-agency approach. *Child and Family Social Work, 4*, 325-335. doi:10.1046/j.1365-2206.1999.00135.x

Cotterill, L., Hayes, L., Flynn, M., & Sloper, P. (1997). Reviewing respite services: some lessons from the literature. *Disability and Society, 12*, 775-788. doi:10.1080/09687599727047

Crnic, K, & Low, C. (2002). Everyday stresses and parenting. In M. Bornstein (Ed.) *Handbook of Parenting Vol. 5: Practical Issues in Parenting* (pp. 243-268). Mahwah, NJ: Lawrence Earlbaum Associates.

Darling, S. M., & Gallagher, P. A. (2004). Needs of and supports for African American and European American caregivers of young children with special needs in urban and rural settings. *Topics in Early Childhood Special Education, 24*(2), 98-109. doi: 10.17777/02711214040240020501

Darrah, J., Magil-Evans, J., & Adkins, R. (2002). How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery. *Disability and Rehabilitation, 24*, 542-549. doi: 10.1080/09638280210121359

Dellve, L., Samuelsson, L., Tallborn, A., Fasth, A., & Hallberg, L. (2006). Stress and well-being among parents of children with rare diseases: A prospective intervention study. *Journal of Advanced Nursing, 53*, 392-402. doi: 10.1111/j.1365-2648.2006.03736

Denney, M.K., Itkonen, T., & Okamoto, Y. (2007). Early intervention systems of care for Latino families and their young children with special needs: Salient themes and guiding implications. *Infants and Young Children, 30*, 326-335. doi: 10.1097/01.IYC.0000290355.77911.78

Dillenburger, K., Keenan, M., Doherty, A., Byrne, T., & Gallagher, S. (2010). Living

with children diagnosed with autistic spectrum disorder. *British Journal of*

Special Education, 37(1), 13-23. doi: 10.1111/j.1467-8578.2010.00455

Dobson, D., & Middleton, S. (1998). *Paying to care: The cost of childhood disability*.

York, United Kingdon: York Publishing Services Ltd.

Donovan, W. L., Leavitt, L. A., & Walsh, R. O. (1990). Maternal self-efficacy: Illusory

control and its effect on susceptibility to learned helplessness. *Child Development,*

61, 1638-1647. doi: 10.1111/j.1467-8624.1990.tb02890.x

Dowling, M., & Dolan, L. (2001). Families with children with disabilities – inequalities

and the social model. *Disability and Society, 16*(1), 21-35. doi:

10.1080/713662027

Duvdevany, I., & Abboud, S. (2003). Stress, social support and well-being of Arab

mothers of children with intellectual disability who are served by welfare services

in northern Israel. *Journal of Intellectual Disability Research, 47*, 264-272. doi:

10.1046/j.1365-2788.2003.00488

Einam, M., & Cuskelly, M. (2002). Paid employment of mothers and fathers of an adult

child with multiple disabilities. *Journal of Intellectual Disability Research, 46*(2),

158-167.doi: 10.1046/j.1365-2788.2002.00383.x

Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping.

American Psychologist, 55, 647-654. doi: 10.1037/0003-066X.55.6.647

Freedman, R. I., & Capobianco Boyer, N. (2000). The power to choose: Supports for

families caring for individuals with developmental disabilities. *Health and Social*

Work, 25(1), 59-68.

Freedman, R. I., Litchfield, L., & Warfield, M. E. (1995). Balancing Work and Family: Perspectives of Parents of Children with Developmental Disabilities. *Families in Society, 76*(8), 507-514.

Glenn, S., Cunningham, C., Poole, H., Reeves, D., & Weindling, M. (2009). Maternal parenting stress and its correlates in families with a young child with cerebral palsy. *Child: Care, Health & Development, 35*(1), 71-78. doi: 10.1111/j.1365-2214.2008.00891.x

Good, K. R. (2001). Parental self-efficacy and educational involvement of parents of children with learning disabilities. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 62*(5-B), 2535.

Gore, N. (2010). Support for fathers of learning disabled children. *Community Care*, *102*, 24-25.

Grant, G., Ramcharan, P. & Flynn, M. (2007). Resilience in families with children and adult members with intellectual disabilities: Tracing elements of a psycho-social model. *Journal of Applied Research in Intellectual Disabilities, 20*, 563-575. doi: 10.1111/j.1468-3148.2007.00407.x

Greeff, A. P., Vansteenwegen, A., & Ide, M. (2006). Resiliency in famili*e*s with a member with a psychological disorder. *American Journal of Family Therapy, 34*, 285-300. doi: 10.1080/01926180600637465

Guralnick, M. J., Hammond, M. A., Neville, B., & Connor, R. T. (2008). The relationship between sources and functions of social support and dimensions of child – and parent – related stress. *Journal of Intellectual Disability Research, 52*, 1138-1154. doi: 10.1111/j.1365-2788.2008.01073

Hanvey, L. (2002). *Children and youth with special needs*. Ottawa, Canada: Canadian

    Council on Social Development.

Harris, S. L., Handleman, J. S., & Palmer, C. (1985). Parents and grandparents view

    the autistic child. *Journal of Autism and Developmental Disorders, 15*, 127–137.

    doi: 10.1007/BF01531599

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with

    an intellectual disability: The effects of parental cognitions in relation to child

    characteristics and family support. *Journal of Intellectual Disability Research,*

    49(6), 405-418. doi:10.1111/j.1365-2788.2005.00673

Hastings, R. P. (2003). Child behaviour problems and partner mental health as correlates

    of stress in mothers and fathers of children with autism. *Journal of Intellectual*

    Disability Research, 47, 231-237. doi: 10.1046/j.1365-2788.2003.00485.x

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with

    developmental disabilities. *American Journal on Mental Retardation, 107*(2),

    116-127. doi: 10.1352/0895-8017(2002)1072.0.CO;Z

Harty, M., Alant, E, & Uys, C. J. E. (2006). Maternal self-efficacy and maternal

    perception of child language competence in pre-school children with a

    communication disability. *Child: care, health and development, 33*, 144-154. doi:

    10.1111/j.1365-2214.2006.0061.x

Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., & Krauss, M. W. (2001). Children

    with disabilities: A longitudinal study of child development and family well-

    being. In Willis F. Overton (Ed.), *Monographs of the Society for Research in*

    Child Development, Boston, MA: Blackwell Publishers.

Herman, S. E. (1994). Cash subsidy program: Family satisfaction and need. *Mental Retardation, 32*, 416-421.

Hess, R. X., Molina, A. M., & Kozleski, E. B. (2006). Until somebody hears me: Parent voice and advocacy in special education decision making. *British Journal of Special Education, 33*, 148-157. doi: 10.1111/j.1467-8578.2006.00430

Hillman, J. (2007). Grandparents of children with autism: A review with recommendations for education, practice, and policy. *Educational Gerontology, 33,* 513-527. doi: 10.1080/03601270701328425

Hodapp, R. M., & Dykens, E. M. (1997). Families of children with Prader-Willi syndrome: Stress-support and relations to child characteristics. *Journal of Autism & Developmental Disorders, 27*(1), 11-24. doi: 10.1023/A:1025865004299

Hogan, D., Rogers, M. L., & Msall, M. E. (2000). Functional limitations and key indicators of well-being in children with disabilities. *Archives of Pediatric Adolescent Medicine, 154*, 1042-1048.

Honberg, L., Kogan, M. D., Allen, D., Strickland, B. B., & Newacheck, W. (2009). Progress in ensuring adequate health insurance for children with special health care needs. *Pediatrics, 124*, 1273-1280. doi: 10.1542/peds.2009-0372

Hornby, G., & Ashworth, T. (1994). Grandparents' support for families who have children with disabilities. *Journal of Child and Family Studies*, *3*, 403–412. doi: 10.1007/BF02233999

Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and advocacy expectations of culturally diverse families' participation in special education. *International*

Journal of Disability, Development and Education, 21(4), 240-251. doi: 10.1080/713671106

Kauser, S., Jevne, R. F., & Sobsey, D. (2003). Hope in families of children with developmental disabilities. *Journal on Developmental Disabilities, 10*(1), 35-46.

Kazak, A. E., & Marvin, R. S. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. *Family Relations, 33*, 67-77. doi: 10.2307/584591

Keller, D., & Sterling Honig, A. (2004). Maternal and paternal stress in families with school-aged children with disabilities. *American Journal of Orthopsychiatry, 74*, 337-348. doi: 10.1037/0002-9432.74.3.337

Kenny, K., & McGilloway, S. (2007). Caring for children with learning disabilities: An exploratory study of parental coping and strain. *British Journal of Learning Disabilities, 35*, 221-228. doi: 10.1111/j.1468-3156.2007.00445.x

Keppel, K. G., Pearcy, J. N., & Wagener, D. K. (2002). Trends in racial and ethnic-specific rates for the health status indicators: United States, 1990–98. *Healthy People 2000 Statistics Notes*, *23*, 1-16.

Kerr, S. M., & McIntosh, J. B. (2000). Coping when a child has a disability: Exploring the impact of parent-to-parent support. *Child: Care, Health & Development, 26*, 309-322. doi: 10.1046/j.1365-2214.2000.00149

Kersch, J., Hedvat, T. T., Huaser-Cram, P., & Warfield, M. E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research, 50*, 883-893. doi: 10.1111/j.1365-2788.2006.00906

Keyes, C. R. (2000). *Parent-Teacher Partnerships: A Theoretical Approach for Teachers. Issues in Early Childhood Education: Curriculum, Teacher Education, & Dissemination of Information*. Paper presented at the meeting of Proceedings of the Lilian Katz Symposium, Champaign, IL.

Lukemeyer, A., Meyers, M. K., & Smeeding, T. (2000). Expensive children in poor families: Out of pocket expenditures for the care of disabled and chronically ill children in welfare families. *Journal of Marriage and Family, 62*, 399-415. doi: 10.1111/j.1741-3737.2000.00399.x

Marcenko, M. O., & Myers, J. C. (1994). How families of children with severe disabilities choose to allocate a cash subsidy. *Journal of Mental Health Administration, 21*, 253-261. doi: 10.1007/BF02521332

Margetts, J. K., Le Courteur, A., & Croom, S. (2006). Families in a state of flux: The experience of grandparents in autism spectrum disorder. *Child: Care, Health, and Development, 32*, 565–574. doi: 10.1111/j.1365-2214.2006.00671

Mash, E. J., & Johnston, C. (1983). Parental perceptions of child behavior problems, parenting self-esteem, and mothers' reported stress in younger and older hyperactive and normal children. *Journal of Consulting and Clinical Psychology, 51*(1), 86-99. doi: 10.1037/0022-006X.51.1.86

McConachie, H. (1986). *Parents and young mentally handicapped children: A review of research issues*. Cambridge, MA: Croom Helm.

McManus, B., McCormick, M. C., Acevedo-Garcia, D., Ganz, M., & Hauser-Cram, P. (2009). The effect of state early intervention eligibility policy on participation

among a cohort of young CSHCN. *Pediatrics, 124*, S368-S374. doi: 10.1542/0eds.2009-1255G

Nachslen, J. S. (2000). Advocacy, stress, and quality of life in parents of children with developmental disabilities. *Developmental Disabilities Bulletin, 28*, 39-55.

National Center for Education Statistics (NCES). (2001). *User's manual for the ECLS-K base year public-use data files and electronic codebook* (NCES 2001-029 Revised). Washington, D. C.: U. S. Department of Education.

Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual & Developmental Disability, 31*(1), 1-12. doi: 10.1080/13668250500349367

Olsson, M. B., & Hwang, C. P. (2002). Sense of coherence in parents of children with different developmental disabilities. *Journal of Intellectual Disability Research, 46*(7), 548-559. doi: 10.1046/j.1365-2788.2002.00414

Olsson, M. B., & Hwang, C. P. (2008). Socioeconomic and psychological variables as risk and protective factors for parental well-being in families of children with intellectual disabilities. *Journal of Intellectual Disability Research, 52*, 1102-1113. doi: 10.1111/j.1365-2788.01081.x

Oppenheim, C., & Harker, L. (1996). *Poverty: The facts*. London, England: Child Poverty Action Group.

Orsmond, G. I., Lin, L. Y., Mailick Seltzer, M. (2007). Mothers of adolescents and adults with autism: Parenting multiple children with disabilities *Intellectual and*

*Developmental Disabilities, 4*5, 257-270. doi: 10.1352/1934-9556(2007)45[257:MOAAAW]2.0.CO;2

Pal, D. K., Das, T., Chaudhury, G., & Sengupta, S. (2005). Is social support sometimes a mixed blessing? *Child: Care, Health and Development, 31*, 261-263. doi: 10.1111/j.1365-2214.2005.00515

Palm, G., & Fagan, J. (2008). Father involvement in early childhood programs: review of the literature. *Early Child Development and Care, 178*, 745-759. doi: 10.1080/03004430802352137

Parish, S. L., & Cloud, J. M. (2006). Financial well-being of young children with disabilities and their families. *Social Work, 51*, 223-232.

Parish, S. L., Rose, R. A., Grinstein-Weiss, M., Richman, E. L., & Andrews, M. E. (2008). Material hardship in U.S. families raising children with disabilities. *Exceptional Children, 75*, 71-92.

Park, J., Turnbull, A. P., & Turnbull, H. R. (2002). Impacts of poverty on quality of life in families of children with disabilities. *Exceptional Children, 68*, 151-170.

Park, J., Hoffman, L., Marquis, J., Turnbull, A. P., Poston, D., Mannan, H., . . . Nelson, L. L. (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research, 47*, 367-384. doi: 10.1046/j.1365-2788.2003.00497

Pisula, E. (2007). A comparative study of stress profiles in mothers of children with autism and those of children with Down's syndrome. *Journal of Applied Research in Intellectual Disabilities, 20*, 274-278. doi: 10.1111/j.1468-3148.2006.00342

Porterfield, S., & McBride, T. D. (2007). The effect of poverty and caregiver education on perceived need and access to health services among children with special health care needs. *American Journal of Public Health, 97*, 323-329. doi: 10.2105/AJPH.2004.055921

Raikes, H. A., & Thompson, R.A. (2005). Efficacy and social support as predictors of parenting stress among families in poverty. *Infant Mental Health Journal, 26,* 177-190. doi: 10.1002/imhj.20044

Ratcliff, N., & Hunt, G. (2009). Building teacher-family partnerships: The role of teacher preparation programs. *Education, 129*, 495-505.

Redmond, B., & Richardson, V. (2003). Just getting on with it: Exploring the service needs of mothers who care for young children with severe/profound and life-threatening intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 16*, 205-218. doi: 10.1046/j.1468-3148.2003.00165

Risdal, D., & Singer, H. S. (2004). Marital adjustment in parents of children with disabilities: A historical review. *Research & Practice for Persons with Severe Disabilities, 29*(2), 95-103. doi: 10.2511/rpsd.29.2.95

Roeher Institute. (2000). *Count us in: A demographic overview childhood and disability in Canada*. North York, Canada: L'Institut Roeher Institute.

Rogers, C. (2007). Disabling a family? Emotional dilemmas experienced in become a parent of a child with learning disabilities. *British Journal of Special Education, 34*(3), 136-143.1503-1509. doi: 10.1542/peds.2007-1680

Rondero Hernandez, V., Montana, S., & Clarke, K. (2010). Child health inequality: Framing a social work response. *Health and Social Work, 35*, 291-301.

Rosenberg, S. A., Zhang, D., & Robinson, C. C. (2008). Prevalence of developmental

delays and participation in early intervention services for young children.

Pediatrics, 121, 1234. doi: 10.1542/peds.2007-1680

Sallfors, C., & Hallberg, L. R. M. (2003). A parental perspective on living with a

chronically ill child: A qualitative study. *Families, Systems and Health, 21*, 193-

204. doi: 10.1037/1091-7527.21.2.193

Schalock, R. L., Gardner, J. F., & Bradley, V. J. (2007). *Quality of life for persons with*

intellectual and other developmental disabilities: Applications across individuals,

organizations, communities, and systems. Washington, DC: American

Association on Intellectual and Developmental Disabilities.

Shelden, D. L., Angell, M. E., Stoner, J. B., & Roseland, B. D. (2010). School principals'

influence on trust: Perspectives of mothers of children with disabilities. *The*

Journal of Educational Research, 103, 159-170. doi:

10.1080/00220670903382921

Shok, A., Harvey, D., & Reddihough, D. (2006). Perceived stress, perceived social

support, and wellbeing among mothers of school-aged children with cerebral

palsy. *Journal of Intellectual & Developmental Disability, 3(*1), 53-57. doi:

10.1080/13668250600561929

Siklos, S., & Kerns, K. A. (2006). *Journal of Autism and Developmental Discord, 36*,

921-933. doi: 10.1007/s10803-006-0129-7

Sloper, P. (1998). Models of service for parents of disabled children. What do owe know?

What do we need to know? *Child: Care, Health, and Development, 25*(2), 85-99.

doi: 10.1046/j.1365-2214.1999.25220120.x

Smith, P. J. (2010). Sacraments for every child. *America*, 12-15.

Sohn, S., & Wang, C. (2006). Immigrant parents' involvement in American schools: Perspectives from Korean mothers. *Childhood Education Journal, 34*(2), 125-132. doi: 10.1007/s10643-006-0070-6

Soresi, S., Nota, L., & Ferrari, L. (2007). Considerations on supports that can increase the quality of life of parents of children with disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 4*, 248-251. doi: 10.1111/j.1741-1130.2006.00087

Speraw, S. (2006). Spiritual experiences of parents and caregivers who have children with disabilities or special needs*, Issues in Mental Health Nursing, 27*, 213–230. doi: 10.1080/01612840500436974

Stalker, K., & Robinson, C. (1994). Parents' views of different respite care services. *Mental Handicap Research, 7*(2), 97-117. doi: 10.111/j.1468-3148.1994.tb00119.x

Stoneman, Z., & Gavidia-Payne, S. (2006). Marital adjustment in families of young children with disabilities: Associations with daily hassles and problem-focused coping. *American Journal on Mental Retardation, 111*, 1-14. doi: 10.1352/0895-8017(2006).111%5B1:MAIFOY%502.0.CO;2

Strom, R. D., & Strom, S. K. (2000). Intergenerational learning and family harmony. *Educational Gerontology, 26*, 261–283.

Teti, D. M., & Gelfand, D. M. (1991). Behavioral competence among mothers of infants in the first year: The mediational role of maternal self-efficacy. *Child Development, 62*, 918-929. doi: 10.1111/j.1467-8624.1991.tb01580.x

Todd, S., & Shearn, J. (1996). Struggles with time: The careers of parents of adult sons and daughters with learning disabilities. *Disability and Society, 11*, 379-402.

Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability, 29*(1), 16-26. doi:10.1080/13668250410001662892

Treloar, L. L. (2002). Disability, spiritual beliefs and the church: The experiences of adults with disabilities and family members. *Journal of Advanced Nursing, 40*, 594-603. doi: 10.1046/j.1365-2648.2002.02417

Trute, B. (2003). Grandparents of children with developmental disabilities: Intergenerational support and family well-being. *Families in Society, 84*, 119–126.

Trute, B., Heibert-Murphy, D., & Levine, K. (2007). Parental appraisal of the family impact of childhood developmental disability: Times of sadness and times of joy. *Journal of Intellectual and Developmental Disability, 32*, 1-9. doi: 10.1080/13668250601146753

Turnbull, A., Turnbull, H. R., Brown, I., & Turnbull, A. P. (2004). *Families and people with mental retardation and quality of life: International perspectives.* Washington, D.C.: American Association on Intellectual and Developmental Disabilities.

Turney, K., & Kao, G. (2009). Barriers to school involvement: Are immigrant parents disadvantaged? *Journal of Educational Research, 102*(4), 257-271. doi: 10.3200/JOER.102.4.257-271

United States Census Bureau (2006). American Community Survey. Retrieved August 4, 2010 from http://www.census.gov/hhes/www/U.S.disability/2006acs.html

Urbano, R. C., Hodapp, R. M., & Floyd, F. (2007). Divorce in families of children with Down syndrome: A population-based study. *American Journal on Mental Retardation, 112*, 261-274. doi: 10.1352/0895-8017(2007)112[261:DIFOCW]2.0.CO;2

U.S. Department of Education, National Center for Education Statistics. (2003). *Parent and family involvement in education: 2002-03,* Washington, DC: U.S.

Van Haren, B., & Fiedler, C. R. (2008). Support and empower families of children with disabilities. *Intervention in School and Clinic, 43*, 231-235. doi: 10.1177/1053451208314908

Veisson, M. (1999). Depression symptoms and emotional states in parents of disabled and non-disabled children. *Social Behavior and Personality, 27*, 87-98. doi: 10.2224/sbp.1999.27.1.87

Vermaes, I. P. R., Janssens, J. M. A. M., Mullaart, R. A., Vinck, A., & Gerris, J. R. M. (2008). Parents' personality and parenting stress in families of children with spina bifida. *Child: Care, Health and Development, 34*, 665-674. doi: 10.1007/BF00916812

Wang, M., Mannan, H., Poston, D., Turnbull, A. P., & Summers, J. A. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons with Severe Disabilities, 29*, 144-155. doi: 10.2511/rpsd.29.2.144

Welterlin, A., & LaRue, R. H. (2007). Serving the needs of immigrant families of

    children with autism. *Disability and Society, 22*, 747-760. doi:

    10.1080/09687590701659600

Willoughby, J. C., & Glidden, L. M. (1995). Fathers helping out: Shared childcare and

    marital satisfaction of parents of children with disabilities. *American Journal on*

    Mental Retardation, 99, 399-406.

Wodehouse, G., & McGill, P. (2009). Support for family carers of children and young

    people with developmental disabilities and challenging behaviour: What stops it

    being helpful? *Journal of Intellectual Disability*, *53*, 644-653. doi:

    10.1111/j.1365-2788.2009.01163

CHAPTER 2

PARENTAL STRESS, SOCIOECONOMIC STATUS, SATISFACTION WITH

SERVICES, AND FAMILY QUALITY OF LIFE AMONG PARENTS

OF CHIDREN RECEIVING SPECIAL EDUCATION SERVICES

For the past two decades, the impact of children with disabilities on family quality

of life (FQOL) has received extensive attention in the literature (e.g., Freedman,

Litchfield, Warfield, 1995; Mash & Johnston, 1983; Park et al., 2003). Researchers have

suggested that a child with a disability may positively influence family quality of life

(FQOL) by fostering the development of love, compassion, and tolerance among their

parents (Kausar, Jevne, & Sobsey, 2003). However, researchers within mental health,

medical, and clinical settings also have identified barriers to FQOL encountered by

families raising children with disabilities such as increased parental stress (e.g., Fidler,

Hodapp, & Dykens, 2000; Hauser-Cram, Warfield, Shonoff, & Krauss, 2001), financial

strain (Dobson & Middleton, 1998; Park, Turnbull, & Turnbull, 2002), and difficulties

related to accessing and being satisfied with social service supports (Freedman &

Capobianco Boyer, 2000).

Family Quality of Life

FQOL is an overarching construct that refers to the degree to which families of

individuals with disabilities are able to meet their needs, enjoy time spent together, and

participate in leisure interests and activities that are important to them (Park et al., 2003).

Domains such as physical health, emotional well-being, interpersonal relationships, social

inclusion, personal development, material well-being, self-determination, and rights are

all considered critical components of quality of life (QOL) for individuals with

disabilities and their families (Schalock, 2004). Researchers have identified positive contributions to FQOL that have been reported by families raising children with disabilities, such as increased feelings of patience, compassion, and tolerance (Kausar, Jevne, & Sobsey, 2003).

Unfortunately, researchers have suggested that the challenges associated with raising children with disabilities also may negatively impact FQOL (e.g., Brown, Anand, Alan Fung, Isaacs, & Baum, 2003; Wang, Mannan, Poston, Turnbull, & Summers, 2004). Based on surveys completed by 69 parents of children with autism, Down syndrome, and typically developing children, Brown and colleagues (2006) found that families of children with disabilities encountered numerous challenges including adequate care for their child and inadequate time to pursue education, career, and leisure activities to enhance overall enjoyment of life. The severity of the child's disability and family characteristics such as socioeconomic status (SES) also have been identified as potential impediments to FQOL (Zuna et al., 2009). For example, in a study of 130 parents of children with disabilities, the severity of the child's disability reliably predicted lower parental satisfaction ratings on a FQOL assessment (Wang et al., 2004). Block and colleagues (2002) reported that families of children with disabilities may be more likely to face barriers to FQOL including low-income, unemployment, and lower levels of education which they attributed to factors such as classism and ableism that impact marginalized groups (e.g., individuals with disabilities and their families).

Family quality of life within schools. While FQOL has received extensive attention within mental health (Davison, Prasher, & Janicki, 2003), medical (Glenn, Cunningham, Poole, Reeves, & Weindling, 2009), and clinical settings (Kersch, Hedvat,

Hauser-Cram, & Warfield, 2006), limited research exists that examines FQOL of parents

of children with disabilities within school settings. However, children with disabilities

often receive special education services through the public school system and researchers

have acknowledged the importance of considering FQOL within education settings

(Brown & Shearer, 2004). The negative impacts of raising a child with a disability

experienced by some parents may impede their ability to effectively need their child's

needs, thereby reducing their child's quality of life as well (Brown, Schalock, & Brown,

2009). Due to these negative impacts on the child as well as the current emphasis on

improving student achievement in the United States, school-based mental health

personnel (e.g., school counselors, school psychologists, school social workers) are

increasingly assuming an ecological approach in an attempt to foster partnerships

between the school, family, and community to address the needs of families of children

with disabilities receiving special education services. It is thought that by meeting

families' needs within the home and community will increase FQOL as well as the

quality of life of the student, thereby increasing the likelihood that children receiving

special education services will be able to succeed at school (Griffin & Steen, 2010).

However, limited research about FQOL exists that includes parents of children with

disabilities within school settings and therefore very little is known about FQOL among

parents of children receiving special education services.

Parental Stress

Researchers have found that parents of children with disabilities have

significantly higher levels of stress than parents of typically developing children (Dellve,

Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Hauser-Cram et al., 2001). Several

factors (e.g., child care) have been identified to contributing to this increased level of stress for these parents. For instance, the increasing child care demands associated with raising a child with a disability (Baker et al., 2003; Fidler et al., 2000) and parental concerns about their child's future, the child's ability to function independently, and the permanent state of the disability may attribute to higher levels of parental stress (Pisula, 2007). Elevated levels of maternal stress also have been linked to mothers' perceptions of being isolated from parents of typically developing children and the inadequate support from their spouse (Glenn, Cunningham, Poole, Reeves, & Weindling 2009).

Researchers have indicated that parental stress levels may be impacted by the presence and intensity of a child's behavior problems more than other disability related characteristics (e.g., intellectual disability) (Baker et al., 2003; Hodapp et al., 1997). Hassel and colleagues (2005) administered self-report questionnaires to mothers of children with comorbid intellectual disabilities and maladaptive behaviors ($N = 46$). They discovered that overall parental stress levels were more related to the frequency and intensity of their child's behavioral difficulties rather than their intellectual limitations. In another study, 60 parents of children with genetic disorders (i.e., Down syndrome, Williams syndrome, Smith-Magenis syndrome) completed questionnaires and found that the strongest predictor of parental stress was the severity the child's maladaptive behavior (Fidler et al., 2000). Hauser-Cram's and colleagues' (2001) found similar results in their study of parents ($N = 183$) of children with disabilities (i.e., Down syndrome, motor impairment, and developmental delay). They found that behavior problems of children with disabilities predicted parental stress more than other disability related characteristics (e.g., intellectual disability, physical disability, developmental delays). Additional

findings from this study indicated that parental stress levels increased over time, and by the child's 10th birthday, four times as many parents of children with severe behavioral problems were more likely to score in the clinical range for stress than parents of typically developing ten-year-olds (Hauser-Cram et al., 2001).

Parents of children with particular types of disabilities (e.g., autism spectrum disorders) have shown higher levels of parental stress when compared to other parents of children with disabilities due to maladaptive behaviors that are commonly observed among children with autism spectrum disorders (Kasari & Sigman, 1997; Tomanik, Harris, & Hawkins, 2004). Kasari and Sigman (1997) utilized self-report questionnaires with parents of children with autism ($n = 28$), mental retardation ($n = 26$), and typically developing children ($n = 28$) and found that parents of children with autism reported the highest levels of parental stress. Tomanik and colleagues (2004) utilized self-report measures to examine the relationship between child behavioral difficulties and maternal stress among mothers ($N = 60$) of children with a pervasive developmental disorder and found that child maladaptive behaviors associated with autism spectrum disorders contributed significantly to elevated levels of maternal stress.

Socioeconomic Status and Childhood Disability

The number of children with disabilities living in poverty (low SES) is disproportionate to the number of typically developing children with recent data approximating that 28% of children with disabilities are being raised in poverty whereas only 16% of children without disabilities live in poverty (U.S. Census Bureau, 2006). Numerous risk factors for the development of childhood disabilities related to low socioeconomic status have been identified, including in the pre-term delivery and low

birth weight (Leonard & Wen, 2002) as well as increased risk for exposure to

environmental toxins, infections, and accidents (Bradshaw, 2001). Families of low SES

raising children may lack access to resources (e.g., medical care, health insurance) that

may further put their child at risk for developing a disability (Lustig & Strauser, 2007).

The relationship between poverty status and childhood disability was evident in

Rosenberg and colleagues' (2008) study of 19,150 parents which indicated that by two

years of age, children residing in poverty were more likely to present with developmental

delays than children whose families were above the poverty level.

Low SES has been attributed to two distinct types of childhood disabilities,

intellectual disabilities (Bigelow, 2006; Bradley, Thompson, & Bryson, 2002) and

behavior disorders (Prochnow & DeFronzo, 1997). For instance, Emerson and Hatton

(2007) analyzed cross-sectional data collected from parents of typically developing

children and children with disabilities ($N = 12,160$) and found that children with

intellectual disabilities were more likely to reside in families of low SES. Low SES has

been referred to as a possible cause of intellectual disabilities attributed to environmental

and social hazards that may impede the intellectual development of children (Leonard &

Wen, 2002). Low SES also may be a factor in the development of behavior disorders in

children due to increased exposure to domestic abuse, violence, and inadequate

parenting/childcare (Kaiser & Rasminsky, 2003). Bigelow (2006) reported that low SES

may contribute to childhood behavioral difficulties such as hyperactivity, inattentiveness,

and conduct problems. This was supported in Emerson and Hatton's (2007) study of

health and mental health of children ($N = 10,438$) which found that low SES was related

to the development of conduct and emotional disorders.

Low SES status also has been identified as a factor that may impede FQOL by impacting parental relationships and satisfaction with parenting (Scorgie, Wilgosh, & McDonald, 1998; Willoughby & Glidden, 1995). For example, low SES families of children with disabilities have been found to demonstrate lower levels of satisfaction with their parenting role than parents of higher SES (Scorgie, Wilgosh, & McDonald, 1998). In a study of 48 couples of children with developmental disabilities or at-risk for developing a developmental disability, lower family income was more related to marital dissatisfaction than families of higher SES (Willoughby & Glidden, 1995).

Social Service Supports

Many parents of children with disabilities utilize social service supports to enhance their FQOL as they meet the demands they face as they care for their child (Schalock, Gardner, & Bradley, 2007). Zuna et al. (2009) defined social service supports as educational, social, behavioral, and health-related activities that are developed to improve outcomes for the individual family. These supports included community services, governmental agencies, private practitioners, and organizations (Schalock et al., 2007) as well as financial assistance to meet the needs of children with disabilities and their families (Braddock, 2007). In a study of families utilizing community services ($N =$ 30) findings indicated that families who accessed the most community services had lower levels of stress and were better able to adapt to the challenges they faced in their lives more than families who accessed fewer services (Greeff, Vansteenwegen, & Ide, 2006).

Unfortunately, many parents of children with disabilities encounter barriers as they attempt to utilize social service supports to meet the needs of their child. These barriers include difficulty accessing services (Freedman & Capobianco Boyer, 2000) and

lack of satisfaction with services that are provided (Brown, Anand, Fung, Isaacs, &

Baum, 2003). Freedman and Capobianco Boyer (2000) found that parents of children

with developmental disabilities ($N = 31$) reported difficulties related to initiating social

service supports for their family as well as difficulty finding information regarding the

types of social services supports that they were eligible to receive. Even when parents of

children with disabilities reported that they were able to access social service supports,

quite often they were not satisfied with the assistance they received (Brown et al., 2003;

Freedman & Capobianco Boyer, 2000). Brown and colleagues (2003) conducted

interviews with parents of children with developmental disabilities and discovered that

parents reported the lowest satisfaction with disability related services as compared to

informal social support, leisure activities, and community activities. Similarly, in a study

of 69 families of typically developing children, children with Down syndrome, and

children with autism, less than 50% of parents of children with disabilities reported they

were satisfied with the support they received from social services (Brown, MacAdam-

Crisp, Wang, & Iaocci, 2006).

Financial assistance is a type of social support service that is utilized by many

families raising children with disabilities (Allard, Gottlieb, & Hart, 1993). However,

parents of children receiving financial assistance have reported feeling dissatisfied with

the amount of monies they received and their ability to cover their child's medical

expenses (Parish & Cloud, 2006). Freedman and Capobianco Boyer (2000) conducted

focus group interviews among parents raising children with disabilities ($N = 31$) and

found that families were dissatisfied with the financial support they received from social

services due to the length of time prior to receiving reimbursement for monies spent, and

the requirement that services had to be initially paid for out of pocket.

Purpose of the Study

Because the majority of studies of SES, parental stress, satisfaction with services, and FQOL have been conducted within mental health (Davison et al., 2003), medical (Glenn et al, 2009), and clinical settings (Kersch et al., 2006) and educational settings differ from those settings in numerous ways. For example, in an educational setting childhood disabilities are classified according to definitions provided by IDEA (Individuals with Disabilities Education Act) rather than medical definitions or criteria outlined in the DSM-IV-TR (American Psychiatric Association [*DSM-IV-TR*], 2000). In addition, within an educational setting services are provided based upon an educational perspective. As such, the child's services, or Individual Education Plan (IEP) are developed to address their educational needs within the school setting with little attention given to life functioning for the majority of students. This study was conducted to examine SES, parental stress, satisfaction with services, and FQOL among parents of children with disabilities receiving special education services within an educational setting. Specifically, this study sought to determine whether differences existed in the sample between parental stress and FQOL depending upon child disability type. It was hypothesized that parents of children with emotional/behavioral disorders and autism would exhibit statistically significantly higher levels of parental stress than parents of children with other types of disabilities (e.g., Hauser-Cram et al., 2001; Tomanik et al., 2004). In addition, parents of children with emotional/behavioral disorders, and autism will report lower FQOL when compared to parents of children with other types of disabilities (Bigelow, 2006; Tomanik et al., 2004). A second aim of this study was to

determine whether relationships existed between SES (as measured by free or reduced lunch (FRL) status and parental stress, satisfaction with services, and FQOL. It was expected that FRL would be positively correlated with parental stress and negatively correlated with satisfaction with social support services (Freedman & Capobianco Boyer, 2000) and FQOL (Scorgie et al., 1998). A final aim of this study was to determine if satisfaction with services and parental stress were significant predictors of FQOL, and whether parental stress moderated the relationship between satisfaction with services and FQOL. It was hypothesized that parental stress and satisfaction with services would be significant predictors of FQOL (Greeff et al., 2006; Pisula, 2007) and parental stress would moderate the relationship between satisfaction with services and FQOL.

Method

Context

This study was conducted in the Southeast region of the United States in a rapidly growing county that is in transition from rural to suburban. The system educates approximately 12,000 students per year in 16 schools. For the 2009-2010 school year, student demographics for this system were predominately Caucasian (65%), followed by African American (13%), Hispanic (11%), Asian (6%), and Multiracial (4%) and approximately half of the students in the system (51%) qualified for FRL. A total of 1206 students in the system received special education services (11% of total school population).

Participants

Parents of children with disabilities ($N = 389$) participated in the study. The children ranged in age from three (preschool) to 12 years of age (fifth grade) ($M = 8.6$, $SD = 2.3$).

The majority of these students were identified as speech/language impaired (*n = 120,* 30.8%), followed by significant developmental delay (*n* =88, 22.6%), and specific learning disability (*n = 61,* 15.7%). All other disability categories for students preschool through fifth grade were represented as follows: intellectual disability (*n = 29,* 7.4%), emotional-behavioral disability (*n* = 18, 4.6%), orthopedic impaired (*n* = 2, 0.5%), hearing impaired (*n* = 3, 0.6%), deaf/hard of hearing (*n* = 1, 0.2%), other health impaired (*n* = 33, 8.3%), vision impaired (*n* = 3, 0.6%), and autism (*n* = 31, 7.9%). Two additional special education disability categories, blind and deaf/blind were not represented in the school system for preschool through fifth grade students (M. Thompson, personal communication, August 16, 2010). The educational levels of the parents ranged from no high school diploma (*n* = 78, 20%), GED (*n* = 135, 34.55%), some college (*n* = 100, 25.71%), associate's degree (*n* = 35, 9.09%), bachelor's degree (*n* = 20, 5.19%), and graduate degree (*n* = 19, 4.94%). Two parents in the sample did not report their education level. Two hundred and fifty of the parents (64%) reported their child with a disability received FRL at school. Demographic information is presented in Table 1.

Table 1

Parent Demographics

		n	% of sample
Marital Status	Married	252	64.77%
	Living w/ Partner	21	5.44%
	Divorced	55	13.99%
	Separated	20	5.18%
	Never Married	32	8.29%
Sex	Male	51	13.09%
	Female	338	86.91%
Ethnic Background	Black	66	16.80%
	Indian	4	1.03%
	Asian	7	1.81%
	Hispanic	30	7.75%
	White	280	71.83%
	Other	2	0.52%
Educational Background	No Diploma	78	20.00%
	GED	135	34.55%
	Some College	100	25.71%
	Associate Degree	35	9.09%
	Bachelor Degree	20	5.19%
	Graduate Degree	19	4.94%
Income	<$13,999	83	21.35%
	$14,000 - 19,999	50	12.97%
	$20,000 - 24,999	26	6.76%
	$25,000 - 29,999	35	9.19%
	$30,000 - 34,999	24	6.22%
	$35,000 - 39,999	22	5.68%
	$40,000 - 49,999	42	10.81%
	$50,000 - 59,999	34	8.65%
	$60,000 - 69,999	17	4.32%
	>$70,000	55	14.05%

Procedure

A list of all children in preschool through fifth grade that were receiving special education services at the time this study was generated by the school system. Packets were prepared for each child's parents and contained questionnaires designed to assess FRL, parental stress, satisfaction with social service supports, and FQOL. To ensure confidentiality, packets were labeled only with the child's Testing Identification Number (TIN) that was assigned to the student by the state upon enrollment in the school system.

The cover letter from one of the system's school psychologists described the reason for the study, asked for parental participation, and explained that involvement was voluntary. A packet was sent home with each child once a week for three consecutive weeks and parents were asked to complete the questionnaires and return them to their child's school in a sealed envelope provided by the school system. Once the parent's completed packet was returned, additional packets were not sent home. Completed packets were then forwarded to one of the system's school psychologists at the centralized board office. The primary researcher was employed with the system during administration of the surveys. The system released the data to the university researchers to conduct secondary data analysis.

A total of 840 packets containing measures to assess family demographics, FRL, satisfaction with social services, parental stress, and FQOL were sent home with each student receiving special education services (preschool through fifth grade) to be completed by their parents. Three-hundred and eighty nine packets were returned yielding a 46% response rate. Listwise deletion, a method commonly utilized in educational research to address the problem of missing data (Peugh & Enders, 2004), was utilized. As a result, packets containing missing data on any of the variables assessed (i.e., SES, satisfaction with social services, parental stress, and FQOL) were excluded from analyses. Therefore, a total of 376 Parental Stress Scales (PSS) (96.1% of the sample), 374 FQOL Surveys (96.1% of the sample), and 135 Client Satisfaction Questionnaires (CSQ-8) (35% of the full sample) were utilized in the analyses. Only parents who reported receiving social support services outside of the school system (*n* = 135) completed the CSQ-8.

In order to address the first hypothesis, that parents of children with emotional/behavioral disorders and autism would exhibit statistically significantly higher levels of parental stress than parents of children with other types of disabilities and statistically significantly lower FQOL when compared to parents of children with other types of disabilities, it was necessary to create groupings of parents based upon their child's disability type. Special education research has been described as "the hardest of the hardest-to-do science" (Odom et al., 2005, p. 139) due to the significant challenges faced by researchers as they attempt to create groups for data analysis. Specifically, the heterogeneity of the characteristics of the students can be problematic when attempting to create groups (Odom et al., 2005). The first hypothesis of this study sought to examine differences between variables based on child disability. The groups were combined according to similarities between characteristics of the disabilities, which is commonly observed in research conducted in clinical settings (e.g., Pisula, 2007; Urbano, Hodapp, & Floyd, 2007). Descriptive analyses for the child disability groups that shared similar characteristics were reviewed. If groups that shared characteristics were notably different on one of the three dependent variables (i.e., parental stress, satisfaction with social services, FQOL) the groups were not combined. For example, maladaptive behaviors are salient features of both emotional/behavioral disorders (Georgia Department of Education, 2007) and autism (American Psychiatric Association [*DSM-IV-TR*], 2000). Descriptive statistics for the sample revealed that parents of children with emotional/behavioral disorders reported more satisfaction with social service supports than was reported by parents of children with autism. Therefore, emotional/behavioral disorders and autism were not combined for analyses purposes in this study. The final

disability groups created for analysis purposes were: autism ($n = 31$), emotional-

behavioral disorders ($n = 18$), general medical conditions (combination of other health

impaired, deaf/hard of hearing, vision impaired; $n = 42$), significant developmental delay

($n = 88$), intellectual disability ($n = 29$), speech/language impaired ($n = 120$), and specific

learning disability ($n = 61$).

Measures

Demographic Questionnaire. Parents completed a demographic questionnaire

that included 14 multiple choice and 4 fill in the blank questions regarding family

composition, parental education level, FRL status, receipt of financial assistance (e.g.,

Medicaid, Social Security Income, food stamps), types of social services utilized by the

family for their child with a disability (i.e., occupational therapy, physical therapy,

speech therapy, medical support, private counseling, and psychiatric support), and

frequency at which parents utilized those services. Parents were asked to list any

additional services they received that were not specifically identified on the

questionnaire. FRL status has been utilized in educational research as a measure of family

SES (e.g., Hogrebe & Tate, 2010) and it was utilized in the current study as the measure

of SES as well.

Parental Stress Scale (PSS; Berry & Jones, 1995). The PSS was developed to

measure stress associated directly with the demands of parenting, unlike other measures

of stress which have been criticized as confounding parental stress with marital or family

stress (Berry & Jones, 1995). Parents respond to each of the 18 items using a 5-point

Likert scale ranging from 1 = *strongly disagree* to 5 = *strongly agree.* Items are then

summed to obtain an overall score. Berry and Jones established support for the reliability

of the PSS in studies of parents of typically developing children and parents of children

with disabilities. Results of those studies indicated that the PSS correlated in expected

directions with other measures of general stress and parenting stress (Berry & Jones,

1995). For example, Berry and Jones assessed the validity of the PSS by comparing it to

the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983), a measure of

general stress, and obtained significant correlations for parents of typically developing

children ($r(233) = .50$; $p <.01$) and parents of children with disabilities ($r(51) = .41$, p

$<.01$). The PSS was also compared to the Parenting Stress Index (PSI), one of the only

other measures "of any direct relevance to parental stress" (Berry & Jones, 1995, p. 464).

The correlation between the PSS and the Total Parenting Stress Index of the PSI was .75,

$p <.01$. The validity of the PSS was determined for the total sample ($\alpha = .83$) with item-

whole correlations ranging from .27 to .59 ($M = .43$) (Berry & Jones, 1995). Disparity

between item-whole correlations was expected and occurred which the authors attributed

to the broadness of parental stress. Test – retest correlation of .81 was reported after a six-

week period. Internal consistency reliability for the current sample was adequate ($\alpha =$

.752). Mean scores for the PSS for the current sample is presented in Table 2.

Table 2

Table of Means, Standard Deviations, and Variances

Group	PSS Mean	PSS SD	PSS Var.	FQOL Mean	FQOL SD	FQOL Var.	CSQ-8 Mean	CSQ-8 SD	CSQ-8 Var.
AU	40.53	6.45	41.65	45.84	17.82	317.67	16.31	3.47	12.06
EBD	42.39	8.64	74.72	46.94	12.72	161.82	18.44	5.66	32.03
GM	39.63	8.78	77.08	42.90	14.73	217.10	14.52	3.87	14.99
ID	37.97	7.15	51.11	38.69	11.20	125.44	12.67	3.74	14.00
SDD	39.86	8.31	69.13	44.80	16.69	278.56	14.58	4.45	19.81
SLD	39.45	8.39	70.34	41.62	16.15	260.79	16.44	3.81	14.53
SI	37.80	8.11	65.71	40.13	11.81	139.37	14.70	4.99	24.93

Note: AU = autism, EBD = emotional-behavioral disorder, GM = general medical condition, ID = intellectual disability, SDD = significant developmental delay, SLD = specific learning disability, SI = speech impaired

Client Satisfaction Questionnaire-8 (CSQ-8; Larsen, Attkisson, Hargreaves, & Nguyen, 1979). The CSQ-8 is an eight-item questionnaire of general satisfaction with services. It was developed "to provide a brief, standardized assessment procedure suitable for use in a variety of service settings (Roberts, Attkisson, & Mendias, 1984, p. 385). Participants respond to each item using a 5-point Likert scale ranging from 0 = *very dissatisfied* to 4 = *very satisfied*. The scores are summed to provide a single measure of client satisfaction. Psychometric properties of the CSQ-8 are sound. Internal reliability has been established (α = .87 and .86) and construct validity has also been observed (r = .6 to .8) when compared to other measures of service satisfaction (Attkisson & Greenfield, 1994; Larsen et al., 1979). The CSQ-8 has been found appropriate for use with different ethnic populations (i.e., Caucasian, African American, Mexican, and other Hispanic origins) (Roberts et al., 1984). Internal consistency reliability for the current

sample was good ($\alpha = .873$). Mean scores for the CSQ-8 for the current sample is presented in Table 2.

Family Quality of Life Survey (FQOLS; Turnbull et al., 2004). The FQOLS was developed by the Beach Center research program of the University of Kansas. It is a 25-item assessment of five factors related to FQOL; family interaction (6 items), parenting (6 items), emotional well-being (4 items), physical/material well-being (5 items), and disability related support (4 items). Each item is scored on a Likert scale ranging from 1 = *very dissatisfied* to 5 = *very satisfied*. The item scores are summed to provide a single measure of FQOL. Single-factor measurement models for each factor had good to excellent fit (Poston, Summers, & Turnbull, 2006). Excellent fit was also observed for the overall scale structure for importance and satisfaction (Importance subscale-only model: $\chi^2(5) = 4.06$, $p = .54$; Importance item-only model: $\chi^2(270) = 644.63$, $p < .01$; Satisfaction subscale-only model: $\chi^2(5) = 9.13$, $p = .10$; Satisfaction item-level model $\chi^2(270) = 439.24$, $p<.001$) (Poston et al., 2006). Significant correlations were observed between the Family APGAR, a measure of family functioning, and the corresponding Family Interaction subscale of the FQOLS ($r(87) = .68$, $p<.001$) as well as the Family Resource Scale, a measure of family resources, and the corresponding FQOLS Physical Well-Being subscale ($r(58) = .60$, $p<.001$) (Poston et al., 2006). Test-retest reliability correlations were significant at the 0.1 level or beyond (*df* ranged from 59 to 63) (Poston et al., 2006). The focus of the current study was overall FQOL. Therefore, only participants' overall FQOL scores were used in the analyses. Internal consistency reliability for the current sample was excellent ($\alpha = .958$). Mean scores for the FQOLS for the current sample is presented in Table 2.

Results

To test the first research question a MANCOVA was conducted to evaluate whether parents of children with different disability types reported significantly different levels of parental stress and FQOL while controlling for the age of the child and FRL status. A priori power for the MANCOVA based upon the obtained sample size, disability groupings, and covariate (age of child) was .954 (Erdfelder, Faul, & Buchner, 1996). Mean scores for the disability groups ranged from No significant differences were observed between parental stress levels and FQOL between the child disability types, Wilk's Lambda = .967, df = 12, F = .985, p = .461. MANCOVA results are presented in Table 3.

Table 3

MANCOVA Summary

	Effect	F	df	Significance
Intercept	Wilks Lambda	648.049	2	.000
Age	Wilks Lambda	.192	2	.825
Income	Wilks Lambda	.468	2	.627
Disability Type	Wilks Lambda	.985	12	.461

*Note: *p < .05.

In order to address the second hypotheses a Point Biserial correlation was conducted to determine if FRL was related with FQOL and satisfaction with social services and positively correlated with parental stress. As shown in Table 4, the correlations between FRL and FQOL (r = .021, p = .686), parental stress (r = -.089, p = .082), and satisfaction with services (r = -.026, p = .770) suggest no relations. Point

Biserial correlation results are provided in Table 4.

Table 4

Point Biserial Correlations for FRL and Parental Stress, Satisfaction with Services, and FQOL

Correlated Variable	FRL	Parental Stress	FQOL	Sat. w/ Services
FRL		-0.89	0.21	-.026
Parental Stress			-.314***	.087
Sat. w/ Services				-.184*
FQOL				

Note: FRL = free or reduced lunch. *p <.05. **p < .01. ***p <.000.

Satisfaction with services and parental stress were then included in a regression equation to predict FQOL as a first step in determining whether or not parental stress was a moderator between satisfaction with services and FQOL. The results yielded a significant model (R^2 = .135, F = 10.323, p = .000) (Table 5). Satisfaction with services nearly reached statistical significance in predicting FQOL ($ß$ = .156, t = 1.924, p = .057) while parental stress reached significance at p = .000 ($ß$ = .320, t = 3.933).

Table 5

Linear Regression Analysis for Satisfaction with Services and Parental Stress in Predicting FQOL

Model	*R*	*R²*	Change in R²	Std. Error of Estimate	*ß*	Significance
1	.368	.135	.135	11.704	-.320 parental stress	.000
					-.156 sat. w/ services	.057

When the interaction between satisfaction with social services and parental stress was included in the model, parental stress was not found to moderate the relation between satisfaction with services and FQOL ($ß = -.824$, $t = -1.479$, $p = .142$). Linear regression analysis for the interaction between satisfaction with services and parental stress in predicting FQOL is provided in Table 6.

Table 6

Linear Regression Analysis for Interaction between Satisfaction with Services and Parental Stress in Predicting FQOL

Model	*R*	*R²*	Change in R²	Std. Error of Estimate	*ß*	Significance
1	.387	.149	.014	11.652	.824 interaction	.142

Discussion

The purpose of this study was to investigate the relationships between parental stress, SES, satisfaction with social services, and FQOL among parents of children with disabilities within a school setting. It provided several unique contributions to the existing literature. This study appeared to be one of the first to examine parental stress,

SES, satisfaction with social services, and FQOL among a sample of parents raising

children with disabilities that received special education services. This study also differed

from previous research in that it attempted to group parents according to salient features

of their child's disability and compared parents raising children with disabilities across a

range of disability types. This was atypical as previous studies have either grouped

parents of children with disabilities together regardless of their child's type of disability

(e.g., autism spectrum disorders, emotional/behavioral disorders, medical conditions,

speech delays, birth defects) (Rogers, 2007) or examined differences between a smaller

number of disability types (e.g., autism and Down syndrome) (Pisula, 2007). Another

unique aspect was that the child disability categories utilized in this study were based

upon special education disability criteria determined by each state whereas the majority

of previous research included disabilities that were clinically (Pisula, 2007) or medically

defined (Honberg, Kogan, Allen, Strickland, & Newacheck, 2009). Yet another unique

aspect of this study is the numerous types of childhood disabilities represented in the

sample and the wide range of severity (i.e., mild to severe). It may be that the severity of

the disabilities was more normally distributed in this sample than in studies conducted in

mental health, medical, and clinical settings in which the samples may represent parents

of children with the most severe disabilities. Twenty-percent of the parents in the current

sample reported having no high school diploma or the equivalent (i.e., General Education

Development Diploma) and 34.32% reported their annual household income was less

than $20,000, illustrating that this study represented a fairly large proportion of parents

with little education and financial means raising children with disabilities. A final unique

contribution of this study is that the sample consisted of 51 fathers (19% of the total

sample), which is atypical since the majority of research conducted in the areas of parental stress, satisfaction with social services, and FQOL tends to include mothers more so than fathers.

A unique contribution of this study was that findings were inconsistent with the vast majority of research that has been conducted within mental health (Davison et al., 2003), medical (Glenn et al., 2009), and clinical fields (Kersch et al., 2006). The first hypothesis in this study was two-fold. First, it was expected that parents of children with emotional/behavioral disorders and autism would present significantly higher levels of parental stress than parents of children with other disabilities (Hauser-Cram et al., 2001; Tomanik et al., 2004) due to the presence of maladaptive behaviors. Finding no differences of parental stress between childhood disability types was inconsistent with previous research findings (e.g., Hassall, Rose, & McDonald, 2005; Kasari & Sigman, 1997) in which the presence of child maladaptive behaviors contributed significantly to elevated parental stress. A possible explanation for none of the previous research samples included parents of children with disabilities obtained from within a school setting. This suggests that, for this sample, parental stress levels for parents of children with disabilities receiving special education services were relatively consistent regardless of child disability type and the presence of maladaptive behaviors. While inconsistent with previous research examining differences in parental stress levels based on child disability type, parental stress levels for each disability type in the current sample were consistent with results obtained from the normative sample (Berry & Jones, 1995; Caldwell, Horne, Davidson, & Quinn, 2007). Second, it was predicted that parents of children with emotional/behavioral disorders and autism, would report lower FQOL when compared to

parents of children with other disabilities (Bigelow, 2006; Emerson & Hatton, 2007).

This hypothesis was not supported in the current study. These findings do not necessarily

imply the parents of children with emotional/behavioral disorders and autism receiving

special education services in this sample experienced lower levels of stress than

previously reported in the literature. It is possible the parents of children with other types

of disabilities (e.g., learning disability, speech/language impaired, specific learning

disability, etc.) were suffering from stress at levels consistent with that of parents of

children with autism and emotional/behavioral disorders. This may be explained by the

fact that researchers have found that utilization of social service supports was effective in

decreasing parental stress (Greeff et al., 2006). However, only approximately one-third of

the sample reported utilizing social support services to assist them in meeting their

child's needs. This lack of social support services may have contributed to increasing

parental stress for all child disability types to levels similar to that of parents of children

with disabilities characterized by maladaptive behaviors. Another possible explanation

for the discrepancy between the literature and the current study's lack of statistically

significant findings of parental stress and FQOL across disability types may be attributed

to the manner in which the various disability types were grouped for analysis purposes. In

the current study, the groups were determined based upon similarities between the

disabilities (Harty, Alant, & Uys, 2006) as well as similarities and differences between

the levels of parental stress, FQOL, and satisfaction with social services across disability

types. As such, group sizes were unequal. The smaller groups would have been more

susceptible to outliers which may have impacted the means included in the analyses and

thereby the significance of the overall results of the MANCOVA.

The second hypothesis posited that FRL status would be positively correlated with parental stress and negatively correlated with satisfaction with social services and FQOL. Results from this sample of parents of children with disabilities receiving special education services failed to support this hypothesis. This suggests that for this sample of parents of children with disabilities receiving special education services, parental stress levels, satisfaction with services, and FQOL do not appear to be related to SES, which contradicts previous research findings (e.g., Monastersky, 2008). Previous research reflects several connections between SES, satisfaction with services, parental stress, and FQOL. Specifically, SES impacts a family's ability to utilize social support services (e.g., McManus, McCormick, Acevedo-Garcia, Ganz, & Hauser-Cram, 2009) and a primary goal of social support services is to assist families in caring for their child with a disability (e.g., Schalock et al., 2007), reduce parental stress (e.g., Greeff, Vansteenwegen, & Ide, 2006), and increase FQOL (e.g., Turnbull, Turnbull, Brown, & Turnbull, 2004). The sample in the current study differed from those described in the literature in that the children, regardless of SES, were receiving support for their disability through the local school system. It may be that the parents' satisfaction of the services provided for their within the school system off-set the expected relationships between SES, satisfaction with services, parental stress, and overall FQOL that have been observed in samples obtained from medical, clinical, and settings.

Results of the linear regression analysis supported the association between parental stress and FQOL, meaning that for this sample, parental stress had considerable impact on FQOL, with higher levels of parental stress associated with lower FQOL for this sample. As for satisfaction with social services in the prediction of FQOL, results of

the linear regression analysis nearly reached statistical significance, yet results were not in the direction that was expected. Specifically, these results suggested that higher satisfaction with social service support was associated with lower FQOL for this sample. It is proposed that families with low quality of life may be more appreciative of social services they receive and as a result report feeling more satisfied with the assistance while families with better FQOL may have higher expectations regarding outcomes and as a result their satisfaction with social services may be lower if those expectations are not realized. Combined, these results implied that for this study both parental stress and to a lesser degree, satisfaction with social services, are contributors in the prediction of FQOL which is consistent with previous literature (e.g., Fidler et al.,2000; Glenn et al., 2009; Pisula, 2007).

This study appeared to be the first of its kind to explore the moderating effect of parental stress on satisfaction with social services and FQOL. It was hypothesized that parental stress would moderate the connection between satisfaction with social services and FQOL yet results of the interaction effect were not statistically significant. This suggested that for this sample of parents of children with disabilities receiving special education services, parental stress did not moderate the connection between satisfaction with social services and FQOL.

Limitations and Future Research

This study had several limitations that may be addressed through future research. First, this study appeared to be one of the first to examine SES, parental stress, satisfaction with social services and FQOL within a school setting. Future research is needed to further explore these variables within school settings in an attempt to replicate

these results. In addition, future research into parental stress, SES, satisfaction with social services and FQOL within school settings may result in identification of additional characteristics of families of children with disabilities who are not utilizing social support services and are therefore not included in studies based within other settings (e.g., medical, clinical). This may be helpful in determining whether or not parents of children with disabilities sampled within school settings differ from parents sampled in other settings.

This study was conducted in the Southeast region of the United States in a rapidly growing county that is in transition from rural to suburban. Therefore it may not generalize to parents of children with disabilities in different regions of the United States or other countries. In addition, the fact that the county is undergoing such rapid growth makes it unique in ways that may have a direct impact on the amount and availability of social support services for these families. As the county has expanded it may be that the social support services have failed to keep up with the increasing number of families of children with disabilities and may help to explain the low percentage of parents of children with disabilities reporting the use of social support services. Future research could address this limitation by exploring SES, parental stress, satisfaction with social support services, and FQOL in various types of communities (e.g., rural, suburban, rural, affluent, impoverished) across the nation and within other countries.

In this study family SES was measured by whether or not the child with a disability received FRL at school. FRL status is determined by multiple factors (i.e., number of people in household, income, receipt of food-stamps) (Georgia Department of Education, 2010), and as such may not accurately depict a family's true SES. In the

future a study in which SES was measured as a continuous variable may provide additional insight into the relationships between family SES, parental stress, satisfaction with social services, and FQOL.

Finally, only parents of children with disabilities participated in this study. Therefore, it may be helpful to conduct a similar study in the future that includes parents of children with disabilities and parents of typically developing children within a school setting. A study including both parent groups may provide information regarding the magnitude of differences between SES, parental stress, and FQOL with the expectation that significant differences may exist between parents of typically developing children and children with disabilities. Specifically, parents of children with disabilities that receive special education services may be found to experience higher parental stress, lower SES, lower satisfaction with social services, and lower FQOL than parents of typically developing children.

Implications for School-Based Mental Health Service Providers

The present study points to several implications for mental health service providers working within school settings. First, mental health service providers need to be aware of the ways in which families' parental stress and FQOL are impacted as they raise a child with a disability so they can effectively meet their needs. This study suggested parents of children receiving special education services in schools are more similar than different regarding parental stress and FQOL and will likely benefit from similar types of support.

Second, researchers have found that parents raising children with disabilities, regardless of the type, experience higher levels of stress than parents of typically

developing children (e.g., Dellve et al., 2006; Fidler, Hodapp, & Dykens, 2000; Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008). As such, mental health providers working in schools may wish to ensure parents of children with all types of disabilities by alleviating parental stress whenever possible. An area in which school mental health providers could have a direct impact is in alleviating parental stress and anxiety related to school-related issues. This could be accomplished through serving as a liason between parents of children with disabilities and the school (Hess, Molina, & Kozleski, 2006) to foster communication and providing information regarding the special education system (e.g., referral for special education, eligibility for special education services, development of Individualized Education Plans, informed consent procedures, and due process rights).

A final implication for school-based mental health service providers is to be aware that many families of students with disabilities may not be utilizing social service supports in the community. Mental health service providers in schools may wish to identify families not receiving social service supports and educate them about the types of services are available in the community. If parents express interest in accessing those social services, school mental health providers could assist parents in contacting those agencies and help facilitate entry into those systems.

References

Agosta, J. M., & Bradley, V. J. (1985). *Family care for persons with developmental disabilities: A growing commitment*. Human Services Research Institute: Boston, MA.

Allard, M. A., Gottlieb, A., & Hart, D. (1993). *Impact study of the family cash assistance project: Year three results*. Waltham, MA: Shriver Center, Department of Social Science, Ethics and Law.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (Revised 4th ed.). Washington, DC: Author.

Attkisson, C. C., & Greenfield, T. K. (1994). The Client Satisfaction Questionnaire – 8. In M. E. Maruish (Ed.), *The use of psychological testing for treatment planning and outcomes assessment*, (2nd ed., pp. 1333-1346).

Bailey, D. B., Hebbeler, K., Spiker, D., Scarborough, A., & Mallik, S. (2005). First Experiences with Early Intervention: A National Perspective. *Pediatrics, 113*(4), 887-896.

Baker, B. L., McIntyre, L. L., Blacher, K., Crnic, C., Edelbrock, C., & Low, C. (2003). Preschool children with and without developmental delay: Behavioural problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4-5), 217-230. doi: 10.1046/j.1365-2788.2003.00484.x

Berry, J. O., & Jones, W. H. (1995). The parental stress scale: Initial psychometric evidence. *Journal of Social and Personal Relationships, 12*(3), 463-472. doi:10.1177/0265407595123009

Bigby, C. (2003). *Ageing with a lifelong disability. A guide to practice, program and*

policy issues for human service professionals. London: Jessica Kingsley Publishers.

Bigelow, B. J. (2006). There's an elephant in the room: The impact of early poverty and neglect on intelligence and common learning disorders in children, adolescents, and their parents. *Developmental Disabilities Bulletin, 34*(1-2), 177-215.

Block, P. Balcazar, F., & Keyes, C. (2002). Race, poverty and disability. Three strikes and you're out! Or are you? *Social Policy 33*(1), 34–38.

Bradley, E. A., Thompson, A., & Bryson, S. E. (2002). Mental retardation in teenagers: Prevalence data from the Niagara Region, Ontario. *Canadian Journal of Psychiatry, 47*(7), 652-659.

Bradshaw, J. (2001). *Poverty: The Outcomes for Children*. London: Family Policy Studies Centre.

Brown, I., Anand, S., Alan Fung, W.L., Isaacs, B., & Baum, N. (2003). Family quality of life: Canadian results from an international study. *Journal of Developmental and Physical Disabilities, 15*(3), 207-230. doi:10.1023/A:1024931022773

Brown, R. I., MacAdam-Crisp, J., Wang, M., & Iaocci, G. (2006). Family quality of life when there is a child with a developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*, *3*(4), 238-245(8). doi:10.1111/j.1741-1130.2006.00085

Brown, R.I., Schalock, R. L., & Brown, I. (2009). Quality of life: Its application to persons with intellectual disabilities and their families – Introduction and overview. *Journal of Policy and Practice in Intellectual Disabilities, 6*(1), 2-6. doi: 10.1111/j.1741-1130.2008.00202.x

Brown, R., & Shearer, J. (2004). Challenges for inclusion within a quality of life model for the 21st century. In D. Mitchell (Ed.), *Special educational needs and inclusive education: Major themes in education,* (Vol. 2, pp. 139-156). London: Routledge Falmer.

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior, 24*, 385-396.

Davison, P. W., Prasher, V. P., & Janicki, M. P. (2003). *Mental health, intellectual disabilities and the ageing process*. Oxford: Blackwell.

Dellve, L., Samuelsson, L., Tallborn, A., Fasth, A., & Hallberg, L. (2006). Stress and well-being among parents of children with rare diseases: A prospective intervention study. *Journal of Advanced Nursing, 53*(4), 392-402. doi: 10.1111/j.1365-2648.2006.03736

Dobson, B., & Middleton, S. (1998). *Paying to care: The cost of childhood disability. Report from the Joseph Rowntree Foundation*. York: York Publishing Services, Ltd.

Emerson, E., & Hatton, C. (2007). Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: A replication. *Journal of Intellectual Disability and Research, 51*(11), 866-874.

Erdfelder, E., Faul, F., & Buchner, A. (1996). GPOWER: A general power analysis program. *Behavior Research Methods, Instruments, & Computers, 28*, 1-11.

Fidler, D. J., Hodapp, R. M., & Dykens, E. M. (2000). Stress in families of young children with Down syndrome, Williams syndrome, and Smith-Magenis syndrome. *Early Education and Development, 11*, 395-406.

doi:10.1207/s15566935eed1104_2

Freedman, R. I., & Capobianco Boyer, N. (2000). The power to choose: Supports for families caring for individuals with developmental disabilities. *Health and Social Work, 25*(1), 59-68.

Georgia Department of Education. (2007). Special Education Rules. Atlanta, GA: Retrieved from http://www.doe.k12.ga.us/ci_exceptional.aspx?PageReq=CIEXCAdoptedRules.

Georgia Department of Education. (2010). Eligibility Standards for Free and Reduced-Price Meals – SY 2009-2010 and SY 2010-2011. Retrieved from http://www.public.doe.k12.ga.us/_documents/FBONutrition/Attachment%20A%20Eligibility%SCAle%202010and%202011.pdf

Glenn, S., Cunningham, C., Poole, H., Reeves, D., & Weindling, M. (2009). Maternal parenting stress and its correlates in families with a young child with cerebral palsy. *Child: Care, Health & Development, 35* (1), 71-78. doi:10.1111/j.1365-2214.2008.00891

Greeff, A. P., Vansteenwegen, A., & Ide, M. (2006). Resiliency in familie*s* with a member with a psychological disorder. *American Journal of Family Therapy, 34*(4), 285-300. doi: 10.1080/01926180600637465

Griffin, D., & Steen, S. (2010). School-family-community partnerships: Applying Epstein's theory of the six types of involvements to school counselor practice. *Professional School Counseling, 13*(4), 218-226. doi: 10.5330/PSC.n.2010-13.218

Harty, M., Alant, E, & Uys, C. J. E. (2006). Maternal self-efficacy and maternal

perception of child language competence in pre-school children with a communication disability. *Child: care, health and development, 33*, 144-154. doi: 10.1111/j.1365-2214.2006.0061.x

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405-418. doi:10.1111/j.1365-2788.2005.00673

Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., & Kraus, M. W. (2001). Children with disabilities: A longitudinal study of child development and parent well-being. *Society for Research in Child Development Monographs, 66*, 1-131. doi: 10.1111/1540-5834.00151

Hester, P. P., Baltodano, H. M., Hendrickson, J. M., Tonelson, S. W., Conroy, M. A., & Gable, R. A. (2004). Lessons learned from the research on early intervention: What teachers can do to prevent children's behavior problems. *Preventing School Failure, 49*, 5-10. doi: 10.3200/PSFL.49.1.5-10

Hodapp, R. M., & Dykens, E. M. (1997). Families of Children with Prader-Willi syndrome: Stress-support and relations to child characteristics. *Journal of Autism & Developmental Disorders, 27*(1), 11-24. doi:10.1023/A:1025865004299

Hogrebe, M. C., & Tate, W. F. (2010). School Composition and Context Factors that Moderate and Predict 10th-Grade Science Proficiency. *Teachers College Record*, 112(4), 1096-1136.

Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the Beach Center Family Quality of

Life Scale. *Journal of Marriage and Family, 68*, 1069-1083. doi: 10.1111/j.1741-3737.2006.00314.x

Honberg, L., Kogan, M. D., Allen, D., Strickland, B. B., & Newacheck, W. (2009). Progress in ensuring adequate health insurance for children with special health care needs. *Pediatrics, 124*, 1273-1280. doi: 10.1542/peds.2009-0372

Janicki, M. P. (1990). Growing old with dignity: On the quality of life for older persons with a lifelong disability. In R. L. Schalock (Ed.), *Quality of life: Perspectives and issues* (pp. 115-125). Washington, DC: American Association on Mental Retardation.

Kaiser, B., & Rasminski, J. S. (2003). *Challenging Behavior in Young Children: Understanding, Preventing, and Responding Effectively*. Canada: Pearson Education, Inc.

Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of Autism and Developmental Disorders, 27*(1), 39-57. doi: 10.1023/A:1025869105208

Kauser, S., Jevne, R. F., & Sobsey, D. (2003). Hope in families of children with developmental disabilities. *Journal on Developmental Disabilities, 10*(1), 35-46.

Kersch, J., Hedvat, T. T., Huaser-Cram, P., & Warfield, M. E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research, 50*(12), 883-893. doi:10.1111/j.1365-2788.2006.00906

Larsen, D. L., Attkisson, C. C., Hargreaves, W. A., & Nguyen, T. D. (1979). Assessment of client/patient satisfaction: Development of a general scale. *Evaluation and*

Program Planning, 2, 197-207. doi: 10.1016/0149-7189(79)90094-6

Leonard, H., & Wen, X. (2002). The epidemiology of mental retardation: Challenges and opportunities in the new millennium. *Mental Retardation and Developmental Disabilities, 8*, 117-134. doi: 10.1002/mrdd.10031

Lustig, D. & Strauser, D. R. (2007). Causal relationships between poverty and disability. *Rehabilitation Counseling Bulletin, 50*(4), 194-202. doi: 10.1177/00343552070500040101

McManus, B., McCormick, M. C., Acevedo-Garcia, D., Ganz, M., & Hauser-Cram, P. (2009). The effect of state early intervention eligibility policy on participation among a cohort of young CSHCN. *Pediatrics, 124*, S368-S374. doi: 10.1542/0eds.2009-1255G

Meyer, D. J. (1986). Fathers of handicapped children. In R. R. Fewell & P. F. Vadasy (Eds.), *Families of handicapped children: Needs and supports across the lifespan* (pp. 35-73). Autsin, TX: Pro-Ed.

Monastersky, R. (2008). Researchers probe how poverty harms children's brains. *Chronicle of Higher Education, 54*(25), 8.

Odom, S. L., Brantlinger, E., Gersten, R., Horner, R. H., Thompson, B., & Harris, K. R. (2005). Research in special education: Scientific methods and evidence-based practices. *Exceptional Children,* 71(2), 137-148.

Olsson, M. B., & Hwang, C. P. (2002). Sense of coherence in parents of children with different developmental disabilities. *Journal of Intellectual Disability Research, 46*(7), 548-559. doi:10.1046/j.1365-2788.2002.00414

Park, J., Turnbull, A. P., & Turnbull, H. R. (2002). Impacts of poverty on quality of life

in families of children with disabilities. *Exceptional Children, 68*(2), 151-170.

Park, J., Hoffman, L., Marquis, J., Turnbull, A. P., Poston, D., Mannan, H., . . . Nelson, L. L. (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research, 47*(4-5), 367-384. doi:10.1046/j.1365-2788.2003.00497

Peugh, J. L., & Enders, C. K. (2004). Missing data in educational research: A review of reporting practices and suggestions for improvement. *Review of Educational Research, 74*(4), 525-556. doi: 10.3102/00346543074004525

Poston, D., Turnbull, A.P., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life: A qualitative inquiry. *Mental Retardation, 41*, 313-328. doi: 10.1352/0047-6765(2003)41<313:FQOLAQ>2.0.CO;2

Prochnow, J. E., & DeFronzo, J. V. (1997). The impact and parental characteristics of juvenile misconduct. *Journal of Emotional and Behavioral Disorders, 5*(2), 119-124. doi: 10.1177/106342669700500206

Roberts, R. R., Attkisson, C. C., & Mendias, R. M. (1984). Assessing the client satisfaction questionnaire in English and Spanish. *Hispanic Journal of Behavioral Sciences, 6*(4), 385-395. doi:10.1177/07399863840064004

Schalock, R. L. (2004). Moving from individual to family quality of life as a research topic. In A. Turnbull, I. Brown, and H. R. Turnbull (Eds.), *Families and persons with mental retardation and quality of life: International perspectives*. Washington DC: American Association on Mental Retardation.

Schalock, R. L., Gardner, J. F., & Bradley, V. J. (2007). *Quality of life for persons with intellectual and other developmental disabilities: Applications across individuals,*

organizations, communities, and systems. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Scorgie, K., Wilgosh, L., & McDonald, L. (1998). Stress and coping in families of children with disabilities: An examination of recent literature. *Developmental Disabilities Bulletin, 26*(1), 22-42.

Soresi, S., Nota, L., & Ferrari, L. (2007). Considerations on supports that can increase the quality of life of parents of children with disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 4*(4), 248-251. doi:10.1111/j.1741-1130.2006.00087

Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability, 29*(1), 16-26. doi:10.1080/13668250410001662892

Turnbull, A., Turnbull, H. R., Brown, I., & Turnbull, A. P. (2004). *Families and people with mental retardation and quality of life: International perspectives*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Vermaes, I. P. R., Janssens, J. M. A. M., Mullaart, R. A., Vinck, A., & Gerris, J. R. M. (2008). Parents' personality and parenting stress in families of children with spina bifida. *Child: Care, Health and Development, 34*(5), 665-674. doi: 10.1007/BF00916812

Wang, M., Mannan, H., Poston, D., Turnbull, A. P., & Summers, J. A. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons with Severe Disabilities, 29*(2), 144-155.

doi:10.2511/rpsd.29.2.144

Willoughby, J. C., & Glidden, L. M. (1995). Fathers helping out: shared childcare and

marital satisfaction of parents of children with disabilities. *American Journal on*

Mental Retardation, *99*(4), 399–406.

Zuna, N.I., Turnbull, A., & Summers, J. A. (2009). Family quality of life: Moving from

measurement to application. *Journal of Policy and Practice in Intellectual*

Disabilities, 6, 24-31. doi: 10.1111/j.1741-1130.2008.00199.x