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# Raising a Child with a Severe Disability: The Impact on Parents and Siblings

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**Raising a Child with a Severe Disability: The Impact on Parents and Siblings**

by

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## Chapter 1: Introduction

Prior to the passage of the Education of All Handicapped Children Act of 1975 (PL 94-142), most children with severe intellectual and developmental disabilities (IDD) in the United States were placed in institutions. Given the dearth of community resources available at that time and lack of societal acceptance, it was too difficult to include a child with significant special needs as an integral part of a family (President's Committee on Mental Retardation, 1977). As awareness and social consciousness increased, families have become empowered to keep children with significant developmental disabilities in the home and include them fully in their family and social lives.

The *Diagnostic and Statistical Manual-5<sup>th</sup> edition* (DSM-5; American Psychiatric Association, 2013) defines individuals with IDD as those who have impairments in academic, social, and self-management skills. In Minnesota, students are eligible for special education services under the category of Developmental Cognitive Disabilities (DCD). Minnesota defines DCD as “a condition resulting in significantly below average intellectual functioning and concurrent deficits in adaptive behavior that adversely affects educational performance and requires special education and related services” (Minnesota Department of Education [MDE], 2011). Students must demonstrate need for support in four of seven adaptive behavior domains: daily living and independent skills, social and interpersonal skills, communication skills, academic skills, recreation and leisure skills, community participation and work and work-related skills (MDE, 2011).

Raising a child with a severe disability can place a significant burden on families. Fortunately, as a result of PL 94-142 and other legislative acts, families now receive more educational and community support to help them cope with the increased stress. Although a

substantial amount of literature exists to document the stressors of families of children with autism spectrum disorder (ASD), less is known about the effects of raising a child with other types of severe developmental disabilities on the family. Thus, this paper explores the impact of having a child with a severe disability in the family.

### **Historical Background**

Until very recently, people with developmental disabilities were not an accepted part of society. Historically, people with disabilities were thought of as sub-human, a burden, a curse, or all three (Beirne-Smith, Ittenbach, & Patton, 2002). A child with severe disabilities identified as such had little chance of survival as they were often put to death. As society evolved, those with disabilities may have had their lives spared but were often destined to live a life of pain and loneliness as they were hidden away in institutions or the family home (MDE, 2011). The shame of having a child with a disability on a family was such that often the family felt there was no other choice than to abandon the child and live their lives as if that child no longer existed.

As society evolved so did its views on those with disabilities. Individuals with disabilities and their advocates demanded better treatment and better services, and over time their voices were heard and change began to take place. During the 1950s and 1960s, the National Association of Retarded Children (now known as The Arc of the United States) helped the federal government develop and validate practices for youth with disabilities and their families (Hallahan, Kauffman, & Pullen, 2009). In spite of this progress, many individuals with disabilities lived in institutions prior to the 1970s. During the 1970s and 1980s, deinstitutionalization and right-to-education efforts significantly decreased the number of children and youth who were placed in institutional settings (Beirne-Smith et al., 2002).

In 1965, Congress passed the Elementary and Secondary Education Act, which was part of President Lyndon B. Johnson's War on Poverty (Hallahan et al., 2009). It provided funding to meet the needs of educationally deprived children, especially through compensatory programs for the poor. Although this law did not target just those with disabilities it was a step in the right direction of realizing that all individuals deserved a public education. In 1973, Congress passed Section 504 of the Rehabilitation Act, which made it illegal for schools and businesses to discriminate against those with disabilities (U.S. Department of Education, 2010).

In addition to these legislative acts, Supreme Court rulings have also contributed to more humane treatment of individuals with disabilities. The *PARC v Commonwealth of Pennsylvania* case of 1972 affirmed that children's rights to education could not be removed without due process of law (Beirne-Smith et al., 2002). This class action lawsuit and the aforementioned legislation provided a significant impetus for passage of PL 94-142.

Public Law 94-142 is considered to be the most comprehensive and inclusive law that addressed the rights of students with disabilities and made it possible for them to be educated in the public school system regardless of the severity of their disability. It fundamentally changed the way students with disabilities were educated and accepted (Hallahan et al., 2009). This law has been reauthorized several times since 1975, most recently as the Individuals with Disabilities Education Improvement Act of 2004 (IDEA 2004) (U.S. Department of Education, 2010). IDEA 2004 has seven principles that apply to all students who qualify for special education: free and appropriate public education, education in the least restricted environment, nondiscriminatory evaluation, an individualized education program (IEP), parental participation, due process procedures, and zero reject.

The 1975 PL 94-142 legislation created the federal educational category of *Mental Retardation*, under which students with intellectual and cognitive disabilities were served. This changed in October of 2010, when President Barack Obama signed Rosa's Law, which renamed the category as *Intellectual Disability* (Diament, 2010). Rosa's Law required that all federal documents use the new terminology. Although this is the federal designation for students who meet eligibility criteria, various states use different terminology to refer to students who receive special education services in this category.

### **Family Resources**

The cost of raising any child can be expensive. The federal government estimates it costs approximately \$245,000 to raise a child (without a disability) until they are the age of 18 (U.S. Department of Agriculture, 2014). For families who have a child with a disability, the costs are even greater. Buescher, Cidav, Knapp, and Mandell (2014) estimated the cost to support a child with a diagnosis of autism with an intellectual disability was 2.4 million dollars over the course of the child's life. Although it is not fair to compare lifetime costs to the cost of raising a child until they are 18, it is safe to assume that families raising a child with a disability will be faced with significantly more financial burden than those raising a child without a disability.

As attitudes and perceptions have changed so has the availability of resources for families. Realizing the higher cost of raising a child with a disability, the Social Security Administration enacted policies that allowed individuals with disabilities to draw Social Security Income. This program eventually transformed into the Supplemental Security Income program that allows for monthly benefits to help cover the costs of raising a child with a disability (Bekowitz, 1999). Supplemental Security Income can be continued into adulthood as long as the disability still exists.

Supplemental insurance programs also exist in each state to help insure the medical needs of a child with a disability. These programs usually charge a flat fee or are based upon family income (Birenbaum, 2010). A 2005-2006 National Survey of Children with Special Health Care Needs found that 9% of families with a child with a disability had no insurance at least for part of the year surveyed, and one in three families claimed that even with insurance the insurance was inadequate to meet the child's needs. Further, one in five families acknowledged they typically spend \$1,000 or more in out-of-pocket medical expenses for their child annually (U.S. Department of Health and Human Services, 2008).

### **Overview of Disabilities**

Children with ID who receive public school education services are diagnosed with a variety of debilitating conditions. In this section, I describe briefly the primary disabilities of participants in Chapter 2 studies.

#### **Cerebral Palsy**

Cerebral palsy is a neurological disorder caused by a non-progressive brain injury or malformation that occurs prenatally or perinatally. The damage to the brain always results in motor impairment, and 30-50% of the time results in cognitive impairments (Batshaw, Pellingro, & Roizen, 2007). Because the brain injury or malformation occurs during a time that the brain is developing, it is considered a developmental disorder. Cerebral palsy's effects are widely variable, with some people being completely affected and needing total physical care to those with a slight muscle tremor who do not require assistance.

It was once thought that cerebral palsy was caused by difficult deliveries, but research has shown that only a small percentage of cases are produced this way. Current research

suggests the preponderance of cases result from abnormal brain development or brain injury prior to birth or during labor and delivery (Batshaw et al., 2007).

### **Down Syndrome**

Down syndrome is a genetic chromosomal disorder caused by abnormal cell division, which results in extra genetic material on the 21st chromosome called Trisomy 21 and affects 95% of people with Down syndrome (Beirne-Smith et al., 2002). The other two types of Down syndrome are mosaicism and translocation. The latter two types are less common but still involve chromosomal abnormalities (National Down Syndrome Society, 2012). Like most developmental disabilities, Down syndrome symptoms can vary widely in severity. Down syndrome may cause significant cognitive delays and physical symptoms such as low muscle tone, hearing loss, and heart defects (Beirne-Smith et al., 2002).

Down syndrome can be diagnosed prenatally or shortly after birth. If not diagnosed prenatally, there are often distinctive physical features that aid physicians in the diagnostic process. These physical features can include a flattened face, slanted eyes, a single deep crease across the palm of the hand, and low muscle tone. Blood tests are also typically conducted to confirm a diagnosis (Beirne-Smith et al., 2002).

### **Developmental Disability/Delay**

Many of the study participants were identified as having developmental disability or developmental delays that were not specified. All participants had significantly below average intellectual functioning and major deficits in adaptive behavior.

## Theoretical Background

The effects of a child with a disability on the family can be described through the Family Stress Theory. McCubbin (1995) first proposed the Family Stress Theory model in 1995 to explain the effects of stress on the family unit. The Family stress theory uses an ABC-X model, which is presented in this section and based upon McCubbin's original work.

The "A" aspect is the stressor occurrence. This could be a single incident or a combination of variables. The "A" aspect could be anything that is stressful and overwhelming to an individual that leads to stress on the entire family. An example of this could be the birth or diagnosis of a child with a severe disability (Darling, Senatore, & Strachan, 2012).

The "B" aspect consists of the coping mechanism that is used to deal with the stressor occurrence. This could be an intrinsic response or come in the form of external support either tangible or intangible. External support could be in the form of financial help, family social support, or spiritual guidance. The more resources that are available in the coping stage can better shield the family from stress.

The "C" aspect of the equation is the way in which the individual or family perceives the stress that is being imposed on the family. Some might view the stress as manageable and feel they are able to deal with the added strain the stress produces whereas others may find the stress factor completely overwhelming and feel they are unable to cope with the stress. Ultimately, the "C" aspect represents how the family perceives the stress, which could range from ultra-positive to ultra-negative and everything in between.

The final aspect of the Family Stress Theory is the "X" aspect. The "X" combines the other three aspects (the stressor, the resources, and the conceptualization of the stress) and formulates a level of adjustment the family has achieved. The range of how the "X" factor is

manifested could go from a well-adjusted family to one with very high stress and maladaptive ways of dealing with that stress.

The ABC-X model describes how having a child with a disability can create hardships for families that cause them to reorganize the way the family functions. A major component of this model is the meaning the family assigns to the stress of having a child with a disability and the resources the family has to cope with the stress.

### **Research Question**

The purpose of this literature review is to ascertain what family variables are associated with raising a child with a severe developmental disability. This can be addressed with three research questions:

1. What is the relationship between maternal stress and raising a child with a severe developmental disability?
2. What is the relationship between paternal stress and raising a child with a severe developmental disability?
3. What is the impact of being raised with a sibling who has a severe developmental disability?

### **Focus of the Review**

Quantitative and qualitative studies published from 1997-2015 were considered for inclusion in Chapter 2. The majority of studies reviewed were published between 2005-2015 but three older studies were included from 1997, 1998, and 2003. Older studies were considered in this review due to the paucity of current studies on this topic that excluded the focus of autism. Participants included individuals with disabilities in the United States, Canada, the United Kingdom, and Australia who ranged in age from birth to 21 and who were diagnosed with

disabilities that included cerebral palsy, Down syndrome, intellectual disabilities, and developmental delays. Although children and youth with autism were participants in some studies, they were excluded from review with regard to data analysis.

Several search terms were used to locate Chapter 2 studies using the Academic Search Premier and PsycINFO databases: *developmental and physical disabilities, parental feelings of stress, family stress, sibling stress, and family stress theory*. In addition, I searched the tables of contents of two journals for the past 2 years: *Journal of Developmental and Physical Disabilities and Journal of Intellectual and Developmental Disability*.

### **Importance of the Topic**

A family raising a child with a severe developmental disability faces many daunting hardships. Financially, it can be extremely expensive to afford increased medical and therapy costs. The time commitment involved in coordinating services as well as the organizing insurances or community services to help pay the expenses can be overwhelming. Parents must also become experts of sorts as they navigate a sometimes complicated and confusing special education system. Legal issues can also be a strain as families struggle to determine their own legal rights and the rights of their child. Those things alone would be intimidating and discouraging but the extra burden does not end there, as a child with a severe disability affects every aspect of their daily lives from social experiences to family and marital stress (Sanders, 2011).

As a parent of a child with a severe developmental disability and as a special education teacher working very closely with the families of the students I serve, I have first-hand experience with the stress that is involved with raising a child with a severe disability. As an educator I feel it is my job to not only teach students but also connect with their families and

make their journey a bit easier. I recognize the importance of helping families understand their child's disability and teaching them to provide the educational and behavioral supports needed in the home setting. Hopefully, this helps mitigate some of the stress of raising a child with a disability. Having a supportive working relationship with families is one of my main goals when working with students.

### **Definitions**

This section provides definitions for relevant terms used in this paper. Definitions for disability categories have been described earlier in this chapter.

*Autism Spectrum Disorders:* The DSM-5 defines autism using three characteristics:

1. Persistent deficits in social communication and social interaction across multiple contexts.
2. Restricted, repetitive patterns of behavior, interests, or activities.
3. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learning strategies in later life).

In the previous DSM-IV-TR, autism diagnoses were differentiated more or less according to functioning level and used the categories of Autistic Disorder, Asperger syndrome and PDD-NOS. The DSM-5 uses levels to differentiate severity based on the level of support the person requires (APA, 2013).

*Perinatal:* occurring in, concerned with, or being in the period around the time of birth (Beirne-Smith et al., 2002).

*Prenatal:* occurring, existing, or performed before birth (Beirne-Smith et al., 2002).

## Chapter 2: Review of the Literature

The purpose of this chapter was to review the research that examines the relationship between stress and raising a child with intellectual and developmental disabilities (IDD).

The review of the 10 studies in this chapter is organized in three sections: studies that focused on maternal stress, studies that focused on paternal stress, and studies that focused on sibling factors. Prior to a review of the studies that examine stress factors in families with disabilities, an overview of assessment measures is provided.

### Assessment Measures

A number of studies in this chapter relied upon the same assessment tools to measure outcomes. To assist the reader, Table 1 lists and briefly describes the assessments are used in multiple studies. These assessment tools will be referred to in the chapter using the acronym identified in the table.

**Table 1**

### Overview of Family Stress and Needs Assessments

ASSESSMENT	DESCRIPTION
<i>Brief Locus of Control Scale</i> (Lumpkin, 1985)	A 6-item scale measuring internal and external locus of control on a 5-point scale
<i>Child Behavior Checklist (CBC-L;</i> Achenbach, Edelbrock, & Howell, 1987)	A 120-item assessment measuring children's internalizing and externalizing behaviors on a 3-point Likert scale
<i>Coping Strategies</i> (Carver, Scheier, & Weintraub, 1989)	A 52-item scale that measures active, adaptive and maladaptive coping within 13-subscales.
<i>Dyadic Adjustment Scale (DAS;</i> Spanier, 1976, 1979)	A 4-sub scale measure of affection, cohesion, conflict and satisfaction within a marriage
<i>Family Adaptability and Cohesion Evaluation Scale III (FACES-III;</i> Olson, Portner, Lavee, 1985)	A 20-item scale measuring emotional family cohesion and adaptability on a 5-point scale
<i>Family Crisis-Oriented Personal Evaluation Scale (FCOPES;</i> McCubbin, Olson, & Larsen, 1987).	A 30-item scale that measures attitudes and behaviors in response to problems and assesses the family's coping patterns with regard to ability to seek support from other individuals and agencies using a 5-point Likert scale
<i>Family Health Status Inventory (FHSI;</i> Norem, Malia, & Garrison, 1988)	A 16-item scale that measures psychological stress

Table 1 (continued)

ASSESSMENT	DESCRIPTION
<i>Family Inventory of Life Events</i> (FILE; McCubbin & Patterson, 1987)	A 70-item scale for fathers that measures life events and changes experienced by families during the past year on a 4-point Likert scale
<i>Family Needs Scale</i> (FNS; Bailey & Simeonsson, 1988)	Assesses six domains of needs for information, support, help in explaining the child to others, help in obtaining community services, financial needs, and help with family functioning
<i>Family Stress and Coping Interview</i> (FSCI; Minnes & Nachshen 1997; Woodford 1998)	A 22-item scale measuring parental stress on a 5-point Likert scale
<i>Family Support Scale</i> (FSS; Dunst, Jenkins, Trivette, 1984)	An 18-item scale measuring the range of formal and informal support provided to the family using a 5-point scale
<i>Home Observation for Measuring the Environment</i> (HOME; Caldwell & Bradley, 1984)	A 45-item scale that measures the nature of a child's environment
<i>Parent Child Interaction Rating Scale</i> (PCIRS; Belsky, Crnic, & Gable, 1995)	A 5-point scale measuring pleasure of both parent and child during a 10-min observation
<i>Parental Locus of Control – Short Form Revised</i> (PLOC; Hassall, Rose & McDonald, 2005)	47-items rated on a 5-point Likert scale in four subscales of Parental Efficacy (PLOC-EP), Parental Responsibility (PLOC-PR), Child Control of Parent's Life (PLOC-CC), and Parental Control of Child's Behavior (PLOC-PC)
<i>Parenting Daily Hassles Scale</i> (PDHS; Crnic & Greenberg, 1990)	A 20-item scale that assesses minor daily stresses and hassles encountered during routine interactions with children using a 5-point Likert scale
<i>Parenting Sense of Competence Scale</i> (PSOC; Gibaud-Wallaston & Wandersman, 1978)	A 16-item scale measuring parenting satisfaction and parenting efficacy measured on a 6-point Likert scale
<i>Parenting Stress Index</i> (PSI; Abidin, 1990)	A 36-item scale that examines perceived stress based on child characteristics and interactions with the child on a 5-point scale
<i>Questionnaire on Resources and Stress</i> (QRS; Holroyd, 1987)	A 285-item scale measuring perception of stress on a 5-point scale
<i>Satisfaction with Life Scale</i> (SWLS; Diener, Emmons, Larsen, & Griffin, 1985)	A 5-point measurement to determine agreement with items related to overall life evaluation
<i>Strengths and Difficulties Questionnaire-Parent Report Version</i> (SDQ; Goodman, 1997, 2001)	A 25-item scale measuring behavior well-being in 5-subcales using a 3 point scale
<i>Stress Index for Parents of Adolescents</i> (SIPA; Sheras & Abidin, 1995)	A 34-item scale measuring reactions to the parenting experience across four subscales
<i>Symptoms Checklist-35</i> (SCL; Derogatis, 1993)	A 35-item scale measuring symptomatology and well-being

## Maternal Stress

Eight studies focused on maternal stress. Studies that focused on family stress as a whole were also included in this section because the mothers completed the questionnaires and responded to interview questions in the studies.

Floyd and Gallagher (1997) evaluated the effects of different types of child disabilities on parental stress, care demands, and service utilization. Their study compared parents of children with “mental retardation” (MR); children with a chronic illness (CI) such as diabetes, asthma, spina bifida, or significant visual or hearing impairments; and children with behavior problems who did not have MR or CI. Further, this study examined differences across families with regard to type of disability, behavior problems, age, and family status.

A total of 112 families were in the MR group: 66 families with a child with MR who did not have significant behavior problems and 46 families with a child with MR who did have significant behavior problems. The CI group included 73 families of children with CI with no significant cognitive impairment: 45 families of a child with CI who had no significant behavior problems and 28 families with a child with CI with significant behavior problems. The third group included 46 families whose children had neither MR nor CI but were classified as having significant behavior problems.

Parental stress and care demands were measured using the QRS. The use of support services was measured with a 23-item, 5-point scale questionnaire assessing access of support services in the four categories of mental health, health, recreation, and other community support services. Child functioning was assessed with the CBC-L as well as a teacher-report form completed by the child’s primary teacher.

MANCOVAs were used to evaluate differences among groups with regard to parent stress and care demands, as measured by the QRS. The authors found that the type of disability and the presence of child behavior problems were the most important determinants of parental stress and care demands. Further, the presence of behavior problems and single-parent status were found to be consistent determinants of greater use of support services.

Group comparisons indicated that although the types of problem behaviors for the children with MR and CI generally did not differ among groups, it was the presence of child behavior problems that was more important than the type of disability in determining the most forms of stress experienced by the parents. Data revealed that mothers of children with behavior problems reported more stress than mothers of children with MR or CI who did not have behavior problems ( $F_{(4,199)} = 7.88, p < .001$ ). Both parents of children with MR and CI reported relatively positive coping when their child did not display problem behaviors, and mothers of children with MR reported the fewest time demands and the least personal depression.

The age of the child did not have bearing on parental stress except when it applied to time demands with mothers reporting less stress during the adolescent period. As children aged, the demands of everyday care decreased, which resulted in decreased stress for that component. Other indicators of family stress did not differ across age groups, and the study failed to detect age-related differences in family stress and well-being during the school-age years. This finding emphasized the importance of continued support services over time, as there seems to be no definite decrease in family stress as the child ages.

Parents reported an increase use in mental health services when children displayed behavior problems, with the most frequent use reported by those families whose children were in the behavior problem without CI or MR group followed by families of children with CI and behavior problems and MR with behavior problems. A significant difference was noted in the use of mental health services between those children who displayed behavior problems and those who did not. With the exception of those with MR group, other health services were accessed equally. Those in the MR group accessed health services more frequently, especially physical therapy. With respect to services in general, group differences in service utilization were

consistent with the nature of the child's disability and their functioning level. Greater service utilization was associated with the presence of child behavior problems, regardless of disability status.

Floyd and Gallagher (1997) concluded behavior problems had a significant impact on parental stress, care demands, and service utilization. Child and family characteristics influenced the nature of stress and types of coping. Decreased access or utilization of services means less respite for family members, which in turn leads to an increase in stress.

Stainton and Besser (1998) observed that the majority of studies on parental stress focused on the negative aspects of raising a child with a disability. The authors decided to research the positive impacts associated with raising a child with a disability and conducted a qualitative study with 6 fathers and 9 mothers from nine family units. All participants had one family member with an intellectual disability-related diagnosis; Down syndrome was the most common. Parents ranged in age from 25 years to over 70, whereas children's ages were evenly distributed in the age ranges of 0-5 and 26-37. Seven families reported having at least one other child without a disability.

Four interviews of the participants were conducted: two group interviews and two single-family interviews. Parents were informed at the beginning of the interviews that researchers were looking for the positive aspects of raising a child with a disability. Narrative data collection techniques were used to gather information from the interviews.

The researchers used the constant comparative method (Glaser & Strauss, 1967) to analyze the transcribed interviews. They identified nine core themes that emerged from the interviews, which are presented in Table 2.

**Table 2****Interview Themes**

THEME	FOCUS
1. Source of joy and happiness	Directly related
2. Increased sense of purpose and priorities	Directly related
3. Expanded personal and social networks and community involvement	Directly related
4. Increased spirituality	Directly related
5. Source of family unity and closeness	Directly related
6. Increased tolerance and understanding	Directly related
7. Personal growth and strength	Directly related
8. Positive impacts on others/community	Not directly related to the positive focus, but a consistent theme
9. Interactions with professionals and services	Not directly related to the positive focus, but a consistent theme

Anecdotal excerpts from the interviews were used to help researchers define each category and explain the positive impact families felt. In Themes 1-7 families focused on the positive impact their child had on the family and themselves with families making statements such as: “I just have so much joy just being in the presence of my daughter,” “He’s made our lives better in a way. It makes you realize what’s important in life you know, it’s not how many things you have or where you live...what’s important is caring for people or being sensitive to others...,” “What it has taught us is tolerance” (Stainton & Besser, 1998, p. 65).

In Theme 8, families expressed their happiness at the positive impact their child has brought to others (e.g., “...he has probably shocked some people in what he’s capable of and shattered some myths that people had”) (Stainton & Besser, 1998, p. 66).

Theme 9 did not align with the researchers’ intent to discuss positive aspects of raising a child with a disability. That is, families addressed the theme so frequently the researchers felt it was too important to discount. Although researchers specifically informed participants the goal was to discuss the positive impacts of raising a child with a disability, every family unit discussed the issue of negative interactions with professionals. Although families reported

negative interactions with many professionals, physicians were mentioned most frequently as a highly negative experience. Families were quoted as saying, “At one point one of the doctors said “Are you going to keep it? Keep it. That’s what they said.” Another family reported, “He (the doctor) was a friend of the family, he was my doctor, and he told her (his wife) “These kids only know how to sharpen pencils, then he’ll do something when he’s older like put erasers on pencils.” Families also reported a lack of resources in general from professionals but felt the lack of those resources more acutely during the point of initial disclosure (Stainton & Besser, 1998, p. 67).

Stainton and Besser (1998) conceded that although their study was small, it added narrative depth to the findings of other researchers in this area. The authors emphasized their study is not meant to imply raising a child with a disability is not difficult or stressful, but rather to highlight the positive aspects in order to contribute to the education of those who provide services for families. Physicians and other professionals who are well informed and empathetic will help alleviate rather than add to the stress of a diagnosis.

Nachshen, Woodford, and Minnes (2003) used the FSCI to measure the stress of families of children with developmental disabilities (DD) over a lifetime. Participants included 106 parents of individuals with DD who ranged in age from 23 to 88 years old, and their children ranged in age from 2 to 59 years old. Levels of disabilities ranged from mild (26.4%) to moderate (56.6%) and severe (15.1%). Diagnoses included Down syndrome, autism, cerebral palsy (CP), problems at birth, and fragile X syndrome. The majority of the children (80.2%) lived at home at the time the study was conducted.

Demographic information was collected using an information checklist. The FSCI was used as a quantitative and qualitative assessment to measure stress, and the *Vineland Adaptive*

*Behavior Scales–Maladaptive Behavior Domain* (VABS-MBD; Sparrow, Balla, & Cicchetti, 1984) assessed maladaptive behavior.

Results indicated that parents of younger children reported more stress on the FSCI than parents of younger adults or older adults ( $F = 3.42, p < 0.05$ ). The FSCI was determined to discriminate between individuals who showed differing levels of maladaptive behavior ( $F = 3.70, p < 0.05$ ). Parents of individuals with higher levels of maladaptive behavior reported significantly increased stress compared to that of parents who reported medium and low levels of maladaptive behavior.

Although not related to the purpose of this literature review, the results showed that the FSCI is a reliable and valid measure of stress of parents over the lifespan of a child with DD. Parents of children under the age of 21 reported higher levels of stress than parents of either younger or older adults. Findings also revealed that when individuals with DD demonstrate increased or severe maladaptive behaviors, the stress level of their parents increased compared to those who demonstrated less severe behaviors.

Glenn, Cunningham, Poole, Reeves, and Weindling (2008) investigated factors predicting parenting stress in mothers of 80 preschool children with CP. Families were referred from 11 child development centers. Eighty children with CP under the age of 4 and their mothers participated in the study. Maternal mean age was 30.9 years old, and the vast majority of mothers were married.

Mothers were assessed using the PSI, FNS, FSS, FACES-III, *Coping Strategies*, and *Brief Locus of Control Scale*. Children were assessed using the *Griffiths Mental Development Scales* (Griffiths, 1971) and the *Gross Motor Function Measure* (Russell et al., 1993). The home environment was also assessed using the HOME.

Analysis of PSI scores revealed 44.3% of participants were above the range where clinical assessment is recommended, 40% were above the threshold for the child domain, and 30% for the parent domain. Items that contributed to this were those in which participants scored at least 1 standard deviation above or below the overall item mean for the scale. Items that seemed to have the greatest influence were significantly different (on a paired  $t$  test) from the scale mean ( $p < 0.01$ ). In the parent domain, high-stress items included feelings of role restriction and isolation, as well as poor spousal support. Children who were less adaptable, easily distracted, and more demanding were high-stress indicators in the child domain.

Significant correlations were reported between high PSI scores with high family needs ( $r = 0.58, p = 0.000$ ), high maladaptive coping ( $r = 0.25, p = 0.041$ ), high life stressors ( $r = 0.26, p = 0.032$ ), low family cohesion ( $r = -0.27, p = 0.024$ ), low family adaptability ( $r = 0.32, p = 0.007$ ), external locus of control ( $r = 0.35, p = 0.003$ ), low HOME score ( $r = -0.25, p = 0.041$ ) and low cognitive quotient ( $r = -0.33, p = 0.005$ ). However, cluster analyses did not necessarily support these correlations. When families were clustered according to key maternal and family characteristics and then compared, it was not conclusive that caring for a child with a severe cognitive impairment was sufficient to explain higher parenting stress levels.

According to Glenn et al. (2008), their findings were consistent with previous studies that found raising a child with a disability causes increased stress to the family. The authors also emphasized the importance of understanding individual families and their dynamics so that supports can be individualized to meet their complex needs.

Hill and Rose (2009) examined the unique stress facing mothers of adult children with intellectual disabilities (ID) as children and mothers grow older and remain in the family home.

The current study tested the applicability of Johnston and Mash's (1989) model of parenting stress to parents of adults with ID. Specifically, the study examined relationships between parenting stress and adult child characteristics, parent characteristics, and environmental characteristics. Forty-four mothers (ages 51-84) of with adult offspring with ID (ages 30-59) in the UK participated in the study. Twenty-four mothers lived with a partner, and 20 were either divorced or widowed.

The PSI was used to measure stressors experienced by the mothers and their perceived efficacy in dealing with them. The VABS was used to assess child maladaptive behavior and behavioral difficulties. Social support availability was measured using the FSS. Maternal self-efficacy was measured using the PSOC. The PLOC was used to measure parental efficacy, parental responsibility, child control of parent's life, and parental control of child's behavior.

Correlation analyses of these data revealed all child, parent, and environmental variables were associated with parent stress. Child characteristics included both adaptive and maladaptive behavior, and associations with maternal stress were reported for both. However, the association was not significant for the relationship between maternal stress and maladaptive behavior, although it approached significance. This is in contrast to the findings of the previous study and other studies.

The second focus of the study was to examine the relationship between maternal stress and parental characteristics. Regression analyses revealed that parental cognitive variables predicted 61% of the variance in parenting stress. The PSOC-S showed that the lower a mother's satisfaction, the higher her stress. Therefore, PSOC-S scores were a significant negative predictor of parenting stress. In contrast, measurement of the mothers' sense of efficacy was not significantly correlated with any parenting stress subscale or total score.

The POC-total positively predicted stress, which means higher external locus of control scores predicted more parenting stress. Mothers with a more internalized locus of control reported lower levels of parenting stress. Again, the mother's sense of efficacy was not significantly correlated with any parenting stress subscale or total score

The third aspect of the study focused on the relationship between maternal stress and environmental characteristics. Significant correlations were reported between social support and parenting stress in that mothers with higher levels of social support had less parenting stress. Informal kinship and social organizations were found to be particularly important. However, mothers indicated the most important element of support is not the amount of support but whether they view the support as helpful.

Hill and Rose (2009) concluded parental characteristics—particularly cognitions—appear to play an important role in parenting stress. They also speculated that the lack of a significant correlation between stress and maladaptive behavior may be because as children age, behavior problems become less of a problem. Although parenting stress is correlated with both adaptive behavior and family support, it appears they may be partially influenced by parenting satisfaction and the perceived efficacy of the support. The authors acknowledged the self-reporting limitation of the information they collected, which they suggested could be mitigated by collecting information from an employer or other service provider. Increasing the sample size and considering the experiences of fathers are recommended for future research.

Gerstein, Crnic, Blacher, and Baker (2009) examined the trajectory of daily parenting stress in families of children with intellectual disabilities (ID). They also explored the specific compensatory factors that seem to affect the family's resilience as they cope with the added stress of raising a child with ID. Participants included 92 families of 3-year-old children who

were taking part in a longitudinal study of families of both typically developing children and families of children with children with ID. Participants were between 30 and 40 months of age and scored between 35-85 on the *Bayley Scales of Infant Development II* (BSID II; Bayley, 1993). Children also had to be ambulatory and free from a diagnosis of autism.

An intake phone interview, questionnaire, and home visits were used to gather initial information about the child. Daily parenting stress was assessed using the PDHS, and parental well-being was measured using the SCL. Marital adjustment was assessed using the DAS, and parent-child interactions were measured for dyadic parent-child pleasure using the PCIRS.

Paired-sample *t*-tests were used to calculate differences in the means of all variables for both parents. The results indicated mothers reported significantly higher parental daily hassles (PDH) than fathers both in level and in the degree over time. Not only did mothers experience higher levels of daily parenting stress than fathers at 48 months ( $t_{(80)} = 3.36, p = 0.001$ ) and 60 months ( $t_{(72)} = 3.462, p < 0.001$ ), their stress increased over the preschool period whereas fathers' stress does not. Gerstein et al. (2009) attributed higher maternal stress to the greater amount of time mothers spend with their children in the home environment.

Structural equation modeling was used to determine if PDH can be predicted from well-being. Mothers' symptomatology at 3 years predicted both mothers' and fathers' PDH at 5 years. The relationship between marital adjustment and PDH was also evaluated. Marital adjustment data from both fathers and mothers at 3 years was negatively associated with parental PDH. Therefore, marital adjustment was not a good predictor of parenting hassles. The researchers also attempted to predict PDH from the parent-child relationship. A positive father-child relationship was associated with fewer paternal PDH. Neither mother-child nor father-child

relationship predicted paternal PDH. The majority of prediction statistics fell within the  $p < 0.001$  level of significance.

The results of the current study suggested that for families with a young child with ID, stress and resilience across time are complex issues that are determined by a variety of factors which operate to predict either the level of stress experienced, the trajectory of stress during the early childhood period, or both. Results indicated that mothers and fathers experience the stress of daily parenting differently at any point in time and in varying degrees over time, with mothers experiencing significantly more stress over time than fathers. The authors suggested mothers may experience more stress over time because of their stronger personal identification with the domain of parenting than fathers. Moving forward, the authors suggested the need for continued assessment of parental stress and coping as it is apparent that stress processes are not shared completely between mothers and fathers and as well as factors leading to resilience are not fully similar.

Hall, Neely-Barnes, Graff, Krcek, and Roberts (2012) used a sequential mixed methods design to explore parental stress in families of children with disabilities. Phase I consisted of collecting qualitative data from 45 parents who were part of a focus group designed to qualitatively compare parent-sibling communication across four diagnoses: autism, cerebral palsy, Down syndrome, and sickle cell disease. Parenting stress findings from the first phase compelled researchers to further examine the parental stress using a quantitative survey.

The PSI-SF was used to classify the 22 Phase II parents into either clinically stressed or non-stressed using full-scale scores: 10 were classified as clinically stressed and 12 were classified as non-stressed. Stressed parents discussed how they felt ostracized from people outside their immediate families, lacked support, and experienced disappointment related to their

child not meeting developmental milestones. Parents in the non-stressed group devoted the majority of their time talking about benefits to siblings of the child with a disability, the strength of the child with a disability, and the future of the child with a disability. Discussions were consistent with appraisal of stress and resources and reflected the Resiliency Model of Family Stress and Adjustment (McCubbin & McCubbin, 1993).

Discussion items were analyzed according to Resiliency Model categories of stressor (A), vulnerability (V), family type (T), family resistance resources (B), appraisal of illness stressor (C), and problem-solving and coping (PSC). This model differs slightly from the Family Stress Theory model in that it incorporates vulnerability, family type, and problem-solving/coping into the equation of family adjustment.

For both groups the stressor was considered to be the diagnosis or presence of the disability. No themes of vulnerability were identified for the non-stress group, although the stressed group discussed feelings of ostracism by people in the community.

With regard to family type, family cohesiveness was identified as a theme for both groups. Participants in the stressed group did not feel supported by extended family members, church members, and others and felt they lacked support and resources in general. Participants in the non-stressed group discussed times they felt supported but also times they felt support was lacking.

The groups varied greatly in their discussions when the discussion topic focused on appraisal of the stressor. Participants in the stressed group discussed at length their frustration and stress when their child failed to meet developmental milestones and admitted difficulty focusing on their child's successes due to increased care demands. Parents in the non-stressed group tended to focus on the strengths of their child as well as the benefits to siblings.

No themes related to problem solving or coping were identified for parents in the stressed group. However, parents in the non-stressed profile talked about how they coped and solved problems by educating family members and planning for their child's future.

Hall et al. (2012) concluded their findings supported the use of the Resiliency Model of Family Stress and Adjustment (McCubbin & McCubbin, 1993) to investigate parental stress in families of children with disabilities. Parents in the stressed profile described a maladjustment experience including family vulnerability, closed communication, negative appraisals of their children's situation, and lack of support. Parents in the non-stressed profile did not discuss vulnerability, and instead described open communication and the use of problem solving and coping strategies to mitigate stress and aid in adjustment and acceptance of their child. Results suggested that positive appraisal, resources, and the ability to engage in problem solving and positive coping contributed to family resiliency against stress.

The researchers asserted these findings have important implications for those interacting with families because it showed that high risk for stress is not related to diagnosis. Assistance to families by healthcare providers should include assessment of parental stress as well as resources and supports. The small sample size, use of a nonrandom sampling method, and a long time interval between the quantitative and qualitative data collection process were factors that should be considered in future research.

Woodman, Mawdsley, and Hauser-Cram (2015) observed that many studies have examined the contribution of children's problems to parental stress. The purpose of their study was to examine bidirectional—or reverse—effects of raising children with DD. Specifically, they examined transactional relationships between parenting stress and child behavior from age 3 through age 18. The study sample included 176 mothers and their children. Disabilities were

evenly distributed across three categories: Down syndrome, motor impairment, and unspecified DD. Fifty-five percent of the children were male children of predominantly White parents. Eighty-two percent of the mothers were married, and approximately half were employed part or full time.

Parents were contacted regarding their desired continued participation in the Early Intervention Collaborative Study (EICS; Hauser-Cram, Warfield, Shonkoff, & Kraus, 2001; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992) 6 months prior to their child's 3<sup>rd</sup>, 5<sup>th</sup>, 10<sup>th</sup>, 15<sup>th</sup>, and 18<sup>th</sup> birthdays. Two trained field staff members—blind to the study hypotheses—visited participating family members in their homes and conducted interviews and child evaluations. At each point, mothers completed age-appropriate versions of the *Child Behavior Checklist* (CBC-L; Achenbach, 1991) that assessed children's internalizing and externalizing behaviors.

Maternal stress was measured at ages 3, 5, 10, and 15 using the PSI. At age 18, maternal stress was measured using the SIPA. The parent domain of each assessment provided the most relevant information for data analysis.

Results showed that parenting stress and internalizing behaviors were highly stable across time. Internalizing behavior at age 3 predicted parenting stress at age 5, and parenting stress at age 3 predicted internalizing behavior at age 5. That is, children with higher levels of internalizing behaviors at age 3 have parents with higher levels of parenting stress at age 5. On the other hand, parents with higher levels of parenting stress at age 3 had children with higher levels of internalizing behaviors at age 5. These patterns were also found from age 5 to age 10. However, these cross effects were not observed from age 10 to age 15 but were again reported from age 15 to age 18. Significance levels ranged from  $p < 0.001$  to  $p = 0.01$ .

In contrast to internalizing behavior findings, externalizing behaviors were not predictive of parenting stress during early childhood period from ages 3-5, nor were reverse directional effects observed. Data regarding children's externalizing behavior predicted parenting stress at ages 5-10 and ages 10-15, but bidirectional relations were not observed. Therefore, with externalizing behaviors, the child's behavior is directly related to parenting stress. However, findings at age 15 were similar to internalizing behavior findings, suggesting that during this time period adolescents are more affected by maternal stress levels.

Woodman et al. (2015) contended these results support the need to examine transactional relations from early childhood through adolescence. They also emphasized the importance of investigating internalizing and externalizing behaviors separately with regard to maternal stress. Findings of this study suggest that internalizing behaviors may become "increasingly intransigent" as children progress through adolescence (p. 272). The authors recommended that interventions be implemented to address internalizing behavior problems prior to adolescence. As in the previous study, findings cannot be generalized with confidence due to the largely Euro-American, well-educated participants in this sample. In addition, self-reported measures of internalizing and externalizing behaviors must be viewed with caution.

### **Paternal Stress**

One study was reviewed for this section that focused specifically on fathers of children with disabilities, their stress, and life satisfaction. Studies concentrating explicitly on paternal relationships were rare. Adding "paternal" or "father" to any search criteria often reduced results from hundreds of articles and studies down to a handful. Applying other criteria, such as eliminating studies directly related to autism, left a single study that fulfilled the desired focus of this paper.

Darling et al. (2012) compared fathers of elementary school children from a large urban school district in the midwest. Two groups were included in the study: 85 fathers of children with disabilities and 121 fathers of children who did not have a disability. Participants included students from kindergarten through grade 5. The mean age of fathers in both groups was similar, and the majority of fathers in both groups were biological fathers. Groups were also similar with regard to demographic variables and number of children in the home. Over 96% of fathers in the total sample were White and employed full time.

Fathers in both groups completed evaluation scales related to the ABC-X model of Family Stress Theory (FST). Two scales were administered to assess A (stressors): the FILE and the PDHS. The B of the FST ABC-X model deals with the family's coping mechanism and was assessed using the FCOPEs. Two measures evaluated C, the way the family perceives stress: the PSI and the FHSI. The SWLS was used to assess X, which is the level of adjustment the family has achieved.

*T*-tests were used to compare the two groups of fathers. Significant differences were reported for all variables in the model on all report measures at the  $p = 0.05$  level. In other words, fathers of children with disabilities had greater stress from family events and changes, more daily hassles, less coping ability, more parenting stress, and greater health stress. Fathers of children without disabilities had higher coping and greater satisfaction with life and were more likely to use internal and external coping strategies compared to those with disabilities. The most reported coping strategy was passive appraisal, followed by reframing, seeking spiritual support, and working with the family to seek help and obtaining social support.

Fathers of children with disabilities tended to cope internally rather than seeking external support. With regard to overall degree of satisfaction for financial status, leisure/recreational

time, material relationships, and relationships with children, fathers of children with disabilities reported significantly lower levels of satisfaction in all four domains. All variables were significant at  $p < 0.05$ .

Fathers of children with disabilities in this study had a difficult time coping effectively with life and displayed significant parenting stress. The additional strains they experienced were manifested in health reactions due to the specialized supervision and complex caretaking pressures they endured. Darling et al. (2012) suggested this increased stress was highly disruptive in various aspects of family life. Although this study did not focus specifically on the nature and severity of the child's disability, fathers of children with multiple disabilities experienced heightened levels of stress. Stressors in this study appeared to be related to developmental milestones, particularly because these reminded fathers of their child's "unmet potential" (p. 276). This demonstrates the need to conduct future research on the effects of stress at different age levels, although the authors cautioned that results of this study may not be generalized to other groups given the rather homogeneous nature of the participant's sample.

### **Sibling Factors**

One study was reviewed for this section that focused on the stress and well-being of siblings of children with disabilities. As with paternal studies, adding the term *sibling* to the search criteria yielded only a handful of studies on this topic. Interestingly, sibling studies were more prevalent than paternal studies, but when the search was narrowed to fit the focus of this paper only a single study was available.

Emerson and Giallo (2014) reviewed the results of a longitudinal study of Australian children to estimate the differences in well-being between siblings of children with disabilities or long-term health conditions (LTHC) and siblings of typically developing children to determine

whether any between-group differences were potentially attributable to differences in socioeconomic status. Data were collected from waves 1-4 of *Growing up in Australia: The Longitudinal Study of Australian Children* (LSAC; Australian Institute of Family Studies, 2001). The primary focus of the LSAC was to examine the well-being of the target child who was recruited into one of two cohorts, and these cohorts were evaluated every 2 years.

The initial B-cohort included 5,107 children ages 0-1 years, and the initial K-cohort consisted of 4,983 children ages 4-5 years. Children were identified in each cohort who were living with at least one sibling who had a disability or long-term health condition (LTHC). Data were compared with children in each cohort who were identified as living with at least one sibling, but none of their siblings had a disability or LTHC. Of the 7,636 study children who were living with a sibling at each wave, 1,232 were living with a sibling with a LTHC and 268 were living with a sibling with a disability.

The SDQ was used to assess child well-being with regard to conduct problems, hyperactivity, emotional symptoms, peer problems and prosocial behavior. Socioeconomic position was assessed with information gathered from the LSAC using indicators of financial strain, maternal education, and neighborhood deprivation. Associated environmental adversities were assessed using the indicators of life events, maternal mental health, maternal physical health, and parenting practices.

Regression analyses at ages 4-5 revealed that children living with a sibling with LTHC had significantly poorer well-being than their peers overall and on four of five subscales of the SDQ. This improved at ages 6-7 when analysis revealed poorer well-being on one of five subscales of the SDQ. Children living with a sibling with a disability had poorer well-being overall when compared to their peers, but not on any of the five subscales of the SDQ. By age

6-7, children living with a sibling with a disability did not have significantly poorer well-being either overall or on any of the five SDQ subscales. The authors noted that all of the effect sizes on well-being were small.

The authors concluded no evidence from this study supported the hypothesis that well-being deteriorated when the study child had either a sibling with a disability or LTHC. They also cautioned that it is important to take into account families' socioeconomic status and other environmental adversities when conducting studies that examine family well-being. The families in this study were more likely to live in disadvantaged neighborhoods, experience familial financial hardship, have low maternal education, more stressful life events, maternal mental health issues, and have less consistent parenting.

### **Summary**

In this chapter, I reviewed 10 studies that investigated the challenges of raising a child with a disability and the effects those challenges have on a family, typically reported as increased stress. Table 2 provides a summary of these studies, which are discussed in Chapter 3.

**Table 3****Summary of Chapter 2 Studies**

AUTHOR (DATE)	PARTICIPANTS/ SETTING	PROCEDURE	RESULTS
<b>MATERNAL FACTORS</b>			
Floyd & Gallagher (1997)	231 parents of children with mental retardation or chronic illness.	Questionnaires, home visits.	The type of disability and the presence of child behavior problems were found to be the most important determinates of parental stress and care demands. The presence of behavior problems and single-parent status were found to be consistent determinates of greater use of support services.
Stainton & Besser (1998)	9 family units with at least one child with an intellectual disability.	Group and family interviews	Families reported positive outcomes to personal and family growth related to the raising of a child with an intellectual disability. Positive responses were not a result of denial of stress or a defense coping mechanism.
Nachshen, Woodford, & Minnes (2003)	Parents of 106 individuals with developmental disabilities	Checklist, questionnaires	Parents of individuals under the age of 21 experienced higher levels of stress compared with parents of older children. Severe maladaptive behavior was found to contribute to higher levels of stress than mild to moderate maladaptive behavior.
Glenn, Cunningham, Poole, Reeves, & Weindling (2008)	80 mothers of children with cerebral palsy	Questionnaires, home observation	Individuality of families, individual characteristics of coping, and family support are associated with variation in amount of stress experienced in parenting a child with cerebral palsy.
Gerstein, Crnic, Blacher, & Baker (2009)	115 families of a 3-year-old with an intellectual disability	Interviews, questionnaires, home observation	Mothers' daily parenting stress significantly increased over time, whereas fathers' daily parenting stress remained more constant.
Hill & Rose (2009)	44 mothers of adults with intellectual disabilities	Interviews, questionnaires	Adaptive behavior was associated with parenting stress as well as association of behavior difficulties and maternal stress.
Hall, Neely-Barnes, Graff, Kreck, & Roberts (2011)	25 parents of children with ASD, cerebral palsy, Down syndrome, and sickle cell disease	Qualitative—focus groups. Quantitative—surveys.	Parents who experience high stress or low stress used different behavioral themes to describe their experiences. Positive appraisals, resources, and ability to engage in problem solving and coping were associated with family resilience.
Woodman, Mawdsley, & Hauser-Cram (2015)	176 families raising a child with early diagnosed developmental disability	Five family visits including structured child evaluation, maternal interview, questionnaire, and analysis of medical records	Bidirectional reciprocal relationships exist between parenting stress and children's behavior problems. The child's behaviors predicted later parenting stress and parenting stress predicted later child behavior problems.

Table 2 (continued)

AUTHOR (DATE)	PARTICIPANTS/ SETTING	PROCEDURE	RESULTS
PATERNAL FACTORS			
Darling, Senatore, & Strachan (2012)	85 fathers of children with disabilities and 121 fathers of children without disabilities	Evaluation scales	Fathers of children with disabilities reported increased parenting stress and difficulty coping, as well as health-related outcomes due to stress.
SIBLING FACTORS			
Emerson & Giallo (2014)	1,232 children living with a sibling with a long-term health condition and 268 children living with a sibling with a disability	Longitudinal questionnaire	Siblings of children with long-term health conditions or disabilities had lower well-being on some indicators.

### **Chapter 3: Conclusions and Recommendations**

Raising a child with an intellectual disability can have a profound effect on families. The purpose of this Starred Paper was to review the literature that sought to measure the increased stress these families may experience. In Chapter 1, the importance of the topic and relevant history and theories surrounding the topic were discussed. Chapter 2 included a review of 10 pertinent studies on the topic. The studies were separated into three categories: maternal factors, paternal factors, and sibling factors.

#### **Conclusions**

The 10 studies reviewed in Chapter 2 confirm that family members can experience high levels of stress due to increased care demands, increased financial commitments, increased social isolation, and many other factors. Eight of the 10 studies addressed factors related to maternal or family stress, whereas I could locate only one study each that addressed paternal and sibling stress factors specifically.

It is not surprising that a child with special needs in the family can change entirely the family dynamics. In this section, I discuss study findings related to variables that contribute to increased stress: differences among mothers, fathers, and siblings and positive effects of having a child with a disability in the family.

#### **Variables that Contribute to Increased Stress in Families**

Researchers identified several variables that had an impact on increased stress in families. Maladaptive behaviors were by far the largest source of increased stress reported by parents. Other factors included lack of family cohesion, role restriction, parental characteristics, professional interactions, and service utilization.

**Maladaptive behaviors.** Floyd and Gallagher (1997), Nachshen et al. (2003), and Hill and Rose (2009) reported an increase in stress in families directly attributed to child behaviors. Interestingly, the presence of problem behaviors in addition to an intellectual disability can have more impact on stress levels than the presence of a disability by itself (Floyd & Gallagher, 1997). Woodman et al. (2015) noted a bidirectional predictive relationship between maternal stress and child behaviors. When a child is less adaptable, easily distracted, and more demanding, parents also reported higher levels of stress (Glenn et al., 2008). It seems dealing with problem behaviors was one of the largest contributors to parents increased stress levels.

**Family cohesion.** Lack of family cohesion and adaptability were also contributing factors for increased stress in the studies reviewed in Chapter 2. Hill and Rose (2009) found when families were able to work together to solve problems related to the disability, family stress decreased. Similarly, perceived lack of caregiver support and feelings of isolation added to feelings of stress (Glenn et al., 2008).

**Role restriction.** Role restriction was a variable that was applied to both parents as well as to the child with a disability as being a source of stress. In one study, parents reported feelings of being restricted in their role as a caregiver as a major source of stress (Glenn et al., 2008). In contrast, Floyd and Gallagher (1997) noted parents worried about the restricted role their child's life may have due to their disability and in this case the stress was focused on trying to provide support to provide for their child's future.

**Parental characteristics.** Hill and Rose (2009) found that parental characteristics appeared to play an important role in parenting stress in that lower satisfaction correlated with increased stress. They found that coping strategies and positive perceptions and cognitions

predicted 61% of the variance in parenting stress. Mothers with higher levels of satisfaction and increased feelings of control over their lives had lower levels of parenting stress.

Along a similar line, Hall et al. (2012) noted parents who were classified as clinically stressed focused on the negative aspects of their experience with their child and expressed feelings of exclusion, lack of support, and disappointment. In contrast, the non-stressed group in the study focused on the positive aspects of having a child with a disability and marveled at the strength of their children and the positive benefits to other family members.

**Professional interactions.** Interactions with professionals—especially at the point of first disclosure—were reported as a major source of stress. Families often felt the professionals with whom they dealt did not bring a positive attitude to their conversations, and many families noted negative and hurtful comments by professionals (Stainton & Besser, 1998). Although the professionals did not mean to be hurtful, it may be that they had no idea the kind of impact their words would have.

**Service utilization.** Researchers noted service utilization to have an impact on stress. Floyd and Gallagher (1997) noted parents reported an increase use in mental health services when children displayed behavior problems. When resources are lacking or parents are unable or unwilling to access services, an increase in stress is likely (Glenn et al., 2008).

**Summary.** A variety of variables play a role in the impact of raising a child with a disability. Although families can address and ameliorate some of these variables (e.g., interactions with professionals or service utilization), most are fixed and are not easily changed. The use of positive coping strategies and increased service utilization has been shown to help decrease stress related to raising a child with a disability.

## **Maternal, Paternal, and Sibling Stress**

Mothers' stress was reported to not only be higher than that of fathers but also increased over time as their child grew and their role as a caregiver expanded (Gerstein et al., 2009).

Gerstein et al. also reported mothers were more significantly impacted due to their self-perceived role as caregivers, whereas fathers more closely self-identified with the role of breadwinner and provider.

When compared to mothers, fathers reported decreased stress as their child grew and they became more comfortable with their role as fathers to a child with a disability (Gerstein et al., 2009). Darling et al. (2012) reported fathers had a difficult time with the continuous and ongoing caretaking and financial pressures associated with raising a child with a disability. Fathers of children with disabilities utilized fewer internal and external coping strategies when compared with fathers of children without disabilities.

Nachshen et al. (2003) found that both mothers and fathers of children over the age of 21 experienced decreased stress compared to parents of younger children. Reported stress in their study went down as children reached adulthood, even though in the majority of cases children continued to live with their parents well beyond typical age.

Siblings were affected differently than mothers or fathers. Siblings have little control over any previously identified stress factors. Emerson and Giallo (2014) found that siblings of children with long-term health conditions or disabilities scored lower on many indicators of well-being. In this study, siblings were more likely to live in the most disadvantaged neighborhoods and with families who experienced significant financial hardship. This may have contributed to reported stress levels.

## **Positive Effects**

In the past, parents who expressed positive thoughts and emotions for their child with a disability were thought to have been fooling themselves or putting on a brave face to hide their true feelings. Thankfully, the research I reviewed revealed positive aspects of raising a child with special needs. Stainton and Besser (1998) reported parents felt their child was a source of joy and happiness not only for their family, but also for their community. Families reported an increase in family unity and closeness as well as an increase in spirituality.

Hall et al. (2012) found that when parents applied positive coping skills to the stress of raising a child with a disability their assessment of their child and the future was more positive. Parents felt their families were positively impacted by open communication as well as enhanced family resiliency. The positive impact to siblings was also reported as a positive impact of raising a child with a disability.

## **Recommendations for Future Research**

Many researchers have investigated the different ways families cope with the stress of raising a child with an intellectual disability and what variables impact that stress. This will continue to be an area of need as researchers dig deeper into family dynamics, socioeconomic status, cultural expectations, and personality type to better understand the effects of stress and to assist professionals in teaching stress mitigation strategies. Family dynamics is a complex and multifaceted subject, so there are many nuances yet to be explored that may help with the implementation of meaningful services.

Hill and Rose (2009) noted the limitations family studies can encounter such as difficulty correlating data when it is self-reported, as many family studies are. The use of independent assessment of some variables is suggested as a possible means to incorporate source variance.

Given the dearth of paternal studies, it is highly recommended that more studies be conducted on this topic. Much of the current research excludes their experiences. Gerstein et al. (2009) noted the importance of researching mothers and fathers separately to determine why stress seems to be experienced differently between the two.

Another component that seemed to be absent from my research was the financial impact of raising a child with a disability. Emerson and Gaillo (2014) recommended that more research be conducted to determine how socioeconomic influences interact with the other stressors of raising a child with a disability.

In addition to these issues, I also wonder about long-term implications of coping with stress. Many of the studies are short-term relative to the big picture of a lifetime. I think it would be interesting to develop a longitudinal study that follows families for longer periods to determine if stress-coping skills have helped them reach a more “positive place.” I suspect that personality plays a great part into how people accept the stress of diagnosis as well as the continued stress of raising a child with a disability, and this should be examined within a longitudinal framework.

### **Implications for Current Practice**

As someone who is impacted by raising a child with a disability both in my personal and professional life I feel more can be done to help families cope with the increased stress. In my practice as a special education teacher I try to meet some of these needs by suggesting programs parents can access. Some of these programs are for parents, such as school support programs or a disability social worker to help them navigate state programs. Some of the programs are geared more toward the enjoyment of their child, such as Special Olympics or adapted sports. I hope to give my parents (and myself) an avenue to pursue support services, as they are able. I

collaborate with social workers and coaches to help families make the most of these services. I also hope to provide a nonjudgmental place where parents can discuss their fears and joys.

In my research I found it interesting—but not surprising—that maladaptive behaviors were one of the largest sources of stress for parents. I have witnessed this firsthand and I understand how stressful it is to receive a call or note home from school that my child “had behaviors” at school, even though I am well aware of the types of behaviors my child manifests. I have made it a practice to not make daily reports home to families about maladaptive behavior, as is the habit of many special education teachers. My own experience has shown me parents do not need to be constantly reminded of the negative things in their child’s life. Instead, I focus on my students’ strengths and positive aspects of their school day. I have found my students and I are most successful when I approach parent interactions with a team-like mentality. I want parents to know I am invested in the education of their child and am willing to help them with any obstacles they encounter.

### **Summary**

Having a child with a disability can be overwhelming for many families. It can be daunting to deal with the financial burden, maze of professional services, and the realization one’s family may not look and function in a way one envisioned. Knowing which variables cause increased stress can help families better understand and diminish those sources of increased stress. Professionals also will benefit from research in this area as they look for ways to improve their own practice when interacting with families and teaching stress mitigation strategies.

On a positive note, it is exciting to read research that supports what parents of special needs children have always known—that there are benefits to raising a child who has a disability.

As one finds inner strength and discovers joy in the everyday moments and triumphs, the journey is one to be celebrated.

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