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This qualitative study proposed to answer the following two questions: Do mothers of children who have multiple disabilities experience feelings that are consistent with chronic sorrow?, and What are mothers' perceptions of the chronic sorrow phenomenon? Seven biological mothers of children who have multiple disabilities were interviewed on two separate occasions about their initial reactions and long-term feelings associated with having a child who has multiple disabilities, and their perceptions on the chronic sorrow phenomenon and the terminology associated with it. Results indicated that mothers experience a sense of loss and feelings of grief long past the initial diagnosis. Trigger events, daily life occurrences that are either expected or unexpected, can make those familiar feelings resurface, so that mothers seem to experience the grief cycle over and over again. Mothers in this study describe feelings that mirror characteristics of post-traumatic stress disorder, anticipatory grief, and chronic sorrow. They also describe experiences of happiness and joy in raising their children and discuss coping strategies that have been most helpful to them.

MOTHERS' EXPERIENCES RAISING CHILDREN WHO HAVE  
MULTIPLE DISABILITIES AND THEIR  
PERCEPTIONS OF THE CHRONIC  
SORROW PHENOMENON

by  
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# **CHAPTER I**

## **INTRODUCTION**

### **Rationale**

One of the purposes of this study was to examine the life experiences of mothers of children who have multiple disabilities. A second purpose of this study was to learn mothers' perceptions on the phenomenon of chronic sorrow and whether or not they identify with the phenomenon. Two central pieces of this study are currently underrepresented in research in the field of education: the experiences of families of children who have multiple disabilities and the phenomenon of chronic sorrow. For the purpose of this study, "multiple disabilities" is defined as the presence of both physical and cognitive impairments which significantly affects one or more life functions.

The term chronic sorrow was initially coined by Simon Olshansky (1962), a sociologist and researcher who was studying the lives of families of children who have developmental disabilities. He defined chronic sorrow as a pervasive and persistent sadness that accompanies the realization of the loss of the longed-for child. He was the first researcher to maintain that parents of children who have disabilities should not be expected to conform to a time-bound model of grief, but rather indicated that parents would experience re-occurrences of grief throughout the life span of the child. Further research interest in this phenomenon did not awaken until the 1980's, when research scientists in the field of nursing began to explore it, again from the perspectives of

parents of children with disabilities. Roos (2002) describes chronic sorrow as a normal reaction to a living or unending loss of self or other due to permanent injury, disability, or illness for which there is no public recognition that legitimizes the grieving process. Roos (2009) predicts that the prevalence of chronic sorrow in parents of children with disabilities will continue to rise, due primarily to the rapid advances in medical technology and therefore the expected longevity of life for children with disabling physical conditions. Furthermore, federal laws that mandate the inclusion of children with disabilities into public school classrooms means that educational systems are likely to see a rise in the number of children who have multiple disabilities in their schools. Unfortunately, our schools are ill-prepared to meet the needs of these children and their families. If parents of children who have multiple disabilities are experiencing feelings consistent with chronic sorrow, it should be realized that educators will be better prepared for their efforts in establishing meaningful partnerships with families if they are familiar with the phenomenon.

### **Theoretical Frameworks**

The design of this study was framed within the literature on stress and coping, grief and loss, and chronic sorrow. The model of stress and coping by Lazarus and Folkman (1984) is still widely used today in research related to stress experienced by parents of children who have disabilities. A multitude of research studies have been completed which sought to understand the factors that contribute to parental stress, the utilization of coping strategies, and their levels of adjustment. Several of the more commonly noted factors that cause families stress include the nature and severity of the

disability of the child, care-giving practices, and family support. These and other factors are addressed in the current study.

The theories related to grief and loss, as well as the theories on chronic sorrow played a key role in the design and implementation of this research study. Fraley (1990) and Roos (2002) maintain that upon the birth and diagnosis of a child with disabilities, parents typically experience feelings similar to those felt by people who have lost a loved one to biological death. Emotions that are typically experienced by parents upon the initial diagnosis include shock, sadness, denial, guilt, bargaining, and anger, feelings which are fairly consistent with Kubler-Ross' (1969) model on grieving. However, grief as it is experienced by parents of children who have disabilities is often complicated by the fact that their grief has no public recognition or social validation because parents do not appear to have sustained a "real" loss as with the biological loss of a child (Roos, 2002). The theory of chronic sorrow addresses the lived experiences of individuals who suffer recurrences of the grief cycle because the loss that they sustain is a "living" or "unending" loss. This research study was purposefully designed to answer the question of whether or not parents of children with multiple disabilities experience feelings consistent with the theory of chronic sorrow.

### **Methods and Results**

Using a phenomenological research design, this qualitative study proposed to answer the following two questions: (1) Do mothers of children who have multiple disabilities experience feelings that are consistent with chronic sorrow? and (2) What are mothers' perceptions of the chronic sorrow phenomenon? Seven biological mothers of

children who have multiple disabilities participated in three interviews on two separate occasions. The first interview aimed to understand their initial reactions and long-term feelings associated with having a child who has multiple disabilities. The second interview, which immediately followed the first, presented participants with a definition of chronic sorrow that included key terminology found within the research on the topic. Participants were asked to read the definition and share their initial responses. None of the participants were familiar with the term prior to being given the definition. Approximately one week later, after being given enough time to process the definition, participants were interviewed a third time at which time they were asked to provide their perspectives of the chronic sorrow phenomenon and the terminology associated with it.

Drawing from personal experiences, mothers indicated an overwhelming sense of loss and feelings of grief which were present at the time of their children's diagnoses and persisted throughout the course of their lives. Specific trigger events, or stressful daily life occurrences that were either expected or unexpected, were frequently noted to induce feelings of grief or sorrow over and over again. Participants in this study also described experiences of happiness and joy in raising their children and discussed coping strategies that have been most helpful to them.

Analysis of the data revealed four central themes which not only reflected the experiences of mothers in raising children who have multiple disabilities but that pointed to their interpretation of those experiences and the feelings associated with those experiences which in many ways were indicative of the presence of chronic sorrow. The first theme refers to the fluctuation of emotions as experienced by mothers from the time

of diagnosis to the present day. These emotions centered around feelings of grief specific to the loss of the healthy child mothers had hoped for, the loss of the experience of motherhood they had imagined, and finally a sense of the loss of self. In addition to the experiences of grief and sorrow, participants also described moments of happiness and joy in their lives. A second theme focuses on how mothers seemed to turn initial feelings of sadness into anger and then that anger into advocacy efforts. Each of the participants indicated that there was nothing they felt they could do with their sadness, and negative experiences with the multiple systems they found themselves having to navigate led to their decisions to put their energy into advocating for their own and other people's children. A third theme refers to the exhaustive nature of constant care-giving. Here mothers described fatigue and lack of energy associated with meeting the nonstop care-giving needs of their children who have multiple disabilities. They also described the lack of understanding by people outside of the family in regards to how much care-giving is required and the stress this sometimes puts on the family unit. Still parents reported that despite the exhaustive nature of care-giving, they found themselves able to function very well in daily routines. Even though feelings of sadness may have been always present, they never felt entirely incapacitated by it. Finally, the fourth theme relates to mothers' perceptions that society stigmatizes people with disabilities. Here participants discussed this perception of stigmatization as the reason for their frequent avoidance of social situations, worry for their children's future, and feeling that society does not validate their feelings of grief related to raising a child who has multiple disabilities. Discussion of these themes addresses in great detail the joy-sorrow concept and the appearance that

mothers were unwilling to discuss the possibility that their feelings of sorrow outweighed the joys they experienced in their lives.

Recommendations for professionals and for other mothers are provided. It is anticipated that the information gleaned from this research study will provide professionals with a deeper understanding of the phenomenon of chronic sorrow and how mothers of children who have multiple disabilities may be affected by it. This line of research will ultimately provide a new model for preparing educators and community service providers to work effectively with families of children who have multiple disabilities as they can begin to better recognize whether or not family members experience disability as a loss and, if so, what types of professional support are most meaningful. The phenomenon of chronic sorrow has not been explored in the field of education and since some parents may experience it, educators will be better prepared for their efforts in establishing meaningful partnerships with families.

## **CHAPTER II**

### **REVIEW OF THE LITERATURE**

#### **Brief Review of the Historical Research on Families of Children with Disabilities**

Traditionally, research has focused on the birth of a child with disabilities as a major life disruption in the lives of families (Hughes, 1999) and has indicated that parents of children with disabilities suffer much greater levels of stress than families without children with disabilities (Scorgie, Wilgosh, & McDonald, 1998). Professionals believed that raising a child with mental retardation, for example, was a completely negative experience, and families were frequently encouraged to place their children in state hospitals or residential schools (Wolfensberger, 1967) and move on with their lives. Whether it was an increase in professional understanding that raising a child with disabilities was something that parents were capable and accepting of or whether it was more to do with a decrease in funding of state hospitals and residential schools, professionals and parents began to explore the option of raising children with disabilities in their own homes and communities. In the 1940s and 50s, groups of parents and interested professionals worked together to develop community support programs for families of children with disabilities. Quickly, these programs evolved into larger organizations which focused on addressing the diverse needs of these families through advocacy at the state and national levels. The efforts of such organizations, including

their success in obtaining the rights for a free and appropriate public education for all children, have brought the field to where it is today (Itkonen, 2007).

For the past several decades, researchers in social and medical sciences have been interested in understanding the ways in which families of children with disabilities function. The family systems theory has been widely used to better understand how families adapt, looking specifically at family resources, family interactions, family functions, and family life cycles (Turnbull & Turnbull, 2001). Family resources refer to the characteristics of the family, including socioeconomic status, culture, religion, individual strengths and personalities, and coping strategies. Family interactions refer to the interdependencies of the family members on one another in terms of their relationships and how they make meaning of those relationships. An in depth analysis of family interactions gives researchers information on cohesiveness and adaptability of the family. Family functions are those that address the needs of the family and the means by which they attempt to meet those needs. For instance, financial needs are typically met through employment of some kind, while healthcare needs are met by identifying appropriate health services. Other needs addressed in this component include recreation, socialization, self-identity, affection, and education. The final component of this theoretical framework is the family life cycle. This includes the sometimes overlapping stages of early childhood, childhood, adolescence, and adulthood. Where a family is within the life cycle plays a role in their ability to function well as a family unit. Knowledge of the family systems theory has given researchers a focal point to begin new research in understanding how families of children with disabilities function. Emphasis in

this type of research typically maintains a strong focus on the identification of family strengths and the contribution of each family member to the family as a whole.

The work of researchers like Wolfensberger (1967), who documented more than 20 years of literature which focused on the negative impacts on families, helped to formulate the types of research questions that were being asked in the field of mental retardation, as well as the types of measures that were used, and the interpretations of research findings (Risdal & Singer, 2004), all leaning toward a more negative light. More current research has begun to challenge this notion that families experience the diagnosis of a child with disabilities as a tragedy and that the child's presence in their lives is a harmful factor (Risdal & Singer, 2004). Frequently found in research today are the theories related to stress and coping to identify the factors associated with success in raising children with disabilities (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001).

Though it is common now for children with disabilities to be raised in their own homes with their biological families, to receive community services and supports, and to be included in local educational programs, there is still much professionals have to learn about the experiences of families in raising these children and the meaning that families make of those experiences.

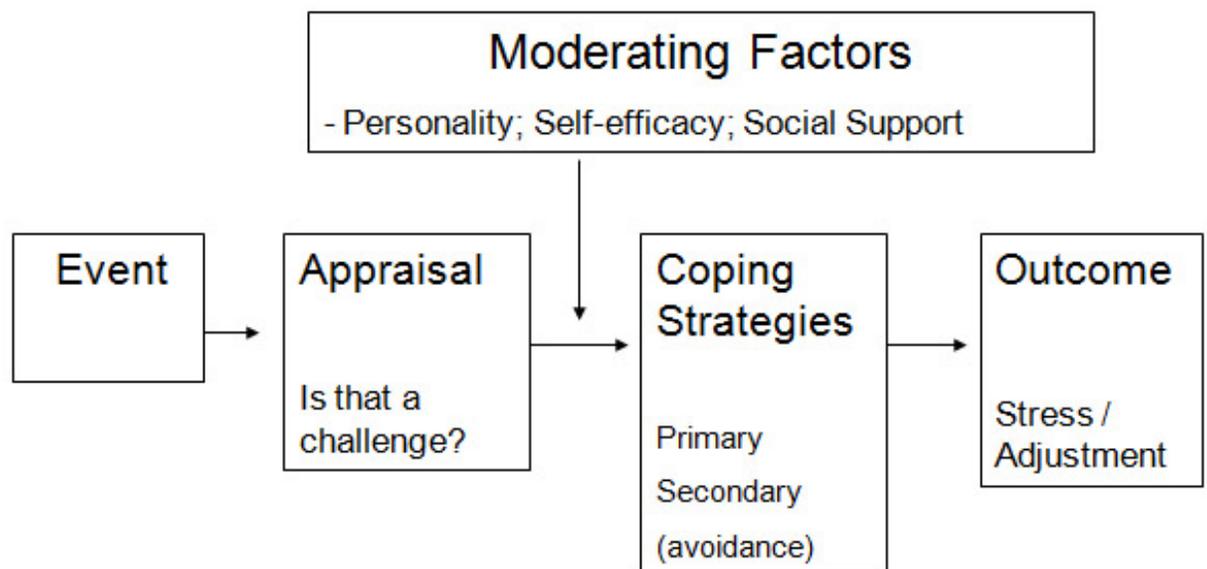
### **Model of Stress and Coping**

Research on the effects of parenting a child with a disability has predominantly utilized theories on stress and coping to guide their studies and enhance their understanding (Seltzer, et al., 2001). Lazarus and Folkman (1984) developed a model of stress and coping (see Figure 1) that is widely referred to in research (Turnbull, Patterson,

Behr, Murphy, Marquis, & Blue-Banning, 1993). The model is described as a process in terms of the occurrence of a stress-causing environmental event which necessitates primary and secondary appraisals, followed by coping activities and finally adaptational outcomes. Primary appraisals are a person's attempt to make meaning of the effects of the event on the self, whereas secondary appraisals involve a person's attempt to draw from available resources with which to handle the stressful event (e.g., personality traits, external emotional support, and informative or material resources). The following literature review specific to families of children who have disabilities uses the lens of the stress and coping model developed by Lazarus and Folkman (1984) because it provides a framework for addressing commonly reported stressful situations for families as well as a variety of common coping strategies.

**Figure 1**

*Lazarus & Folkman Stress & Coping Model (1984)*



## **Stress and Families of Children with Disabilities**

Research has long indicated that families of children with disabilities experience a significant amount of disability-related stress (Gallagher, Beckman, & Cross, 1983; Quine & Pahl, 1986; Dyson, 1993). Stress is described by Lazarus and Folkman (1984) as a relationship that develops between a person and an environmental factor or event. Specific negative emotions are felt by a person when an event seems threatening and especially if the person does not have an adequate coping response. Patterson and Garwick (1994) explain that any major stressful life events, especially those that are unexpected, can significantly affect the ways in which families function. How families make meaning of the stressful event in their lives can also change their definitions of family roles and even their views of the world (Patterson & Garwick, 1994).

Though all of the stress factors experienced by families of children with disabilities cannot possibly be examined thoroughly in one review of the literature, the following is representative of those most commonly reported: the responsibilities of caregiving (Stein & Reissman, 1980; Seltzer & Heller, 1997) and the severity of the disabling condition (Retzlaff, 2007; Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008), financial burdens (Stein & Reissman, 1980; Seltzer & Heller, 1997), interactions with people outside of the family (Cameron, Snowdon, & Orr, 1992; Jackson, Tsantefski, Goodman, Johnson, & Rosenfeld, 2003), and the perceived or real experiences of social isolation (Jackson et al., 2003). A further review of the literature on stress in families of children with disabilities explores whether or not stress levels increase or decrease as the child continues to grow. There is also a brief examination of the research tools that are

typically used to measure stress in families of children with disabilities and their impact on research findings.

### **Care-giving and the Severity of the Disability**

Researchers generally agree that care-giving responsibilities can cause a great deal of stress among families of children with disabilities (Seltzer & Heller, 1997). Multiple variables associated with care-giving may contribute to parental stress, including excessive time involved in completing tasks, the presence of challenging behaviors on the part of the child during care-giving tasks, and the complexity of care-giving tasks due to the severity of a child's disability (Haveman et al, 1997). In a study of 83 parents of children with spina bifida, physical dysfunctions of children with disabilities, rather than cognitive impairments, contributed more to parental stress because physical demands more frequently interfered with the family's physical environment and routines (Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008). Specifically, families in this study (Vermaes et al., 2008) participated in daily care-giving that included significant amounts of time for the intake of medicines, catheterization, and management of bowel dysfunction. Erickson and Lynne (2004) have reported that in middle childhood, as parents begin to transition the responsibility of care from parent to child, parents feel increased levels of stress related to fears of whether or not the child will be successful in attending to his or her own needs. These fears are believed to stem from having witnessed their children missing out on opportunities to participate in social relationships due to their physical needs (Erickson & Lynne, 2004). Further, parents also experience stress related to their concerns for their children's future in terms of the kind

of care-giving they will receive after their own death (Freedman, Krauss, & Seltzer, 1997).

Though some studies indicate that the demands associated with care-giving can have detrimental effects on families and contribute significantly to parental stress (Plant & Sanders, 2007), other studies indicate that families feel uplifted by care-giving duties. Parents may feel a sense of pride in the accomplishments of their children, attributing the child's success to their own care-giving practices (Grant, Ramcharan, McGrath, Nolan, & Keady (1998). Parents have also reported feeling satisfaction in the role of care-giving itself, indicating that they feel strengthened in their religious faith and feel a greater sense of personal growth (Turnbull, Guess, & Turnbull, 1988). In a study of 120 families of children with intellectual disabilities, parents reported gratification in the opportunities to learn new skills associated with care-giving and test their own abilities (Grant et al., 1998). A study of older parents who had been providing care for their adult children with disabilities indicated that a feeling of strengthened family ties was common among families sharing care-giving responsibilities (Greenberg, Seltzer, & Greenley, 1993).

The level of stress experienced by families of children with disabilities might also be influenced by the severity of the child's disability (Retzlaff, 2007), including specific and ongoing medical needs and the limitations of the child due to the disabilities over time (Turnbull, 1988). In a study of 46 mothers and 37 fathers of children six to fourteen years of age with spina bifida, the severity of the child's condition had a strong correlation with levels of parental stress (Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008). Hoare, Harris, Jackson and Kerley (1998) found that the severity of a child's

disability, specifically related to the physical dependency of the child on the caregiver, incontinence, and sleeping difficulties, can have a negative impact on parental mental health. Little is known about the long-term impacts of care-giving, (Jackson et al., 2003), however it is presumed that the impact of chronic illness on families differs at various stages and across the lifespan.

Roos (2002) suggests that whether or not a person views the care-giving responsibilities as burdensome or rewarding, depends somewhat on the type of parent they had hoped to be in the first place. For instance, parents who were looking forward to having *babies*, who need constant care, may respond more positively to the long-term needs of care-giving for a child with disabilities; whereas parents who were looking forward to having children for the purpose of those children growing to be independent and successful may feel more challenged with care-giving responsibilities due to a disability.

### **Financial Burdens**

Financial burdens are not uncommon among families of children with disabilities, especially if the children have healthcare needs beyond that of a typically developing child (Jackson et al., 2003). Hospital bills add up very quickly and even with good insurance, families typically have to pay a large sum out of pocket. Rural families who have to travel to appointments accrue additional costs in travel and long-distance telephone calls (Jackson et al., 2003). In addition to medical and other bills, families have to take time away from paying jobs in order to accompany their children to many

appointments, including doctors and physical, speech, or occupational therapists, among others.

The division of family roles into traditional roles of a stay-at-home mother and a working father is more common among families of children with disabilities than families of typically developing children, mostly due to the special needs of the child (Vermaes et al., 2008). Children with disabilities, especially young children, are commonly enrolled in early intervention types of services including physical, occupational, speech and language therapies, with many of these services being delivered in the home. Children with special health care needs or chronic illness can require extensive physical care-giving by a parent or other care provider, multiple medical appointments, procedures, and surgeries. In many cases, in two-parent families where both parents work, a family decision is made for one parent to remain home to take care of these needs and services (Jackson, Tsantefski, Goodman, Johnson, & Rosenfeld, 2003), thus cutting the family income in half. Families of children with disabilities who reported high incomes and financial stability despite the financial demands associated with medical needs, are reported to show less stress than families who are struggling financially (Scorige, Wilgosh, & McDonald, 1998). Single mothers of children with disabilities are often found to be living at or below the poverty line and are at a high risk for mental health problems attributed to daily stressors (Lloyd & Rosman, 2005).

### **Stress Related to Interactions with Professionals and Others Outside of the Family**

Some studies suggest that the sources of stress in families of children with disabilities are not caused by the child at all (Luescher, Dede, Gitten, Fennell, & Maria,

1999). In fact, many families experience more stress related to their interactions with professionals than in interactions with their children (Stainton & Besser, 1998; Poston et al., 2003). Stainton and Besser (1998) conducted interviews with 17 families in an effort to learn about the positive impacts of a child with disabilities on their families. Despite the fact that each of the interview questions only asked about positive impacts on the family by the child, every participant mentioned negative interactions that they had experienced with professionals, most frequently with physicians. Families felt victimized in how they were given news that their child was born with a disability, many of them being given the direst of prognoses and at a time and in a place that offered them no support upon hearing this news. The researchers deemed this as critical information to the field as it was clear that those negative interactions had had a serious impact on the family.

In a study of 13 families of children with craniopharyngioma (a congenital brain tumor which can cause multiple disabilities by presentation or treatment) all between the ages of five and nineteen years of age, most families were found to remain close and supportive of one another, with stressors relating more to interactions with others outside of the home environment (Jackson, Tsantefski, Goodman, Johnson, & Rosenfeld, 2003). Other families have noted that they feel stress related to how their children are perceived by society (Cameron, Snowdon, & Orr, 1992). Mothers reported more feelings of anger and frustration as their children grew older. This was directed at the behaviors and attitudes of community members who seemed to stigmatize not just the children with disabilities but the entire affected family (Cameron, Snowdon, & Orr, 1992).

## **Social Isolation**

Whether or not it is agreed upon what exactly affects parental levels of stress or coping abilities, the literature does appear to concur on one thing—that is the impact of social isolation. Social isolation is not uncommon for people affected by loss (Roos, 2002, p. 156), especially for people affected by disabilities. There is a degree of social isolation experienced by many parents of children with disabilities because they find that they cannot go out and participate in social gatherings as freely as they may have in the past (Jackson, Tsantefski, Goodman, Johnson, & Rosenfeld, 2003).

When a child is diagnosed with disabilities, many families describe feeling suddenly very alone and isolated from the very people who have been there for them their whole lives (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006). In many instances, they actually are. This is hardly ever a deliberate effort on the part of family or friends to isolate them, but rather a consequence of family and friends not knowing how to respond. If there is no prior experience with disabilities within the social circle, it is likely that the sudden presence of disability will make for some level of discomfort (Cameron, Snowdon, & Orr, 1992). Further, in the face of a parent's grief, it is not uncommon for friends and even close family members to withdraw physically from the parents and child because they simply cannot imagine how they can help. (Cameron, Snowdon, & Orr, 1992).

Families of children with disabilities may suddenly feel that they no longer belong in the society and culture they have known all their lives (Land, 1998). They begin to feel instead as though their identity has been redefined and has to be redeveloped into

something that is entirely unfamiliar to them. This new self appears to fit more comfortably into what is termed the “culture of disability” (Land, 1998). The culture of disability consists of people from every walk of life, representing different races, ethnicities, classes, religions, and levels of education. The one thing people of this culture share, which is the most important thing in their lives now, is what Land (1998) describes as the “trauma of dashed expectations.” Only someone from this culture would understand the feelings of guilt, shame, resentment, sorrow and joy in raising a child with a disability. This can be helpful in terms of learning to cope and not feeling isolated, yet it can also hurt and lead parents to feel resentful for having to sacrifice so many of their hopes and dreams.

There is also a social isolation experienced by the child (Rodriguez, Smith-Canter, & Voytecki, 2007). A child with disabilities may be socially isolated from his peers because of physical limitations, meaning the child’s physical disabilities make it impossible for him to participate in certain activities, or because of the child’s inability to communicate effectively with his peers. Seeing their children left out of events and activities that other children engage in is difficult for parents. In a qualitative study of children suffering from craniopharyngioma and their families (Jackson, Tsantefski, Goodman, Johnson, & Rosenfeld, 2003), one of the difficulties parents discussed was the social impact that the condition had on the child and the family, specifically feelings of social isolation. Not only did parents witness their children being teased, they also saw their children losing the friends they had before the diagnosis and in some cases losing

extended family members who no longer felt comfortable in the presence of the child.

### **Stress Over Time**

Studies indicate that parents of young children with disabilities experience more stress than parents whose children are older (Glidden & Johnson, 1999) probably because of the length of time that has passed since an initial diagnosis. Given enough time, it is believed that many parents are able to adjust to life with a child with disabilities quite well (Glidden & Johnson, 1999), having had ample time to learn the healthcare, community and educational systems as well as the jargon related to each field.

In other research there is indication that stress is found to be more prominent in families of older children (Jackson, Tsantefski, Goodman, Johnson, & Rosenfeld, 2003). Bristol (1987) found that parents of young children with mental retardation cope more effectively and positively. Parents of adolescents with mental retardation report less support and more stress (Bristol & Schopler, 1984) than parents of young children with mental retardation. This may be because services have dropped off, there may be new systems to navigate, and/or there is little support or preparation for transitions (Jackson, Tsantefski, Goodman, Johnson, & Rosenfeld, 2003).

Turnbull (1988) emphasizes that the real challenge for families is how they approach their unique life circumstances “over time.” As a child with disabilities begins to grow in age and development, the child’s needs may change and families have to re-adapt. This can be a life-long process of adaptation and it can be a struggle for some families to maintain resiliency over an extended period of time (Mussatto, 2006).

A decrease in stress levels over time in terms of the current population of families of children with disabilities may be affected by policies that have mandated more services and supports be provided for them (Hauser, Seltzer, Greenberg, Floyd, Pettee & Hong, 2001). The Individuals with Disabilities Education Act of 1975 and the subsequent revisions of that act may have a significantly positive effect on family experiences, resulting in decreased levels of stress and increased resiliency. In earlier studies, before the passage of IDEA in 1975, parents of children with disabilities were reported to show major family disruption, high levels of stress, and life-long struggles (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001).

### **Measuring Stress**

Since so many studies that seek to assess stress levels use quantitative measures, what actually contributes to stress may still remain to be learned. Glidden (1993) argues that reliable data on family stress cannot be obtained solely through the use of questionnaires because many of them appear to be designed to demonstrate that families of children with disabilities are under more stress than parents of children without. The Questionnaires on Resources and Stress (QRS) (Friedrich, Greenberg, & Crnic, 1983) ask questions that can inflate stress scores, without truly determining whether or not parents feel stress (Flaherty & Glidden, 2000). For example, one of the questions asks whether or not the child uses a wheelchair or walker—if the answer is yes, this inflates the score. Another question asks how many times the child is seen annually by a doctor—if the number is high, stress is indicated. A qualitative study on family quality of life (Poston, Turnbull, et al, 2003) found that parents are uncomfortable with their stress levels being

measured with quantitative instruments. They expressed concern that if they were to score too low on the scale they would be labeled as dysfunctional. On the other hand, if they were too score to high, indicating lower levels of stress, they would fear the loss of services and supports.

### **Coping in Families of Children with Disabilities**

Newer research has suggested that even though families of children with disabilities may indeed experience unique stresses, as compared to families of children without disabilities, many are able to function well and manage their lives effectively (Turnbull, Turnbull, Erwin & Soodak, 1995, Scorgie, Wilgosh, & McDonald, 1996). It is not then so much the existence of stressful situations as it is the way in which families cope with the stress (Stainton & Besser, 1998). Coping is defined by Lazarus and Folkman (1984) as the strategies that one uses to manage stress-causing events. The personal meaning that one makes of an event has a significant influence on their coping activities (Lazarus & Folkman 1984), and that personal meaning is usually affected by their life goals, personal values and beliefs (Folkman & Moskowitz, 2000).

There are essentially two types of coping strategies commonly used by parents of children with disabilities – one type aimed at how families problem-solve, and another type aimed at how families handle their emotions (Graungaard & Skov, 2006). Problem-solving is a skill that becomes perfected with time and practice. For new parents of a child recently diagnosed with a disability, this style of coping involves collecting information about the disability, learning skills necessary to care for the child, experiencing appropriate and effective ways to interact with professionals, and making

educated decisions about the child's ongoing care (Graungaard & Skov, 2006).

Emotional coping strategies include what researchers have recognized as maintaining hope, preparing for the future, seeking social support (Graungaard & Skov, 2006) or even parental denial of a child's disability (Ho & Keiley, 2003). Factors such as problem-solving skills, family hardiness and the ability to effectively allocate roles and responsibilities are important for coping effectively (Scorgie et al., 1998). The following section addresses several commonly reported coping strategies of families of children with disabilities, including denial, the influence of family, faith and culture, use of respite services or support groups, participation in advocacy, and personality traits. In addition, this section looks at the research that suggests that families who remain positive increase coping abilities.

### **Denial**

Denial, for many people, is a valuable coping mechanism. To deny that a stressful event has even occurred, or to deny the severity of it or the effect of it, is a method of defending one's self against further traumatization, sometimes referred to as re-traumatization (Roos, 2002). When a child is diagnosed with a disability, many parents remain locked for a time in a particular stage of grief marked as denial, and this response may be identified by untrained professionals as a parent's stubbornness or unwillingness to accept the child's disability (Ho & Keiley, 2003). It is one of the most challenging defense mechanisms that professionals have to face when working with parents and frequently leads to increased tension between them (Seligman & Darling, 1997). Denial is also a mechanism which is useful in preventing depression (Solnit & Stark, 1961). As

parents receive the news that their child is not the child they had dreamed of, they may convince themselves that a mistake has been made in the identification of their child as disabled. If denial is short-lived, it can provide a certain amount of hope, but after a while it can be detrimental not only to the parents' mental states, but to the interventions established for the child. Langridge (2002) suggests that persistent denial of the disabilities makes it difficult for professionals and parents to communicate. It also makes it a challenge for parents to absorb necessary information in caring for the child. The fact that a professional and a parent disagree on whether or not a disability exists, even when it clearly does, sometimes stems from the different meanings each has for disability, or essentially how it will affect their lives (Ho & Keiley, 2003). For a professional, if the child is diagnosed with a disability, he or she can make a referral or add the child to their own caseload – this is part of their job. For the parents, on the other hand, the firm acceptance of a diagnosis is life-altering. In truth, parents' denial may be an effort to guard themselves against the reality of a truth they do not yet feel capable of knowing (Rolland, 1994). Regardless, it is widely accepted as a valuable coping strategy for families at least during the time in which an initial diagnosis has been suggested (Marshak & Seligman, 1993; Rolland, 1994; Seligman & Darling, 1997; Ho & Keiley, 2003).

### **Family, Faith and Culture**

As has been discussed, a great deal of research has leaned more to the expectation that the birth of a child with disabilities is a traumatic event with negative effects on the family leading to high levels of marital dissatisfaction and even divorce (Bristol,

Gallagher, & Schopler, 1988). Risdal and Singer (2004) completed a historical review of the literature which examined the impacts of children with disabilities on marital and other familial relationships and noted that much of the research made negative assumptions. A re-examination of that body of work using meta-analytic methods, and focusing on adaptation and family resilience, actually found a much smaller effect on the marital dyad (Risdal & Singer, 2004).

Though there is documented variability in gender responses, many studies indicate that the marital dyad is actually strengthened (Tannila, Kokkonen, & Jaervelin, 1996) and families are found to be more cohesive (Besser, 1998). In addition, social support within a family has been reported to lead to more effective coping strategies (Hamlett, Pellegrini, & Katz, 1992; Hassall, Rose, & McDonald, 2005) with marital happiness playing a large role in this. Powell and Gallagher (1993) maintain that marriages in families of children with disabilities are frequently strengthened through a shared sense of purpose and a sense of optimism about their family life. A sense of humor among family members has been shown to assist families in moving from previously perceived negative situations into positive ones which are within their own control (Rieger, 2004). In addition, humor within the family has been linked to higher levels of affection among family members (Jarzab, 2004).

Faith in a higher power has shown to play a significant role in how well families cope with disability (Hughes, 1999). African-American families are typically reported to have less stress and better coping styles than Caucasian families, and this is attributed, at least in part, to their religious faith and their extended family support systems (Rogers-

Dulan, 1998). Brown, Ndubuisi, and Gary (1990) note that, historically, the church has a major influence upon the personal beliefs and world views of African-American families, having sustained their communities for years when they have been faced with the challenges of limited access to schools, banks, housing, and other social institutions.

A family's cultural background plays a large role in how supportive they can expect their family and friends to be. Different cultures have different meanings for the birth of a child with disabilities and their belief systems frequently effect the direction of their responses. For example, African-American families are usually bound by religious faith and a strong belief that the birth and the life of any child is God's will. In this faith, the social circle of family and friends draws together to support the family of the child born with disabilities (Rogers-Dulan, 1998). On the other hand, Asian families are more likely to find themselves isolated from their social circles because their culture has such a high regard for physical health and well-being, success, and intelligence. A child born with a disability may not meet their standards, so to speak, and they will sometimes respond by withdrawing from relationships with the child and his/her family (Ali, Fazil, Bywaters, Wallace, & Singh, 2001). European-American families place importance on a child's development of independence and self-reliance. A child who shows signs of not being able to fit that criterion is sometimes ostracized by the community, thus immediate family members of a child with disabilities will typically turn to one another for support (Burden & Thomas, 1986).

The presence of a social circle of family, church members, or close friends who share a culture or faith often proves to be a helpful resource for families, though in some

instances interactions among family members can be strained, especially if a family lacks good coping strategies. In these cases, opportunities may present themselves for family members to seek support outside of their immediate social circle in organized community support groups.

### **Respite Services and Family Support Groups**

In most communities, families of children with disabilities are usually eligible to receive some sort of respite service from the county or state in which they live, allotting the families a designated space of time in which they can rest and pass care-giving responsibilities to someone else for a short while (Chadwick, Beecham, Piroth, Bernard & Taylor, 2002). These services offer families a brief reprieve from their constant care-giving by sending a trained care provider to watch their child for anywhere from a few hours to a few days. Parents then have a bit of freedom in which they might run errands, spend time with their spouse or other children, or simply rest and renew their energies.

Whether or not respite services effectively support families in the way they propose to is not widely known though. Very little research addresses the question of respite care quality or the benefits received from parental perspectives. It does appear that the severity of a child's disability has much to do with whether or not parents make use of respite care services (Treneman, Corkery, Dowdney, & Hammond, 1997), with parents of children with severe intellectual disabilities and severe behavioral challenges finding services to be especially helpful in reducing their levels of stress (Chadwick, Beecham, Piroth, Bernard & Taylor, 2002). Another study, however, emphasizes that parental usage of respite services indicates higher levels of parental distress, maintaining that families

who are coping well do not need respite services (Hoare, Harris, Jackson, & Kerley, 2001). In addition, parents of younger children are less likely to be receiving respite services than are families of older children (Robinson & Stalker, 1993), indicating that families may be experiencing more stress over time, though this needs further research.

Most communities also offer family support group opportunities where parents can meet other parents of children with disabilities face-to-face. Families who participate in support groups do tend to report lower levels of stress experienced in their daily lives (Hamlett, Pellegrini, & Katz, 1992; Kerr & McIntosh, 2000; Mandell & Salzer, 2007). Accepting support in this manner, though, does not come naturally to all families. There are a couple of known reasons for this. Families who do not characterize their children as burdens or perceive themselves as overwhelmed by the disability may not feel the need to seek other families for support (Read, 2001). In other cases, families who may actually benefit from being involved in a family support group do not wish to do so because admitting that they need support is perceived as yet another loss in their lives. Through qualitative interviews, Brett (2004) explored the journey that parents of children with profound disabilities often take that leads them to a place in their lives where they feel they can accept support. She examined the perceptions of parents who participated in family support groups and found that many of them reported feeling vulnerable, embarrassed, and feeling like they had failed somehow. Those parents who had taken pride in their previous coping abilities suddenly felt that they had been deceiving themselves and that others perceived them as bad parents.

Some families find their involvement in support groups less about emotional support and more about opportunities to advocate for all of their children, however.

### **Advocacy**

There is a certain passion to be found in parents who advocate single-handedly or those who do it in groups that helps them to maintain their momentum and drives their work. These groups differ from other organizational structures because they are led by a motivational factor that is deeply personal (Itkonen, 2007). Itkonen (2007) described parent success in implementing change at the political level as having to do with their unique ability to convert very private experiences into largely public issues. Because the impact of their efforts directly affects their family's well-being, members of these groups do not tire easily and are unafraid to break rules to get the services that they need (Itkonen, 2007). While advocacy can be exhausting work, parents who participate in these groups frequently report that they feel obligated, in a sense, to advocate for their children and it improves their services while providing them with opportunities to socialize with other families (Wang, Mannan, Poston, Turnbull, & Summers, 2004).

Wang, Mannan, Poston, Turnbull, and Summers (2004) interviewed 104 families and identified involvement in advocacy efforts as a strong variable for enhanced coping in families of children with disabilities. Though sometimes adding to their stress levels because of the hard work behind their advocacy efforts, the overall effect for most families was a perceived improvement in their quality of life. Reasons for this included a renewed sense of self-confidence and the learned skills that are necessary in being an effective advocate. These parents explained that they had more in-depth knowledge of

their child's disability, their legal rights, and available resources than parents who do not advocate. Still, there is a great degree of stress related to advocacy, and parents in this study indicated that they felt like they were always having to fight for services for their children. They reported their preferences for services to be provided in a way that does not necessitate constant advocacy by parents.

This advocacy piece is a challenge however for many parents of children with disabilities, as they describe advocacy efforts more as a *fight* than as collaborating with team members for the sake of their child. In a study by Poston, Turnbull, et al. (2003), parents consistently used terminology and phrases typically reserved for battlefields, such as "combat," and "I needed as much ammunition as I could find.")

### **Personality Traits**

Personality traits are assumed to be intimately tied to a person's genetic disposition and, not being entirely unchangeable, somewhat affected by prior experiences and relationships (Vondra, Sysko, & Belskey, 2005). Certain personality traits, such as extraversion, emotional stability and agreeableness, lend themselves to a more overall positive affect which in turn lends to more positive perceptions of self, others, and life events (DeNeve & Cooper, 1998). An example of a person with positive affect is someone who views the resolution of a stressful situation as something successful and experiences a sense of pride for their ability in coming through it (Lazarus & Folkman, 1984); whether or not the resolution was favorable – they have the perception of growth and the acquisition of new coping skills (Folkman & Moskowitz, 2000). In terms of coping, individual personality traits such as positive affect and resiliency are key in

determining how well a person sees his or herself through stressful situations (Folkman & Moskowitz, 2000). The types of personality characteristics a person has plays a central role in the kind of parent they turn out to be (Belsky & Barends, 2002). Obviously, personality also has much to do with how well parents adjust to having a child with a disability (Vermaes, Janssens, Bosman, & Gerris, 2005), and intrapersonal resources can actually counterbalance what may be perceived as the negative impacts of rearing children with disabilities (Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008).

Resiliency refers to a person's behavior patterns and their individual competence in handling stressful situations (McCubbin, Thompson, & McCubbin, 1996). Family members who are resilient, who influence other family members with their response to stress, are typically able to adapt very well to stressful circumstances and have more positive outcomes (Mussatto, 2006). Though families may appear to be resilient, there are still many factors that will affect their process of adaptation, including the severity of the child's disability and the prognosis, the family's methods of problem-solving and coping strategies, and level of social support (Mussatto, 2006). In addition, families who have had opportunities to practice coping skills due to prior experience with stressful situations may adapt more quickly to new stressful situations; whereas, families who have not had previous experiences that required learning coping skills may perceive new situations as more challenging (Mussatto, 2006).

Researchers have not had the advantage of opportunity to separate the effects of a child's disability on parents from the effects of the parents' personality traits prior to the diagnosis (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). In one attempt, however,

Retzlaff (2007) completed a qualitative study of six families in which he explored life course factors that contributed to the resiliency of families of young children with Rett syndrome, a severe neurogenetic disorder. For these families it was noted that the presence of social support and changes in worldview were the essential elements for positive adaptation. Their narratives depicted greater satisfaction and a renewed sense of balance in life. Retzlaff (2007) suggests that prior life experiences may have an effect upon the ways in which these families confront their situations, but this theory needs further exploration.

### **Positive Perceptions**

Some research suggests that parental positive perceptions can have a dramatic effect on the outcomes of families raising children with disabilities. Many families report that raising a child with disabilities has given their lives meaning and purpose and that the family is more cohesive than ever (Besser, 1998).

Indeed many researchers, and families, have challenged the notion that experiences of families are negative (Turnbull, Blue-Bannings, Behr & Kerns, 1986; Risdal & Singer, 2004). Part of this challenge comes from a recognition of the detrimental effects that a focus on the deficit model of disabilities can have on families and individuals with disabilities (Helff and Glidden, 1998; Yau & Li-Tsang, 1999). The deficit model is one which focuses on what resources or coping strategies are missing from a family rather than on the resources or strengths they do already have in place (Ho & Keiley, 2003). Other researchers have noted that families of children with disabilities have many strengths and that professionals should build upon these instead (Yau & Li-

Tsang, 1999). Another part of this challenge stems from the very fact that many families report that their children with disabilities are a source of joy, love, and pride in their lives.

Some research speaks of the experience as positively “transformational” for families, suggesting that the experience leads to greater personal growth, fulfillment, and a source of pride and strengthening of the family (Turnbull, Blue-Bannings, Behr, & Kerns, 1986). Besser (1998) maintains that the positive impact of children with intellectual disabilities on the family include feelings of a renewed sense of purpose, reorganization of priorities, expanded social networks, increase in spirituality, family cohesiveness, increased tolerance and understanding, personal growth, recognition of personal strength, as well as the positive impacts on others in the community who interact with the child and family.

### **Multiple Disabilities**

The Americans with Disabilities Act (2008) defines disability as a “physical *or* mental impairment that substantially limits one or more of the major life activities” of an individual [Section 902.1(b)(A)]. Because of the interdependence of developmental domains, when any *two or more* of the domains are affected by disability, a person is considered to have “multiple disabilities” (Luescher, Dede, Gitten, Fennell, & Maria, 1999). This could include, for example, deaf-blindness. However, another definition which is more commonly used in the literature, and with which this study concurs, specifically refers to the presence of physical impairments with the presence of intellectual disabilities (Ho & Keiley, 2003).

An increasing number of children who have multiple disabilities is having, and will continue to have, a significant effect on organizations designed to deliver child disability services (Pharoah, Platt, & Cooke, 1996). The ever-increasing pace of technological advancements in medicine has made for a significant decrease in the mortality rates of infants born with multiple health impairments (Roos, 2002). As a result, community disability services and educational programs are having to find the means to provide appropriate services to children who ten or twenty years ago would not have been expected to live long enough to need those services (Roos, 2002). This indicates that families may have a harder time finding the kinds of services that meet the multiple needs of the child, as well as the needs of the family.

Unlike people diagnosed with one disability, those diagnosed with multiple or severe disabilities obviously endure additional challenges in life (Cass, Price, Reilly, Wisbeach, & McConachie, 1999). For parents, raising a child with any type of disability is challenging, but the dual diagnoses of physical disability with intellectual disability can obviously add an even greater degree of difficulty in child-rearing. Parents of children who have multiple disabilities have to navigate multiple systems, such as healthcare, education, and community services, with which they may have no familiarity, but for which they have to become familiar all too quickly. The time spent in learning the intricacies of such systems takes away from time spent at their regular jobs, time spent with other siblings or family members, as well as leisure time (McConkey, Truesdale, and Chris Conliffe, 2004). Families of children who have multiple disabilities including deaf-blindness report other stressors apart from care-giving responsibilities including

frustrations of working with numerous professionals (or lack of coordination) and feeling excluded from educational teams (Giangreco, Cloninger, Mueller, Yuan, & Ashworth, 1991).

Being able to communicate effectively with the child who has multiple disabilities has also been shown to have a profound influence on the ways in which a family, caregivers, and the child cope (Pedtry, Maes, & Vlaskamp, 2004). Hoare, Harris, Jackson, and Kerley (1998) interviewed families of children with severe intellectual disabilities to investigate the relationship between the characteristics of the child and the psychological adjustment and stress levels of the parents. Parents who showed the poorest levels of psychological adjustment and highest levels of stress were those whose children were physically more dependent upon them *and* who were unable to communicate their needs. This group specifically referred to those children who had multiple disabilities and included those who depended upon others for toileting, feeding, and dressing. Though interviews were conducted with families in this study, no qualitative analysis appears to have been completed which may have provided more valuable information.

### **Down Syndrome Advantage**

Children with Down syndrome typically fit into the category of multiple disabilities since they exhibit physical or health impairments frequently accompanied by intellectual disabilities of varying degrees (Hodapp, Ly, & Fidler, 2001). Indeed, their families face the same stressors that other families of children with disabilities face. Only in the past decade have researchers begun to examine the families of children with Down

syndrome by themselves, rather than clustering them into variant groups of children with intellectual disabilities. Many of these more focused studies have revealed what has come to be known as the “Down syndrome advantage” (Hodapp, Ly, & Fidler, 2001), a term meant to describe the decreased stress levels and better coping skills of parents of children with Down syndrome when compared to parents of children with other types of disabilities. Reasons that have been suggested for the Down syndrome advantage include the typically sociable and charming personalities of children with Down syndrome (Kasari & Freeman, 2001) and the availability of family support through many large, active parent organizations (Hodapp, 2007). In addition, Hodapp (2007) suggests that the positive portrayal of children and adults with Down syndrome in the media may play a role in the Down syndrome advantage. As public audiences begin to feel more familiar and comfortable in their knowledge of people with Down syndrome, their reactions to them and their families is likely to be more positive than it would be to others with disabilities they do not recognize or with disabilities that have a greater social stigma attached (Hodapp, 2007). Even though mothers of children with Down syndrome may appear to have other advantages which help them better cope, their stress levels have been documented to increase over time (Most, Fidler, & Booth-LaForce, 2006).

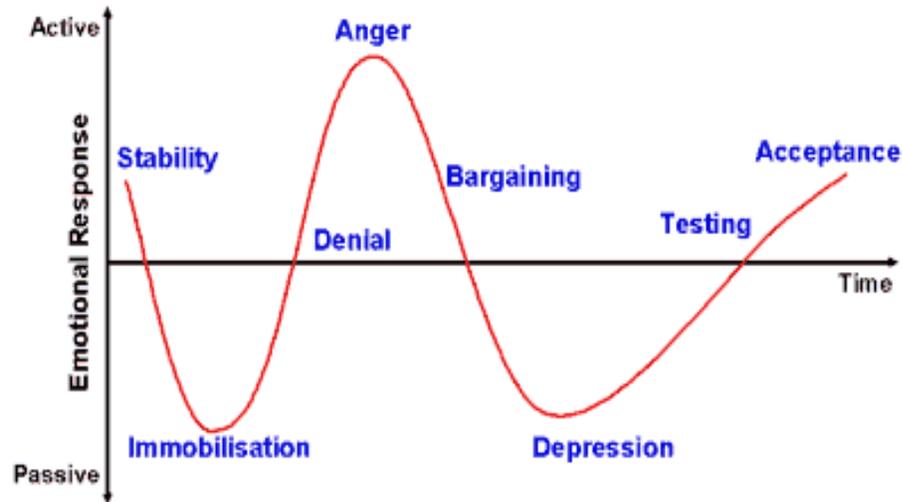
### **Research on Grief and Loss**

Researchers who study grief of any kind are familiar with the work of Kubler-Ross (1969) who developed a time-bound model (see Figure 2) of grieving that includes five stages of emotional response to the anticipated death of self or the biological death of a loved one. These stages are denial, anger, bargaining, depression, and acceptance.

Denial is explained as a temporary defense mechanism upon learning of a terminal illness or actual death. Anger is often the second reaction experienced by those who are grieving and is frequently targeted at caregivers. People in this stage may also experience feelings of jealousy of others who represent life or have not experienced a loss. The stage of bargaining involves an effort to delay or change the circumstances of death and is typically a negotiation of sorts between the grieving person and their higher power. The fourth stage of depression is an important time in the grieving process, as patients or survivors begin to come to terms with the loss. During this time they may cry frequently and try to distance themselves from others. Finally, the stage of acceptance represents a time of making peace with the knowledge of loss and the person may no longer express or even feel pain or sadness. Kubler-Ross (1969) indicates that a person typically goes through all of these stages in that precise order. It is further suggested that failure to come to the final stage of acceptance is indicative of a pathological problem. Other researchers, including Worden (1995), suggest that grief is experienced uniquely for each individual, that these stages may happen out of order, and one stage may last for a longer period of time than others.

**Figure 2**

*Kubler-Ross Stages of Grief Model*



Literature from the field of counseling on the topic of grief and loss explains that society plays an important role in guiding a person through their grief. Klass (1988) proposes that grieving is a social event in which one needs support through interpersonal interactions and validation from others. Acceptance is facilitated by public recognition of the loss, accompanied by a burial or other ritual which provides the surviving person with closure (Klass, 1988). When there is no such recognition, people may experience what is referred to by Doka (1989) as disenfranchised grief. In addition, another form of grief is “anticipatory” in which the person grieves because they expect a loss of some kind.

**Disenfranchised Grief**

Society appears to have in place a set of social norms which distinguishes “who, when, where, how, how long, and for whom people should grieve” (Doka, 1989, p. 4).

An example of this is the length of time that employers will allow a person for bereavement (e.g., a week for a spouse or child, three days for a parent or sibling, etc.). When a person experiences feelings of grief related to a loss that is not socially recognized (e.g., the loss of a homosexual partner), the grief is seldom publically acknowledged, mourned, or supported (Doka, 1989). Another example of a loss that is not publically recognized is the presence of *invisible* disabilities, such as mental illness or socially stigmatizing illnesses such as AIDS. Many families of people suffering from mental illness feel a sense of anger, guilt and shame in association with this kind of loss (Jones, 2004). Jones (2004) interviewed 47 family members of adults suffering from mental illness, with most reporting a feeling of loss of the person who had been diagnosed. Most also reported that they feel supported by extended family and friends but that they do not believe their grief is recognized or understood. Doka (1989) has termed this phenomenon “disenfranchised grief” and maintains that it can produce damaging consequences and complicate other aspects of a person’s life.

### **Anticipatory Loss**

Anticipatory loss tends to be more related to loss that you know is going to happen, such as the expected death of a family member who has been diagnosed with a terminal illness. However, research in grief and loss in the field of counseling has recently begun to look at this phenomenon as it is related to the expectation of losses that may not actually occur (Rolland, 2004). “Anticipatory loss can become emotionally disabling if not balanced by efforts to use the experience to improve the quality of life...the meaning of possible loss evolves over time with changing life cycle demands”

(Rolland, 2006). The challenge for families is finding a way to sustain hope and prepare for loss at the same time (Rolland, 2004).

### **Grief Related to Parenting a Child with Disabilities**

Many parents report experiencing feelings associated with grieving when their child has been diagnosed with a disability (Fraley, 1990). At the time of diagnosis, many parents feel shock, a sense of devastation and intense grief as they associate the diagnosis with the loss of the child they had dreamed of having (Fraley, 1990). Many parents experience a feeling of loss in terms of their hopes for the person their child might have become if s/he had not been diagnosed with a disability (Turnbull, Patterson, Behr, Murphy, Marquis, & Blue-Banning, 1993). It is, therefore, common for these families to experience varying levels of anxiety, anger, guilt, and lowered self-esteem as they try to cope with the initial diagnosis (Zeitlin, Williamson, & Rosenblatt, 1987). These feelings reflect similar emotions experienced by people who are grieving the biological death of a loved one or the expectation of their own death, including shock, anger, bargaining, depression, and acceptance (Kubler-Ross, 1969). Many professionals believe that parents go through these stages of grief until they reach the final stage of acceptance of their child or their child's disability (Blacher, 1984), though most agree that the passing through of these stages is not necessarily linear. Some maintain that the whole process of grieving has no end but repeats itself through the life stages as trigger events evoke feelings similar to those experienced at the time of diagnosis.

Grief as experienced by some parents of children who have disabilities is often complicated further by the fact that their grief is not validated by any social means (Roos,

2002), thus they are experiencing disenfranchised grief. In terms of families of children with disabilities, parents may experience feelings of grief specific to the loss of their dreamed-of child, but because there is no actual death, their grief goes publically unrecognized (Cameron, Snowdon & Orr, 1992). Rather than acknowledge their grief, extended family and friends typically provide feedback such as “You are so special,” “This child is a gift from God,” or “You are so strong...I could never do what you do.” Being “special” leaves them with a feeling of being set apart from their peers even more than they already are (Roos, 2002). Being perceived as “strong” implies to them that they cannot show weakness (Roos, 2002), and being told that they have received a gift from God makes some families angry at God (Roos, 2002). In essence, these well-intended responses do nothing to support families and actually isolate them more.

The problem with applying a time-bound model to parental grief over having a child with disabilities, as is frequently done in teacher education programs (Anderegg, Vergason, & Smith, 1992), is that it implies families should accept their child’s disability and move on with their lives. However, parents of children with disabilities do not typically experience their grief in this way. For them, there is the loss of the “expected” child, and yet their child has not actually deceased (Cameron, Snowdon & Orr, 1992). There is no ceremony, no public notice like an obituary, and essentially no opportunity to mourn. Cameron, Snowdon and Orr (1992) conducted a study of 63 mothers of children with developmental disabilities and found a primary theme to be sadness similar to what is experienced when a loved one dies. Mothers in this study indicated that the experience was worse than a death because they could not just grieve and be done with it, but rather

“it will always be there” (p. 98). Another mother in this study said that just when she feels she has come to accept her child’s disability, it becomes painfully clear to her that society has not, and she begins experiencing those same grief-related emotions all over again (p. 100).

A review of the literature related to parental grief when a child has a disability indicates that there is a wide discrepancy among researchers about whether or not extended periods of grieving are pathological or not (Blacher, 1984).

### **Research on Chronic Sorrow**

Over the past 46 years, with a lag of about 20 years in between, all available research on chronic sorrow has been contained within the fields of nursing, counseling or social work, focusing on the relationships that parents of children with special needs have with healthcare providers, therapists, and caseworkers. There are several themes from that literature, which will be addressed in this section of the literature review: a) variant definitions of chronic sorrow; b) comparisons of chronic grief and chronic sorrow with an emphasis on grief counseling; c) trigger events that force sorrow to resurface, d) the joy-sorrow concept, e) experiences of different family members, and f) coping with chronic sorrow.

### **Defining Chronic Sorrow**

Olshansky (1962) was one of the first researchers to suggest that a family’s grief should not be bound by limitations of time and that families may in fact never reach the final stage, but re-experience each of the stages of grief throughout the lifespan of the child. In essence, parents cycle through the five stages of grief described by Kubler-Ross

(1969) in random order for many years, if not the entire life of the child, such that their reactions do not fit the more familiar model of time-bound grief and a final place of acceptance. Chronic sorrow, as identified by Olshansky (1962), differs from time-bound grief in that the emotional responses to a loss reoccur for as long as the cause of the grief is still present. He notes that chronic sorrow is not continuous, but that there are peaks in the re-experience of the grief stages. Professionals understandably, but unfortunately, confuse the definition of chronic sorrow with chronic grief (Roos, 2002). Chronic grief is a long-term sadness in response to a single loss or a single event causing multiple losses and is typically deemed to be pathological. Chronic sorrow, on the other hand, is an underlying sadness in response to multiple losses over time.

Roos (2009) describes chronic sorrow as a normal reaction to a living or ongoing loss of self or other due to permanent injury, disability, or illness for which there is no public recognition that legitimizes the grieving process. In many instances, the extent of the loss may not be fully realized for years to come, as those with chronic sorrow begin to recognize the resurgence of their grief responses throughout the life cycle (Roos, 2009). Roos (2009) further describes the phenomenon of chronic sorrow as a disparity between reality and fantasy—the existence of the loss and the dreams of what might have been or still may be. Langridge (2002) studies the concept of chronic sorrow from the perspective of healthcare providers working with families of children with chronic illness, and describes what parents go through as experiencing many “little deaths.” They cannot grieve in the same manner as those who have lost someone to biological death, but rather they experience many disappointments, many fears. Parents have to learn to adapt to the

difference between what is and what could have been and this can be an ongoing and painful adaptation (Langridge, 2002).

Analyzing the concept of chronic sorrow, Eakes, Burke, and Hainsworth (1998) concluded that it is the interruption of an “anticipated life course” that brings about sorrow. According to their analysis, this is applicable not just to people with an ongoing loss but to people who experience a traumatic single loss, as well. (See Figure 3 for Eakes et al. model of chronic sorrow.) The authors maintain that it is the ongoing disparity, not the ongoing loss, which defines chronic sorrow. In other words, this would be grief that doesn’t go away, even for those who may have actually lost a loved one to biological death. This definition, however, is in sharp contrast to the foundation laid by Olshansky (1962). The difference between grieving over a biological death and grieving over a living loss is that with biological death there is a body laid to rest, and a ceremony or ritual to perform. In addition, with a biological loss there is social validation of the grieving process and the loss itself. With a living loss and the constant caregiving required of children who have disabilities, the grief is re-experienced every day. The presence of the absence can be all-consuming.



others. However, chronic sorrow in relation to a living loss, which is quite different from the more widely accepted and socially supported bereavement period, is not openly acknowledged by society. One of the reasons that families of children with chronic illness and disabilities suffer from isolation is because so many people are uncomfortable, not with the child, but with the family's sorrow (Cameron, Snowdon, & Orr, 1992). This may also be the reason that many parents suppress their grief (Cameron, Snowdon, & Orr, 1992).

### **The Problem with Grief Counseling**

Teel describes what is referred to in the literature as grief work. Grief work is a therapeutic process that humans go through in order to break the bonds they have with a person who has died and to reestablish themselves effectively in the same environment without that person (Teel, 1991). People who are experiencing chronic *grief* may benefit from counseling to resolve their grief, whereas typical therapeutic models for grieving are not suitable in addressing the needs of persons with chronic sorrow (Roos, 2002). For instance, a person who is experiencing chronic grief related to a biological loss of a loved one may be encouraged to disengage, to express anger, or to "cry it all out." These methods are not practical for a mother of a child who has multiple disabilities since she cannot disengage from her own child, does not want to express anger toward him, and could never cry it all out because it is unending. In the case of a living loss, parents cannot detach themselves, emotionally or physically, from the child who has a disability. Instead, they alter their life expectations and they learn to adjust, though they may never stop grieving. Roos (2002) adopts what is known as the companioning model of

counseling for bereavement (Wolfelt, 1998) because it focuses on personal growth and understanding of the situation, as opposed to resolving grief. This model recognizes that chronic sorrow is normal and expected when a person has a living loss. It encourages others to be aware of the impact of the loss on the family, and suggests that they do not bind families to a timeframe for grieving.

In addition, others mistake chronic sorrow for depression. Characterized as a sadness that is pervasive, permanent, periodic, and potentially progressive in nature (Olshansky, 1962), chronic sorrow is not thought to be a pathological reaction such as depression because parents still function very well (Cameron, Snowdon, & Orr, 1992) and continue to find joy within the sorrow (Kearney & Griffin, 2001).

Professional and family perspectives may differ in terms of what is time-bound grief or chronic sorrow. Social workers, in one study for example, were surprisingly very accurate in their perceptions of parental emotions, but they typically underestimated the reoccurrence of parental grief as the child aged (Wikler, Wasow, & Hatfield, 1981). In keeping with Olshansky's (1962) description of chronic sorrow, these parents did not report characteristics of continuous sorrow, but rather provided evidence that the sorrow came and went periodically, triggered by a variety of events in their lives that made their differences as a family more apparent to them (Wikler, Wasow, & Hatfield, 1981).

### **Events that Trigger Sorrow**

For those who are familiar with the concept of chronic sorrow, either as researchers or as persons suffering, there are predictable trigger events. These include times at which the child should be reaching developmental milestones, transitions into

school or between services, and missed opportunities to join social clubs or groups. If a child is diagnosed at birth with a disability, parents may experience shock and sadness, and eventually they come to adjust. Unfortunately, it may be just at this time that their children are entering school, at which time parents are reminded of their children's differences from peers in appearance, cognitive ability, and social skills. The grieving process starts all over again.

Fraley (1990) asked 79 parents to describe their emotions at the time of typical trigger events in the life of their child. These events included the discovery of additional medical problems, being surpassed developmentally by siblings or other children, exhibiting behavior problems, beginning day care, and beginning school. Using a scale prepared by the researcher, parents consistently reported feelings of shock, frustration, anger, irritability, depression, helplessness, self-pity, and self-blaming in response to such events. In a much smaller, but in-depth qualitative study, Johnsonius (1996) interviewed three parents of children with chronic illnesses who had reported chronic sorrow to assess what events trigger their sorrow. All three shared that missing developmental milestones and missing opportunities for social activities that other children enjoy were major reasons they experienced sorrow. Themes evolving from these interviews included disappointment in the loss of the hoped for offspring, the presence of emotional and financial stress within the family support system, and feelings of parental self doubt.

In a study of chronic sorrow through personal narratives (Scornaienchi, 2003), one mother describes the increase in her sorrow when she receives her son's school pictures. Seeing him every day, she has a very different picture in mind. She notes that

school photographers always manage to catch her son drooling or with his hair out of place, to capture that moment and make it a defining one of how the world perceives him.

The constant demands of daily care-giving are another trigger for chronic sorrow. Parental exhaustion, pain in seeing the child suffer, and even financial strains can deliver much higher levels of depression and anxiety in parents of children who have disabilities as compared to parents of healthy children (Melnyk, Feinstein, Moldenhouer, & Small, 2001). Parents can become exhausted, even resentful, for having to spend so much of their time and energy in the physical care of their child with disabilities. Ievers and Drotar (1996) examined the literature relating to parental coping and coined the term *chronic burden of care*. It is a huge challenge for most families to balance the care-giving responsibilities with other family obligations and needs. Coupled with that is the constant uncertainty about the emotional and physical future for family and child.

Triggers of chronic sorrow can be external events or internal thoughts. Northington (2000) followed a sample of twelve mothers of children with sickle cell disease over an 18 month period. An initial interview of the mothers revealed the general feeling of being overwhelmed with care-giving responsibilities and feeling that many aspects of their own lives had been sacrificed so they could focus on the needs of the child. An interview 18 months later revealed similar feelings. The mothers described internal triggers that included thoughts about the future and possible death of the child. Many of these mothers turned to religion when they felt overcome with sadness. External triggers among these mothers were specific to residual effects of sickle cell disease, financial concerns, and interactions with their children's schools. In many cases, mothers

stated that they got their strength to go on from watching their children endure so much and yet keep positive attitudes. One mother stated that her daughter's "high-spirited self" was especially encouraging.

### **Joy-Sorrow Concept**

Chronic sorrow is typically interspersed with episodes of joy, happiness, and satisfaction, which prevent grief from becoming incapacitating (Eakes, Burke, & Hainsworth, 1998). In their study of parental experiences raising children who have disabilities, Kearney and Griffin (2001) write about a place between joy and sorrow. Four mothers and two fathers were interviewed several times over an 18-month period. The two major themes pulled from these interviews were joy and sorrow. Among these study participants, they found that parental joys are associated with personal interactions with their children and that the sorrows experienced are brought on by interactions with other people. Parents expressed feelings of being torn between joy and sorrow from one moment to the next. They talked about how lucky they were that their children were living, but simultaneously they grieved for all that their children were missing because of their disabilities or illnesses. With this information, Kearney and Griffin (2001) developed a model to help professionals better understand parental reactions to expected tensions, or what lies in between joy and sorrow—despair and defiance, hope and hopelessness, confusion, doubts, and ambiguities.

Scornaienchi (2003) interviewed two mothers of children with lissencephaly (a rare genetic brain malformation). One of them described time alone with her son as feeling like she was "in the presence of angels." At the conclusion of an interview, this

mother wondered why she had not been asked about the joys of parenting a child with disabilities, making it clear that joys are indeed present. In further discussion, she talked about how much meaning her son had brought to her life and how he had made her into a better person. This theme is reflected in almost all personal narratives written by parents of children who have disabilities. Many talk about the courage and resilience of their children and the meaningful lessons they teach others.

### **Chronic Sorrow from Different Perspectives within the Family**

Family members may react differently to life with a child with chronic illness, because of gender differences, age, personality, or previous life experiences and family situations. They may even experience different levels of chronic sorrow and different trigger events. Several studies address the differences between maternal and paternal, sibling, and grandparent reactions to life with a child who has chronic illness or disabilities.

**Parental.** Mallow and Bechtel (1999) compared the experiences of mothers and fathers of children who have developmental disabilities. They found that both experienced intense sorrow at the time of the child's initial diagnosis, but that over time, fathers became resigned to the disability. Mothers, however, experienced the reoccurrence of grief and intense sorrow throughout the child's life. Whereas mothers were more dramatically affected by health care issues, fathers were more easily frustrated by conflicts with the social norm.

Damrosch and Perry (1989) studied the difference between paternal and maternal reactions to having a child who has a disability. Surprisingly they found that chronic

sorrow for both parents decreases as the child gets older. However, it is important to note that this study used a very small sample size and the children were very young, between the ages of six months and three years old. As much of the research suggests, chronic sorrow is chronic because of the longevity of the sorrow. Fraley (1986) studied the re-experience of sorrow among parents of children who were born prematurely but who did not suffer with chronic illness or even disability. In this study, he found that over the years and especially during times of predictable trigger events, these parents experienced chronic sorrow simply out of anticipation of what their child may or may not be able to do as a result of the prematurity at birth.

**Siblings.** Studies of siblings of children who have a chronic illness reveal a variety of responses and coping strategies. Cox, Marshall, Mandelco, and Olsen (2003) reviewed the literature on this topic and found that siblings typically have different roles in the family than do their friends. For instance, siblings may have to accept more household chores, care-giving responsibilities for the sibling with a disability, and even provide emotional support to the parents. In many cases, siblings proved to be emotionally strong and excellent at developing coping strategies. However, in a few studies, it was found that behavior problems may develop when siblings feel excluded, since parents are busy with doctor appointments, therapies, and school meetings regarding the child who has the disability.

**Dual Chronic Sorrow.** As the parent of a parent of a child who has a chronic illness, grandparents suffer twice the living loss. In addition to the unexpected change in life of having a grandchild who has a chronic illness, grandparents must also suffer

because of bearing witness to their own child's pain. Trapp (1994) examined how grandparents of children who have a chronic illness responded. Grandparents can be a strong system of support for parents, but it is challenging when they don't have all the information they need. The problem is that they typically receive secondhand news about the child's condition, news that has already been processed by the parent. This makes it especially difficult for them to cope with their own feelings and makes them focus more on the chronic sorrow experienced by the parent. In cases where the child who has a chronic illness dies, grandparents suffer what is described as survival guilt, as it is almost unbearable for them to conceive of outliving their grandchildren.

### **Coping with Chronic Sorrow**

Though many families experience chronic sorrow as a result of having a child who has disabilities or chronic illness, not all cope the same way (Warda, 1992). Warda (1992) discusses in her article how previous life experiences, and especially societal role expectations, influence how well a person copes and whether or not they develop the skills they need to deal with society's attitudes about children who have disabilities. Chronic sorrow, coupled with a confusing reversal of roles within the family, leaves families much more vulnerable to secondary problems (Roos, 2002). The family can become disorganized, depressed, fearful, isolated, and self-conscious. Warda (1992) also notes that societal views of people who have disabilities have a lot to do with the self-esteem of parents of children who have disabilities.

**Functioning with chronic sorrow.** Having a child who has a chronic illness or multiple disabilities means taking on many roles for which families may not be prepared.

For a study of mothers of children with spina bifida, Burke (1989) developed the Chronic Sorrow Questionnaire. This tool assisted her in concluding that the demands of caregiving and constant crisis management are indeed triggers for chronic sorrow, but that mothers were able to perform these duties without fail or even apprehension. It is typical that parents or family members find themselves having to perform tasks that they may not be comfortable with or adequately trained for (e.g., inserting feeding tubes, fitting colostomy bags). They are also expected to make spur-of-the-moment decisions that may have a lasting impact on the child and family. Generally, they are expected to completely modify their home, their lifestyle, their expectations, and their dreams. Somehow, they do that and keep on going.

**Depression.** Coping strategies are essential for the prevention of depression, especially for parents of children who have disabilities who may exhibit characteristics of chronic sorrow (Roos, 2009). Hobdell (2004) studied the relationship between depression and chronic sorrow using 132 parents of children with neural tube defect between the ages of six months and six years. Her findings concluded that depression is present for many families and that depression inhibits families from adequately caring for their children who have chronic illnesses. This is in contradiction to most other research which indicates that parents suffering chronic sorrow are still able to function quite well (Roos, 2002). It is also in contrast to what parents have written in narratives of their experiences, that though they may feel deep sadness, they simply do not have time to be consumed by it. It is conceivable, though the sample was quite large, that Hobdell's (2004) findings of depression among parents might be related to other factors in their lives besides rearing

children who have disabilities. The author does point out that only 18% met the criteria for clinical depression and that situational depression, in terms of just feeling sadness, was not something that was measured. Roos (2009) maintains that the onset of major depression is certainly a complication of chronic sorrow, and that people with chronic sorrow are at risk for developing post-traumatic stress disorder, problems in identity development and disordered intimacy and attachment.

There are many strategies that people can use to help them cope more effectively with chronic sorrow and to feel more in control of their lives. Hainsworth, Eakes, and Burke (1994) suggest that individuals use action strategies, such as remaining actively involved in personal interests and activities. This is a challenge for most parents who, because of the demands of care-giving, cannot find the time to fulfill their own interests. Pursuing opportunities for respite care is especially helpful. Hainsworth and colleagues (1994) also suggest maintaining interpersonal relationships and having others to talk to, especially those who are sympathetic and understanding of what the parents are experiencing. Many parents find relief in letting themselves break down and cry or by relying on spiritual beliefs and practices.

Given that the concept of chronic sorrow has yet to be explored in the field of education and that parents have not been given this term to ponder, it is important to begin this research with the theories related to grieving as the lens through which to examine parental perceptions of raising a child who has multiple disabilities, chronic sorrow and its effects upon their lives and relationships.

Though many studies of families of children who have disabilities focus on family experiences within the first year or so of diagnosis, there is still much research that needs to be done which examines how parents experience grief over time. Though parents may accept the disability initially, as the child grows and the family faces unexpected life events due to the disability, they may find that they will go through the grief process again and again (Olshansky, 1962; Wikler, 1986; Roos, 2002).

### **Rationale**

Many studies have been conducted with parents of children who have disabilities, seeking to understand their experiences. Unfortunately, most of them focus on families of children with easily recognizable diagnoses (e.g., Down Syndrome) (Damrosch & Perry, 1989), or they have used surveys and questionnaires and therefore only tell half of a parent's story (e.g., Cameron, Snowdon, & Orr, 1992). Other researchers have used one-shot interviews of parents to determine whether or not they experience chronic sorrow (Wikler, Wasow, & Hatfield, 1981; Hobdell, 2004). The problem with questionnaires and surveys is that parent perspectives are translated beforehand into words chosen by the researcher. They do not give parents the opportunities to explain their answers fully, and making sense of the meaning of their words is left to the researcher. Interviews which are very structured and only done once may not provide the depth and quality that the field requires to better understand the unique needs of these families. Essentially, these studies share stories in a language that is defined by someone other than the parent.

The literature on family experiences, stress, and coping addresses the perspectives of families of children who have a variety of disabilities from rare, life-threatening

disorders to more common diagnoses such as autism. There is still much to explore regarding how multiple disabilities affect families and whether or not these families experience or identify with the concept of chronic sorrow. Unlike families of children with a single diagnosis, for example ADHD or autism, both high-incidence disabilities, families of children who have multiple disabilities fit into a category of lower incidence. Finding local support groups and appropriate services where the multiple needs of the child and family can be met is more challenging (Cass, Price, Reilley, Wisbeach, & McConachie, 1998). In addition, because of the lower incidence of multiple disabilities these families are an underrepresented group among research related to families' lived experiences. There are several reasons that these families' perspectives may not be more frequently seen in research. One of the reasons may be that it is difficult to locate significant numbers of these families for large studies and they are unlikely to all live in one easily accessible, researchable area. Another reason may be that lower incidence disabilities tend to be more complicated and the needs of families are harder to determine. A third reason may be that since their needs are not common to more people, there is not as much support from granting entities to study them, as is the case with disabilities affecting more of the population (e.g., autism).

Amid the scant research addressing whether or not mothers of children who have multiple disabilities are affected by chronic sorrow, there is no evidence that mothers, themselves, have provided their insight on the topic. Given the term, mothers may find it empowering, justifying, or they may completely disagree with the concept of the chronic sorrow phenomenon. Rather than adding to the wealth of inferences about mothers'

emotional reactions and how they might be labeled, this study proposed to share the concept with mothers and add their own perspectives to the research.

Given that the topic of chronic sorrow has yet to be studied in the field of education, the current study offers a valuable contribution to educators who seek to understand the lived experiences of mothers of children with multiple disabilities. Specifically the introduction of the phenomenon of chronic sorrow through the voices of individuals who experience it offers an important perspective for educators. This line of research, ultimately, will provide a new model for preparing educators and community service providers to work effectively with parents of children who have multiple disabilities as they recognize the effects that parenting a child with a disability may have on the family, and their relationships with them. This study is Phase 1 in this line of research in which mothers of children with multiple disabilities were interviewed for their perceptions of chronic sorrow and how it does or does not apply to their lives. Future research would include the voices of fathers, grandparents, aunts or uncles, foster and adoptive parents, siblings, or other long-term care providers.

## **CHAPTER III**

### **DESIGN**

This qualitative study utilized a phenomenological research design method to assist in understanding the lived experiences of mothers of children who have multiple disabilities, the meaning they make of these experiences, and their perceptions of the chronic sorrow phenomenon. Phenomenological research is used to describe human experience from the research participants' own points of view to capture the essence of a particular phenomenon as they experience it (Kvale, 1996; Kensit, 2000). The intent is to find the most in-depth meanings that participants make of a phenomenon, recognizing the significance of their feelings and beliefs (Welman & Kruger, 1999) as central to the research.

Phenomenological research is increasingly being used in educational research to better understand social and psychological phenomenon (Welman & Kruger, 1999) that affect individuals, addressing not only what they do but how they make meaning out of their lives, their jobs, or other specific situations.

This research design places enormous value on parent perspectives, noting that they are the experts on what it means to raise children who have multiple disabilities. The use of this design methodology in this study provided an opportunity for educators to learn about the lived experiences of mothers of children who have multiple disabilities and how they interpret the effects of these experiences on their lives. Further, this design

engaged parents in the discussion and provided them the opportunity to share their own thoughts on the chronic sorrow phenomenon, whether or not they identified with the phenomenon and the terminology associated with it based on their own life experiences.

### **Sample**

The sample of participants for this study consisted of seven biological, English-speaking mothers of children who have multiple disabilities who met the criteria for experiencing chronic sorrow. The Americans with Disabilities Act (2008) defines disability as a “physical *or* mental impairment that substantially limits one or more of the major life activities” of an individual [Section 902.1(b)(A)]. For the purpose of this research, *multiple* disabilities is defined as having an intellectual disability *accompanied* by physical disabilities or special health care needs that significantly affect one or more daily life functions. To determine whether or not mothers met the criteria for chronic sorrow, they were asked a series of short questions during the recruitment phase from an adapted version of Burke’s (1989) Chronic Sorrow Questionnaire and one question from the model of chronic sorrow as developed by Susan Roos (2002). If, based upon their answers to those questions, they did not appear to be experiencing feelings consistent with chronic sorrow, they were not considered for the study.

Participants with a history of mental illness or depression were not included in this study since the emotional intensity of the qualitative interviews may have posed a risk to them. The study was limited to biological mothers but open to mothers of any ethnicity, race, religion, or culture. Future research will examine perspectives of fathers, siblings, extended family members, other full-time care providers, and adoptive families.

Children of the research participants needed to be diagnosed with multiple disabilities and of school age, between 8 and 21 years old. In addition, at least two years needed to have passed since the date of the children's diagnoses. The intention for excluding parents of children within the first two years of diagnosis was to eliminate confusion between mothers' initial reactions to their children's diagnoses and the variety of experiences that have become part of their individual lives. Within the first year or two of diagnosis, especially as multiple diagnoses are given, parents typically experience feelings of grief as depicted in Kubler-Ross's grief cycle (1970). As time passes, however, these feelings tend to re-occur, triggered by a range of life events (e.g., birthdays, medical crises, planned surgical procedures, or the perceptions of being excluded from school or social activities). These events are referred to in the literature as "trigger events." It has been suggested that these recurrences of grief-related feelings are what contribute to chronic sorrow (Olshansky, 1962; Eakes, Burke, & Hainsworth, 1998; Roos, 2002). Therefore, this research study intended to examine only the experiences and perceptions of mothers who have been living with their children's diagnoses for at least two years and who have likely experienced trigger events.

### **Participant Invitation and Recruitment**

Participants were located with the assistance of the Exceptional Children's Assistance Center (ECAC), a non-profit organization which provides educational advocacy services to families of children who have disabilities. The Assistant Director, using the Invitation Script (see Appendix A), contacted mothers who fit the criteria above, briefly explained the purpose of the research study, and divulged that the primary

researcher is herself the mother of a child who has multiple disabilities. She gained permission from mothers for the primary researcher to contact them by telephone to explain more about the research project. The Assistant Director of ECAC also informed mothers that she would have no way of knowing whether or not they were recruited to participate in the study and that their participation in the study would in no way affect the services they receive from ECAC. Approximately 18 mothers from across the state of North Carolina were identified, and 7 of those met the criteria and agreed to participate in the study.

After participants were identified by ECAC, the primary researcher contacted each participant by telephone and obtained enough information to determine whether or not they fit the criteria for the study (see Appendix B). If mothers did fit the criteria and expressed an interest in participating, the researcher proceeded with an explanation of the research study and details of compensation, risks, and benefits to them. The researcher explained that participation would involve three face-to-face interviews on two occasions and that each participant would be reimbursed for their time with \$25.00 for each occasion, to be paid at the conclusion of the second meeting in the form of a \$50.00 gift card. If, for any reason, mothers did not participate in the second meeting, they would still be paid \$25.00. If mothers agreed to participate in the study, a date and time was set for the interview. The researcher reminded participants of the need for a quiet place where they would feel most comfortable and informed them of the amount of time that would likely be needed (approximately 2 hours) so that they could plan accordingly. So that mothers felt a sense of being able to prepare for the interview, the researcher verbally

informed mothers that the types of questions to be asked would be related to their personal experiences, thoughts, and feelings in raising a child who has multiple disabilities.

### **Site of Research**

Five of the participants were interviewed in their homes, one in the public library, and another in a coffee shop during a quiet time of day. The subject material that the interviews covered was very personal in nature, so a quiet space of their choosing where participants felt relaxed and free to honestly express themselves was needed.

### **Description of Participants**

With assistance from the Exceptional Children's Assistance Center, only 18 mothers of children who have disabilities were identified for this study, with the anticipation of including ten. Three of those did not return the researcher's phone calls. Another eleven did not fit the criteria for the study. Of those 11 who did not fit the criteria, one had a child who was too young, one had a child who was too old, three had children who did not have physical disabilities of any kind, two did not indicate feelings consistent with chronic sorrow during the telephone screening, and one who otherwise met all the criteria was actually a friend of the researcher and so was not considered for the study. Seven mothers of the 18 identified did meet the overall criteria and agreed to be participants in the study (see Table 1). Incidentally, none of the participants in this study had heard of the phenomenon of chronic sorrow before it was brought to their attention for the purpose of this study, though this was not a requirement.

Each of the seven participants was the biological mother of a child who has multiple disabilities between the ages of 12 and 18. Following is a brief description of each mother and her child.

Renee is the mother of 13 year old Robert and two year old Felicity. Renee is Caucasian, 41 years old, married, and works part-time as a substitute teacher in the public school system and sometimes as a one-on-one aid for children with disabilities in local school settings. Her son Ryan is diagnosed with cerebral palsy. He is a happy child who brings joy to his family and friends through his smiles and any indications of his happiness. He is nonverbal, unable to walk, requires constant care for daily living and functioning. The home was equipped in every room with lift bars, special seating/standing chairs, and a special shower stall with bathing chair for purposes of moving, seating, dressing, and bathing Ryan. He is severely cognitively disabled. Ryan's mother reports that her two year old daughter is a healthy and happy child and is already curious about learning how to help with the care of her brother.

Melissa is the mother of 13 year old Trent and 12 year old Jesse. She is Caucasian, 31 years old, married, and does not work outside of the home. Her elderly mother who recently had a stroke is living with her and her husband and children. Trent is described by his mother as a child with a sweet disposition whose developmental age level is at five-years. He was diagnosed around the time of birth with tubero scoliosis and epilepsy, and was diagnosed at age of three with autism. He is nonverbal and has severe cognitive disabilities. He is currently enrolled as a student in a class for children with autism in a regular public school, but at the time of the first interview, had been

suspended from school for a period of five days for inappropriate behavior toward his teacher.

Denise is the mother of 18 year old Catherine. She has an older son who is in college and a younger daughter who is in high school. She is 50 years old, Caucasian, recently divorced, and though highly educated in her field of healthcare, has not worked outside of the home since the birth of her daughter with disabilities. Catherine was diagnosed with Angelman's syndrome at about the age of six months old. She is described by her mother as a happy and mostly healthy adult child. She is able to walk with assistance but requires constant care-giving for bathing, toileting, feeding, and other basic needs. Denise very recently had to have her daughter legally declared as incompetent so that she could continue in her role as caregiver and decision-maker for her.

Shauna is the mother of 12 year old Kevin. She is African-American, 34 years old, and unmarried. She works full-time as a nurse. Kevin was diagnosed at 2.5 years old with Hunter's Syndrome, a degenerative condition with an approximately life expectancy of 15 years. Over the years he has lost his ability to speak and learn, is beginning to show signs of incontinence, and is slowly losing his ability to walk unaided. Shauna reports that he is losing interest in activities he once enjoyed as well, such as video games, television shows, and playing ball. Kevin attends a special education class in a public school. He has a 17-year-old sister, who lives with him and his mother, and he sees his father less frequently than he used to, about once every couple of months now.

Stephanie is the mother of 13 year old Jason and 15 year old Lauren. She is Caucasian, 44 years old, married, and works part-time outside of the home for a non-profit organization directing families in how to advocate effectively for their children with disabilities. Jason was diagnosed with hydrocephaly in utero and Dandy-Walker syndrome shortly after his birth. He attends a public school and is included in general education classes with assistance. He is able to walk and care for basic needs independently, but has moderate cognitive disabilities and has endured multiple life-threatening surgeries. He is an extremely sweet and affectionate child and during the first interview came out of his room to hug his mother and ask her how her day had been. Stephanie's husband had recently lost a high-income job and her teenage daughter had recently been diagnosed with depression and anxiety.

Lorraine is the mother of 12 year old Michael. She is Caucasian, 38 years old, married, and does not work outside of the home. She has two other young children, Austin and Eric, ages six and three, respectively. Michael, according to his mother, has a pleasant disposition and loves to be read to. He was incorrectly diagnosed in utero as having Trisomy 18, a fatal condition, and was officially and correctly diagnosed with an extremely rare 1 P deletion syndrome in infancy. According to Lisa, there is only one other person in the world with the exact same diagnosis. Michael is severely cognitively disabled and has been hospitalized on several occasions for illnesses that almost claimed his life.

Karen is the mother of 13 year old Christa. She is Caucasian, 45 years old, married, and works outside of the home in a high position for a finance company. Christa

attends a special education class in a regular public school. She likes to stay busy with after-school activities and happily mimics the behaviors and styles of typically developing girls her age. She was diagnosed with autism at about the age of two and epilepsy and Landau-Kleffner syndrome around age three. She was further diagnosed with a blood disorder when she was nine years old. Christa has a 15 year old brother, Marcus, and when she was just 11 months old, her older sister, Rebecca, aged seven at the time, died in her sleep due to an epileptic seizure and complications with medication after a tonsillectomy. When Karen was reporting to doctors that she was seeing signs of something wrong with Christa around age one, she was told that she was “transferring her grief” from her daughter who had passed away onto her youngest daughter.

**Table 1***Participant Demographics*

| <b>Mother's Name &amp; Current Age</b> | <b>Child's Name &amp; Current Age</b> | <b>Child's Diagnosis</b>                         | <b>Child's number of siblings</b> | <b>Mother's Marital Status</b> | <b>Mother's Race</b> | <b>Mother's Employment Status</b> |
|--|---------------------------------------|--|-----------------------------------|--------------------------------|----------------------|-----------------------------------|
| Denise, 50                             | Catherine, 18                         | Angelman's syndrome, epilepsy                    | 2                                 | Divorced                       | Caucasian            | Unemployed                        |
| Stephanie, 44                          | Jason, 13                             | Dandy-Walker syndrome, hydrocephalus             | 1                                 | Married                        | Caucasian            | Part-time                         |
| Melissa, 31                            | Trent, 13                             | Tubero scoliosis, autism, epilepsy               | 1                                 | Married                        | Caucasian            | Unemployed                        |
| Renee, 41                              | Robert, 13                            | Cerebral palsy                                   | 1                                 | Married                        | Caucasian            | Part-time                         |
| Lorraine, 38                           | Michael, 13                           | 1 p deletion syndrome                            | 2                                 | Married                        | Caucasian            | Unemployed                        |
| Shauna, 34                             | Kevin, 12                             | Hunter's syndrome (degenerative)                 | 1                                 | Unmarried                      | African-American     | Full-time                         |
| Karen, 45                              | Christa, 13                           | Autism, Landau-Kleffner syndrome, blood disorder | 1 (and 1 who has died)            | Married                        | Caucasian            | Full-time                         |

## **Methods of Data Collection**

### **Instruments**

A condensed version of Burke's (1989) Chronic Sorrow Questionnaire, with the addition of one question pulled from Roos' (2002) model of chronic sorrow (see Appendix B) was used as a screening instrument to assist the researcher in determining whether or not potential participants appeared to experience feelings consistent with chronic sorrow. Burke's (1989) questionnaire is a validated instrument which has been commonly used in the field of nursing to establish whether or not a person displays feelings consistent with chronic sorrow. Recruitment questions taken from this questionnaire included: "Can you recall your feelings immediately after the diagnosis of your child?", "Have there been other times you've had similar feelings?", "Were other people aware that you were having these feelings?", "What feelings do you have right now when you think about your child?" and "Do you ever perceive the circumstances related to the disabilities as a loss? Why or why not?" Mothers who did not appear to experience feelings that are consistent with chronic sorrow based on this instrument were not considered for the study. However, mothers whose answers indicated that feelings of sadness do re-occur or who indicated feelings of loss associated with the disabilities and who met the additional criteria for the study were asked to participate in two follow-up interviews.

Participant interviews were conducted with the intention of identifying themes which reflect individual experiences related to the phenomenon as well as common themes across the sample. The interviews, developed by the researcher, were open-ended

(see Appendices D and E) and semi-structured (see Appendix F) and drawn from the models of chronic sorrow as proposed by Olshansky (1962), Eakes, Burke, and Hainsworth (1998), and Roos (2002). The open-ended type questions allowed the researcher to delve deeper into mothers' individual experiences while the semi-structured interview allowed for a more in-depth understanding of their perceptions on the phenomenon of chronic sorrow and the terminology associated with it.

Interviews were audio taped using a digital audio recorder with each mother's written consent. Digital audio files were then transcribed by a hired transcriptionist.

**Interview #1A.** Before the initial interview began, approximately 10 or 15 minutes were spent with each mother with the purpose of establishing rapport, engaging in simple conversation about the home, the child, the weather, etc. The purpose was to put the participant at ease with the researcher. Before the initial interview began, the researcher reviewed the purpose of the research study and asked if the participant had any questions or concerns. A consent form (see Appendix G) was provided at this time and the participant was given as much time as they needed to read it before signing their name. A copy of the consent form was also given to the participant at this time. The researcher then asked a series of demographic questions (see Appendix C), explaining that the information would be held confidentially and no names would in any way be associated with the information provided. It was further explained that the demographic information would only be used if significant differences were found among participants to assist in extended analysis of the qualitative data. After this paperwork was completed,

the researcher began the initial interview and with re-affirmed permission started the digital audio recording of it.

Interview #1A was open-ended with three main questions and several probing questions for each. The first question asked participants how they had learned about their child's disabilities and asked them to talk about the feelings they had at the time of diagnosis. The second question asked participants to describe experiences they may have had in which they found themselves experiencing those same feelings all over again. Finally, a third question asked participants about support systems. Overall, these questions served to invite participants to talk freely about their experiences raising their children who have multiple disabilities and to expand upon the meaning they had made of those experiences. (See Appendix D for full interview protocol.)

**Interview #1B.** Interview #1B took place at the same date, time, and place as Interview #1A. It was separated from and analyzed individually because of the presentation of new material. The reason for withholding this information until this time was so that the introduction of new terminology would not influence their descriptions of their experiences. It was important to the study to have participants initially share their stories in their own words. Toward the conclusion of the initial meeting with the researcher, each participant was presented with a 3 x 5 card with the following literature-based information typed on it:

Chronic sorrow is a term used to describe the feelings some people have when they are living with unending losses, usually specific to life with a disability. The feelings of chronic sorrow are usually brought upon by specific trigger events experienced in daily life. Chronic sorrow is a normal response and contains the elements of both sorrow and joy. Chronic sorrow does not typically affect a

person's ability to function effectively in normal daily routines. Chronic sorrow is also reportedly related to the fact that feelings of grief are not validated because a person does not appear to have sustained a real loss as with the death of a loved one.

The participants were given as much time as needed to read and review the information quietly before the researcher asked the following question: "Based on what you have just read, what are your thoughts about this definition of chronic sorrow?" The purpose for the delivery of the definition of chronic sorrow in this manner was specifically so that the researcher's personal bias (her own identification with chronic sorrow) had no opportunity to affect the way in which the definition of chronic sorrow was presented, through voice, gestures, or expression, to the participant. (See Appendix E for full interview protocol.)

At the conclusion of the initial meeting, a second meeting date and time was scheduled for the third interview. The researcher briefly explained to the participants that the next interview would ask them to expound upon their thoughts on the chronic sorrow phenomenon, giving them a week to process the definition they had just received.

**Interview #2.** After having been given at least one week to process the definition they had been given on chronic sorrow, participants met a second time with the researcher to answer questions related to their feelings and beliefs about the chronic sorrow phenomenon, reflecting on the meanings they have made of their own personal experiences. Specifically, participants were asked to share their insights on the following terms or phrases which were included in the definition: (a) unending or living loss; (b) trigger events; (c) the description of chronic sorrow as having both the elements of

sorrow and joy; (d) the description of chronic sorrow as not affecting a person's ability to function in normal daily routines; and (e) the description of sorrow related to feelings of grief not being validated. Participants were also asked to share what they would tell a mother of a child newly diagnosed with multiple disabilities about the kinds of feelings she might expect to have. Finally, participants were asked to share recommendations that they might have for professionals working with mothers of children who have multiple disabilities. (See Appendix F for full interview protocol.)

**Field notes.** The researcher kept a record of observational field notes before, during and after interviews, noting the setting where the interview took place, who was present, the physical atmosphere, any non-verbal cues from the participant, and any other information about the participant that seemed relevant to the research. In addition, directly after each interview, the researcher made methodological field notes which served as 'reminders, instructions, or critiques' (Groenewald, 2004) to herself on the interviewing process. The observational field notes were helpful in the period of explication of the data (or data analysis process). Methodological field notes served a purpose in keeping the researcher focused on the purpose and practice of data collection.

### **Explication of the Data (Data Analysis)**

Because the word "analysis" implies breaking into parts, which can ultimately be detrimental to the study of a phenomenon (Hycner, 1999, p. 161), this research study instead used the term "explication of the data," which involves an examination of the specific elements of a phenomenon described by research participants while maintaining the essence of the experience in its entirety (Hycner, 1999). This method of analysis

ensured that the researcher refrained from reducing the phenomenon to what may otherwise be characterized as a cause and effect scenario (Groenewald, 2004). A research assistant participated in the process of explication of the data for the purpose of establishing inter-rater reliability. Explication of data involves a five-step process (Groenewald, 2004): 1) Bracketing or phenomenological reduction, 2) delineating units of meaning, 3) clustering of units to draw themes, 4) summarizing and validating individual interviews, and 5) extracting general themes from all of the interviews. The researcher and research assistant frequently discussed their individual findings for six of the 14 total interviews, until establishing 100% agreement on the identification of units of meaning and themes.

### **Bracketing**

In an effort to prevent the researcher's own interpretations of the phenomenon being studied from having undue influence on the meaning that participants make of the phenomenon (Creswell, 1998), explication of data in a phenomenological study should begin with the researcher repeatedly listening to the participants' own words to describe their experiences. Hycner (1999) suggests that the researcher listen to the audiotapes of interviews several times. In this study, though the interviews were transcribed by a person not affiliated with the study, the researcher listened to each audio-taped interview at least once and read each transcript at least three times, making notes of key words used by the participants in each interview. This process of bracketing assists the researcher in delineating units of meaning (Groenewald, 2004).

### **Delineating Units of Meaning**

In a phenomenological study, the researcher's second step in the process of explicating data should involve the notation of literal content found in each interview (Groenewald, 2004). This step involves identification of the number of times participants referred to a specific meaning related to the phenomenon and elimination of redundant units (Moustakas, 1994). The list of units developed in the bracketing process is helpful in this step, but seeks meaning in participants' words and repeated words.

### **Clustering of Units of Meaning to Form Themes**

In this step, the researcher puts into groups the units of meaning to form a list of themes (Creswell, 1998). This was done by the researcher for each individual interview, and by the research assistant for 9 of the 21 total interviews. Close examination of the units of meaning involved going back to the transcribed interview in order to accurately pull meaningful themes that may have seemed to overlap.

### **Summarizing and Validating Each Interview**

Using all of the themes identified in each individual interview, it is suggested by Hycner (1999) that the researcher writes a short summary to document the complete picture. The purpose of this step -in the explication process is to summarize the way in which participants' seem to make sense of the phenomenon, through their words and the delivery of their message (Hycner, 1999). In this step, the researcher would also conduct a validity check by sharing individual summaries with each participant to ensure that the essence of their feelings and beliefs has been captured (Hycner, 1999). For the current study, the researcher chose not to summarize the interviews, but to instead send exact

transcripts of interviews to participants for validation. Participants were asked to report back on any inaccuracies that they recognized and to add to or further clarify any part of the interview that they felt was appropriate.

### **Extracting General Themes**

In this final step of the process of explication of the data, the researcher extracted general themes identified across all of the interviews and documented individual variations (Hycner, 1999). The purpose here was to transform the common interpretations of individual experience into an expression of the phenomenon as experienced by the whole (Sadala & Adorno, 2001, p. 289).

## **Reliability and Validity of the Study**

### **Reliability**

Exact transcriptions of the interviews were provided for each of the participants to check for accuracy and to provide them with the opportunity to make any clarifications or expound upon certain aspects of the data collection procedures. Further, a research assistant who is knowledgeable about family research, but who is not a parent of a child with disabilities and who did not participate in the collection of data, assisted with the explication of the data using the same methods as indicated above. The research assistant read the transcriptions of 9 of the 21 interviews, identified units of meaning, pulled individual themes, and generated themes overall. The researcher and research assistant met frequently to discuss their findings until a goal of 100% inter-rater reliability had been attained.

## **Validity**

As the parent of a child who has multiple disabilities, it was possible that the unique perspective of the researcher could skew the data collected and the analysis of it. In an effort to keep her own experiences or beliefs from affecting her ability to remain objective and to make real meaning of the life experiences that individual participants shared, the researcher removed herself whenever possible—for example, having participants read a definition of chronic sorrow, rather than reading it aloud to them, greatly decreased any chance that her voice, facial expressions or gestures would lead the participants to answer in a specific way. In addition, rather than transcribing the interviews herself, the researcher hired an outside person. Finally, the researcher stayed in frequent contact with her faculty supervisor who helped her remain grounded and think objectively. This contact also helped the researcher from becoming too isolated in her work which could have had detrimental effects on how she made sense of the data.

Although the researcher's own experiences did pose a risk to the validity of this study, the fact that she is a parent of a child who has multiple disabilities and shares in the culture of living with disabilities seemed beneficial. Parents, who may not have felt comfortable sharing their stories or feelings with other researchers, did appear to be at ease sharing with her, likely because she was able to clearly understand their perspectives.

Participants were asked to review transcripts of their individual interviews to ensure that their words, their thoughts and their feelings were documented accurately (Ashworth, 1997). Participants were also provided with the primary researcher's email

address and phone number so that they could contact her with questions or provide her with additional information they deemed important to the study.

### **Confidentiality and Deception**

Participants were not deceived in any way for this study. However, the term “chronic sorrow” was withheld from any conversations that took place between the researcher and participants (including the invitation and recruitment to participate in the study) until the very end of the initial face-to-face interview. The purpose of withholding the term “chronic sorrow” until the end of the initial interview was so that knowledge of that term, of which all were unfamiliar, would not in any way color their responses to the questions asked in interview 1A.

The researcher obtained signed consent forms from participants (Appendix G). These consent forms were approved by the Institutional Review Board of the University of North Carolina at Greensboro and, along with the digital audio files, were kept in a secure location in accordance with the IRB requirements. Transcriptions and analyses of the data were stored on a password protected computer, in accordance with the IRB requirements. Participants were given copies of the consent forms and copies of confidentiality agreement forms signed by the researcher, transcriptionist and research assistant, as well as the researcher’s supervising faculty member. These are the only people who had access to the digital audio files and transcribed data. The participants were assured of confidentiality and of their rights to withdraw at any time from the research study without penalty or prejudice. Participants were told that their names would not be associated with any of the data, but rather they would be assigned a random

number. One separate file existed on a password protected computer which matched their names with their research numbers, but this information was not available to any person other than the researcher herself.

### **Ethical Issues**

**Risks.** The content of this study is intense and, in some cases, may have been emotionally painful for participants. This was considered when selecting participants, as those with a history of mental illness or depression were intentionally not included. Participants were asked to sign a consent form prior to their engagement in this study indicating that they had no such diagnosis. The Exceptional Children's Assistance Center (ECAC) assisted in the project by identifying families who met the study criteria and who they felt would be able to participate honestly and openly without being harmed in any way. One faculty member on the doctoral committee has clinical training in working with families suffering loss and was available to provide guidance if issues arose that would need to be addressed from a clinical perspective. In addition, participants were given a list of local mental health programs that could assist them in dealing with feelings of sadness or depression.

**Benefits to participants.** Though the primary researcher asked participants to share the details of what may be perceived as traumatic life events, it was expected that participants would find the interview process to be therapeutic (Burke, Hainsworth, Eakes, & Lindgren, 1992; Gill, 1997; Roos, 2002). Hurley and Levitas (2004) maintain that discussion of chronic sorrow with families could be helpful because it provides them a cognitive framework for their emotional reactions which helps them to feel less alone.

Further, research indicates that because families of children with disabilities sometimes experience disenfranchised grief (Doka, 1989), or grief that is not publicly recognized, they do not typically find many people with whom they can share their story (MacGregor, 1994). This interview process provided them with a safe place and a safe person with whom they could share the realities of their everyday experiences and any sense of grief or loss that may be part of that reality.

**Benefits to society.** The information obtained from this study will introduce the topic of chronic sorrow to the field of education and provide educators with a new lens with which to view the lives of families of children who have multiple disabilities. Currently, the field of education takes the perspective of Kubler-Ross' grief cycle which implies that individuals should come to "accept" their circumstances. The theories on chronic sorrow suggest that this may, in fact, never happen, and that the failure of professionals to recognize a family's sorrow may actually contribute to it (Doka, 1989). This is valuable information for educators to have, possibly affecting the ways in which they interact with families, and will thus benefit families a great deal in the future.

## **CHAPTER IV**

### **RESULTS**

One of the purposes of this study was to examine the life experiences of mothers who have been raising school-age children who have multiple disabilities, and who are at least 2-years post diagnosis. Under these conditions, it was expected that mothers would have a number of life experiences with their children and a significant time frame from which they could reflect to provide answers to the interview questions. A second purpose of this study was to learn mothers' perceptions on the phenomenon of chronic sorrow and whether or not they identify with the phenomenon. The lived experiences of the mothers interviewed for this study reflect a mixed pool of emotions ranging from the types of feelings related to grief, particularly sadness and anger and some level of acceptance, to feelings derived from joy. The first interview of each of the mothers allowed for their free description of their personal experiences and expression of any emotions related to raising children who have multiple disabilities. The second interview, which immediately followed the first, provided them with a definition of chronic sorrow, including terms associated with chronic sorrow, on a 3x5 index card. After reading the definition, participants were asked if they needed clarification for any part of what they had read and then they were asked for their thoughts on what they had just read. This allowed for the research to make note of initial reactions to a term for which all of them were unfamiliar. The third, more structured interview engaged mothers in sharing their thoughts on

specific terminology related to chronic sorrow and the phenomenon overall and asked for their recommendations for professionals and mothers of children newly diagnosed with multiple disabilities.

Using a type of content analysis referred to as “explication of the data” in phenomenological research designs, specific themes were identified that not only reflect the experiences of mothers in raising children who have multiple disabilities but that point to their interpretation of those experiences and the feelings associated with those experiences which in many ways are indicative of the presence of chronic sorrow. This was no surprise since the chosen screening method for participants of this study was used to determine the likelihood of mothers showing characteristics of feelings related to chronic sorrow. The purpose of that screening method was to recruit participants who did have those characteristics, and to then interview them for information about their experiences and their perceptions on the phenomenon of chronic sorrow. Mothers who reported during the screening that they did not experience feelings of recurring grief were not included in the study, as they would likely not have been able to provide perceptions on the phenomenon that were based on personal experiences.

Four central themes drawn from the explication of the data will be shared in this chapter with subthemes for each of those (see Table 2). In addition, this chapter will include a description of variances among the participants, recommendations by mothers for professionals working with families of children who have multiple disabilities, and recommendations by mothers for mothers of children who are newly diagnosed with multiple disabilities.

## Themes

After explication of the data, using phenomenological research design methods for analysis, four central themes were identified which reflected mothers' experiences in raising children who have multiple disabilities and their perceptions of the chronic sorrow phenomenon. The first theme refers to the fluctuation of emotions as experienced by mothers from the time of diagnosis on through to the present day. A second theme identified focused on mothers' tendencies to turn sadness into anger and anger into advocacy. A third theme had to do with the exhaustive nature of constant care-giving. Finally, the fourth theme relates to mothers' perceptions that society stigmatizes people with disabilities. Subthemes for each of the four central themes will also be described. Each of the themes and subthemes reflect definitions of terms consistent with chronic sorrow, as will be supported through quotes obtained directly from selected interviews. Quotes that are selected for inclusion in this chapter as supportive evidence are those that most clearly summarize the experiences as described by most of or all of the participants.

**Table 2**

### *Themes*

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|          |   |
|----------|---|
| Theme 1: | Fluctuation of emotions as experienced by from the time of diagnosis on through to the present day<br>Subthemes:<br>Grief related to feelings of loss<br>Experiences of joy and happiness |
| Theme 2: | Mothers' tendencies to turn sadness into anger and anger into advocacy  |

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Subthemes:

Feeling mistreated by healthcare professionals  
Feeling misunderstood by educators  
Becoming informed and active advocates for their own and other children with disabilities

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Theme 3: Exhaustive nature of constant care-giving

Subthemes:

Fatigue experienced by mothers serving as primary caregivers  
Extensive care-giving has effect on the entire family  
Extended family support and support outside of the family do not appear to be present  
Mother's are able to function effectively despite feelings associated with chronic sorrow

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Theme 4: Mothers' perceptions that society stigmatizes people with disabilities

Subthemes:

Avoidance of social situations  
Worry for the child's future  
Feeling like society doesn't validate mothers' feelings of grief

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**Theme 1: Fluctuation of Emotions from Time of Diagnosis to the Present**

This theme of fluctuation of emotions from the time of child's diagnosis to the present time is meant to describe the pervasive feelings experienced by mothers over a period of time. Participants explained feelings they had at the time their children were diagnosed with multiple disabilities and then went on to explain how those feelings remained with them, went away and came back or seemed to change over time. As an example of the fluctuation of emotions, one mother described her combined experiences over time as an "emotional roller-coaster." Two subthemes fit into this category of the fluctuation of emotions: a) descriptions of grief-related type feelings specific to a variety of identified losses and how these feelings could be brought upon by specific trigger

events in daily life; and b) the experiences of joy and happiness in raising a child who has multiple disabilities.

**Grief related to feelings of loss.** During the first interview, participants identified feelings they each had experienced around the time of diagnosis of their child who has multiple disabilities. These feelings reflected typical emotions experienced by those beginning the grieving process as described by Kubler-Ross (1969) and included shock, disbelief or denial, and sadness in response to the apparent loss of the longed-for healthy and typically developing child as well as the expectations associated with motherhood. Stephanie described her feelings at the time of diagnosis as including numbness and devastation, and even some denial.

When they first said it, it was like I was just cut off, like from my chest down I couldn't feel anything. I mean it was like it wasn't real . . . I was just devastated. I don't really remember what I was thinking except it can't be real. It can't be real. I don't want this to happen. I just cried all day.

At the beginning of the very first interview, when simply asked to explain how she found out about her child's disability, Lorraine went right into explaining how she felt about the whole initial experience. Having had no prior experience with people with disabilities or what it would mean to raise a child who has disabilities, she had this to say: "I felt complete and total despair, an incredible fear of the unknown."

Further, responses of mothers indicated that this sense of loss does not go away. Karen has continued to feel that something is missing, something which she was not able to define or even describe other than to say a type of emptiness.

The feeling never goes away. You learn to live with it. If someone had to do like a diagram, a color diagram of people like us who have children with disabilities and regular people, we have this hole right in the center of us. This hollow. But you learn to live with that hollow.

Two mothers talked specifically about lost dreams and described the emotional pain associated with the recognition of those lost dreams as something that may change over time, but never seems to be something that is acceptable or stops hurting. Stephanie elaborated on her above comment with this explanation:

Today the pain is different, because now I look at lost dreams. You know I look at him when he wakes up and especially when he waits for the bus in the morning and you know it's just so painful because he deserves to be normal.

Denise explained how an attempt to build new dreams can seem pointless:

I got a book one time and it was titled "Dream New Dreams" or something like that. And I had in my mind dreams that she'll walk or dreams that she'll do something. Dreams that you create new but they are often re-shattered by the system, by other people, by bureaucrats, by natural losses. By a lot of things ... You know you kind of go through a lot of hopeless, helpless [times]. Those are the lows and then you go, "Wait a second! I'm alive and she's alive and we've got to make something out of this!" And you pull yourself out of the well and you start again. And then whoosh, somebody throws you back to the bottom. And you know it's that constant pulling yourself up by the bootstraps, but it's not just once, it's over and over again and I guess that's that kind of living loss. I keep losing the remade dreams.

As participants began to talk more in-depth about the kinds of feelings they have today regarding that sense of loss, they described how they have come to the realization that this is something that they will never get over. Lorraine describes how a sense of sadness can be something that is prolonged.

It's not something you get over. It blows my mind. He's 13. And there's still just that underlying sadness. Even though I love him very much, he brings us much joy, there is just that sadness that won't go away ... It's always there. But you know you kind of get through it, you make yourself get over it. You make yourself move on, but it does kind of rear its ugly head, every now and then.

When asked about grief-related feelings recurring, Melissa said specifically that she does not feel like she really grieves anymore about her child's disability after being given that initial diagnosis, though there were multiple references throughout her interview to times when she feels sad or angry. Here, she describes what other mothers also mentioned which is a type of anticipatory grief, to be discussed in greater detail in Chapter 5.

Yes, I grieved in the beginning and now I don't think so .... When I think about grief I think about just being sad and wanting something back that you've lost. I think when I lost my father that is how I was. But I don't feel that with this situation. Yes, I grieve because we found out he had tubero scoliosis, but the only time when grief comes back to me is every year when we have the scans done. Because there's a period of time when you worry about the scans coming back and something being changed or wrong.

Each mother spoke in some way about feeling a sense of grief and loss, not just in the sense of their longed-for child, but in the experience of motherhood itself. The

experience of motherhood was not what any of them had expected and they explained feeling sometimes rather like a therapist or teacher than a mother. Renee explains how she is inclined to feel more like one of the many care providers that comes into her home than a mother, and since he is nonverbal, some of this stems from the fact that she has never heard him call her “mom.”

I mean I am Ryan’s mom ... but sometimes I feel like I’m more of a caregiver than his mom ... I do feel that loss of that connection with mother and son, because yeah I would like to hear him say it.

Lorraine elaborated on this theme a bit more in talking about how she misses being able to have a reciprocal relationship with her son who is nonverbal:

I feel loss in him not being able to communicate with me to tell me what he’s thinking, that relationship developing more. I know he loves me, I know he knows that I’m his mom. But just, I’ve lost that. I’ve lost the chance to have a really deep meaningful relationship with him as a person because of all these communication difficulties.

Continuous emotional reactions of mothers reflected feelings at the time of initial diagnosis to some degree, but over time, mothers began to recognize not just the loss of the dreamed-of child or motherhood, but a loss of themselves and the lives they had hoped for within this whole experience. Denise talked a great deal about the life she might be able to lead if she were not burdened with the constant care of her daughter, which reflected the reported feelings of at least five of the seven participants in this study. What stands out most in the following quote is that after so much time, parents were beginning to forget who they were themselves.

I've been out of life for so long, I have no idea who I am, I have no idea what I like, I have no idea what I want. I don't even know what I need . . . I feel like throughout my 18 years with Catherine that I have been expected to change to everybody's guidelines and I don't even recognize myself anymore . . . I kind of had to ask, do people just live on survival mode until they die, or is that just how I will?

**Experiences of joy and happiness.** By the second interview, specific to the perceptions on the phenomenon of chronic sorrow, participants began to label their emotions based upon unique terminology related to the phenomenon and openly talked about the joys associated in raising their children.

Karen reported finding joy in watching her now teenage daughter imitate the behaviors of typically developing girls her age.

I think some of the happiest moments I have is when, you don't even notice that she's different. She doesn't make a noise, she tries hard not to make a noise. She's trying hard to fit in. She's laughing when they laugh, she flips her hair back when they do. She does all the typical stuff.

Though each of the mothers were able to respond at least in some small way to the question posed to them about joys they experienced, all of these were described as bittersweet. In response to a question about her thoughts on the concept of joy and sorrow both being present, Melissa quickly turned the conversation back, as did each one of the mothers, to the sorrows of what they face every day.

Trent is a joy in my life, but there is a lot of sorrow there because he is the way that he is. You know, you think, why? Why did the Lord choose to make him the way that he is? Why couldn't he just be.. Why is ... How would Trent be today if he did not have this disease? How would his life

be? Who would he be? Ummm, you know where would his future be going? But then you think, yeah well we wonder about that, but we can't do anything about that.

Lorraine took some time in answering the question posed to her about joys she experiences with her son who has multiple disabilities, and cried as she finally answered that there is lots of joy present.

He just really brings a lot of joy to my family and to my life. You know it wouldn't be the same without his smile, without him here every day, his hugs. So I like that, you know, because I think you can feel both at the same time.

Though there seems to be a fluctuation of emotions for mothers from the time of diagnosis to the present, feelings associated with sorrow appear to be dominant. Parents frequently did describe happy or funny moments in their lives, yet each time that a joy was mentioned it was quickly followed up with how bittersweet those joys were in relation to the reality of multiple losses. There appeared to be a significant amount of grief especially early on that most mothers channeled into different energies. The next theme shows how mothers began to try to set their feelings of grief and sadness aside and think instead about how they could begin to make change.

## **Theme 2: Turning Sadness into Anger, Turning Anger into Advocacy**

Upon the initial diagnosis of their children, mothers in this study reported experiencing feelings of sadness and a sense of loss. However, in time, each of them found those sad feelings turning to anger. This evolution of their feelings seemed to stem from the ways in which they were finding themselves to be treated by professionals. In

addition, it happened to be a coping strategy, giving them something that they could do in situations where they sometimes felt helpless.

In the following quote, Melissa makes it clear that in the beginning she would mostly cry, but indicates up front that she now feels more anger than sadness.

I'm more angry at situations than I am sad now. I guess the triggers of different things happening in Trent's life and you know he's not the one that has to deal with them, we are ... Now in the very beginning, Trent would do little things and I would just sit down and cry because I just didn't know how I was going to get through the day.

Karen, who is a staunch advocate for her own child and children of others, had this to say in an effort to explain the change of emotion.

I guess I didn't let the grief and the diagnosis consume me. At times I might have let my advocacy consume me ... Anger has taken more of a forefront over the years ... My desire to not allow anyone to consider a budget cut before my daughter. Not allow anyone to tell me they can't afford to give her this type of therapy in a school system .

Three subthemes fell under this theme of turning sadness into anger and anger into advocacy. They are 1) feeling mistreated by healthcare professionals, 2) feeling misunderstood by educators, and 3) becoming informed and active advocates for their own and other children who have disabilities.

**Feeling mistreated by healthcare professionals.** All of the mothers in this study had experiences in both healthcare and educational settings, since their children were diagnosed with physical health care needs in addition to cognitive impairments. All of them reported negative experiences with healthcare professionals, including

misdiagnoses or no diagnoses, which led directly to their realizations that they would have to become the experts on their children's disabilities.

Three of the seven mothers who participated in this study had suspected that their children were not developing typically before doctors mentioned it. Of these, those who shared their concerns with their primary doctors were initially dismissed as seeing things that were not there. For example, Karen, who had lost a school-aged child to an epileptic seizure in her sleep 11 months prior to the diagnosis of her youngest daughter, was told by doctors that she was simply transferring her grief and that she was seeing things that did not exist. Karen describes the experience in the following statement.

She wasn't reaching milestones so I kept on asking why and first they said that her older brother and sister were doing everything for and waiting on her hand and foot so it was because of them. So I dropped the issue but she continued not to reach milestones. Then they said I was seeing things that weren't there because my other daughter just died so I had to keep on advocating for the fact there was something wrong. They said I was transferring my grief from my oldest daughter to my youngest.

Denise explained her belief that parents have more reason than doctors, because of personal investment, to learn and become the expert on the child's disability.

When it comes to these disability issues, they don't know necessarily more than I do because they don't live it. What has been a real challenge is finding people in those professions who understand that, you know. Not every parent, but a lot of parents know as much if not more, particularly with the internet now, we research everything to the Nth degree, where they don't. We have a lot at stake. They don't.

**Feeling misunderstood by educators.** In addition to their frequently negative experiences in healthcare settings, mothers found educational systems to be a place where

they had to advocate fiercely in order to have the needs of their children met sufficiently. Four of the seven mothers specifically said that they believed themselves to be perceived by educators as “difficult parents” because of their advocacy efforts. That belief both hurt them and angered them, and they felt as if they were not supported in their efforts by school personnel. Melissa discusses here the lack of understanding and compassion on the part of some of the educators who work with her son.

They don't recognize your feelings. They take the feelings the wrong way. They don't see that it upsets me, and that it saddens me, when they've got to call me to tell me Trent is doing dah dah dah. They have the big and bad attitude, like Trent is doing this and they have to tell me the consequence. You know, I just went through that last week. She didn't care. She didn't have any compassion. She was mad with me. She was mad with Trent. And that in turn made me mad.

Denise reported again and again being made to feel that her expectations of her daughter in school are too high, and the frustration she felt at that sentiment.

I've been told by my ex-husband and by the school system that I needed to lower my expectations. So while as a society we say, the goal of education is to raise expectations, when it comes to our disabled people we're supposed to lower them. Because God knows you can't have a Cadillac of services, they only offer the Chevy. I've had that jammed down my throat I don't know how many times. And so there is that constant sense of anger and frustration.

After so many seemingly pointless battles with educators, many of the parents began to give up. Stephanie expressed how she had grown tired of fighting for her child's rights in the classroom because of the way she knew she was perceived and the fear that her child would suffer the consequences.

When you go to school and you walk in and you try to advocate as best you can for your kid, and you're known as the bitch ... I've just learned to back off, okay let them have at it, do what you can do, because I don't want to be the bitch, because if you're the bitch then your kid gets treated badly that way.

Melissa reiterates this feeling of worry for her child, not necessarily because of her own involvement in his education, but because she simply feels that the educators do not care for her son.

I'm just very, very angry that I have my child in a classroom that is supposed to be all about helping children with disabilities and it seems to be against him more than it is for him. So, I have to be upset and worried sick every day of my life that I'm sending him to an environment [school] that does not care about him.

**Becoming informed and active advocates for their own and other children with disabilities.** As their children grew in age, mothers in this study reported a feeling of less support from professionals. It was this feeling and a weariness of consistent battles with health care professionals and educators that turned at least four of the mothers into self-described fierce advocates not only for their own children, but for all children. Each of the mothers in her own way have taken on advocacy roles that may effect change in the lives of other families of children with disabilities, however.

Shauna, for example, went into the field of nursing with hopes of being able to make a positive impact on the health care experiences of parents of children who have multiple disabilities. Susan has taken a part-time job for a non-profit organization that works directly with parents of children with disabilities helping them to navigate systems

and learn how to advocate for their children. Melissa is a powerful voice in her son's school system and within the community not just for her own son's needs, but for the needs of all children. Renee, Karen, and Lorraine all offer their time to assist in pre-service training for future teachers by serving on parent panels in university classrooms and by allowing students to come to their homes to observe or interview them about their experiences.

In the following statement, Denise describes her efforts as “paving the road for future generations.”

It took me a lot of years to kind of stand up against these very large, very powerful systems. And I see a lot of other children suffering because their parents won't, or don't, or can't, for a number of different reasons. And I felt blessed at that time that I did have the option to stay home because we did have an income that allowed me to do that, it wasn't a survival issue. And that it was something that I could do to help not only my own child, but hopefully others as well.

The experiences these mothers have had in both the healthcare and educational settings appear to have played a significant role in the kinds of parents they have become. They seem to have built upon their initial reactions of sadness, turning the experience into something positive, rather than wallowing in it. Unfortunately, most of them had to get incredibly angry to get there.

### **Theme 3: Exhaustive Nature of Constant Care-giving**

Families of children who have multiple disabilities have additional challenges in raising their children because with multiple disabilities comes multiple services, systems, and care needs. All of the participants discussed in one way or another a feeling of

exhaustion or fatigue associated with constant care-giving. Four subthemes fit into this theme of the exhaustive nature of care-giving. They are 1) fatigue experienced by mothers who serve as primary caregivers of children who have multiple disabilities, 2) extensive care-giving has effect on the entire family; 3) extended family support and support outside of the family do not appear to be present; and 4) mother's are able to function effectively despite feelings associated with chronic sorrow.

**Fatigue experienced by mothers serving as primary caregivers.** As mothers in this study indicated, it is difficult for people who do not live with disabilities to understand the sometimes exhaustive nature of care-giving. Renee, whose son is completely dependent upon her and other care providers for all of his basic needs points to the reality of caring for a child who has multiple disabilities from the perspective of another mother she met who had a child with just one disability:

I didn't get that typical child that I was wishing for and hoping for and wanting to be a mom to, you know I got a child with all kinds of issues. And I met one mom [who] said, "Gosh my kid was just blind! I can't imagine dealing with all that." She said just one issue was enough, is plenty to handle, let alone five or six.

Stephanie explains how very real and frightening the exhaustion can be as she described one of the first nights back at home after an extensive hospital stay.

I had been exhausted. We had just come back from a stay at the hospital, and I couldn't wake up. I had Josh sleeping in bed with us, and I couldn't wake up, and I couldn't wake up and I could hear him crying in my sleep. And then when I finally did wake up in the morning, he was just a rag doll. He was hardly breathing. He was almost dead.

Stephanie went on to describe feelings of being too tired to even care much about the care-giving responsibilities: “You do get tired. You’re only human. You can only deal with so much . . . sometimes I feel like I just don’t want to do this anymore. I just... am sometimes too tired to even care.”

**Extensive care-giving affects on the entire family.** Each of the participants in this study had at least one other child, and all but two were currently married. Mothers were keenly aware of the effect of their constant care-giving on these other immediate family members. Only one talked about not having enough time to spend with her husband, but all of them discussed the positive and negative effects on siblings. In the following quote, Stephanie cries as she discusses the very early years when her son who has disabilities was frequently hospitalized on an emergency basis, and the impact of those unexpected events on her then three year old daughter.

I just felt so bad for Jessica, because she... I wasn’t there for her. And then when I would come home...it’d be in the middle of the winter, and I’d get up in the middle of the night to go to the bathroom or whatever, and she’d be on the floor and I’d almost step on her. She’s not covered up, she’s just so afraid that I’m gonna leave in the middle of the night that she’d sleep beside my bed. (crying) so it just took such a toll on her.

Stephanie’s daughter Jessica is today 15 years old and has recently been diagnosed with anxiety and depression and Stephanie reports feeling a great deal of guilt about this as if she is solely responsible for her daughter’s diagnoses and might have done something to prevent it.

In discussion of chronic sorrow directly, several mothers reported that they could see how siblings and fathers were affected by this phenomenon, too. Karen spoke of how

she believes her oldest son has been affected both by the biological loss of his older sister and by his younger sister's disabilities:

I think [her brother] has a little bit of this, chronic sorrow... he knows that Ellie won't marry and have children. He says I want to be an uncle...he's reaching.

Shauna, whose son has a degenerative condition, recognized the descriptors of chronic sorrow as that which she sees in her son's father:

I started trying to think maybe from more from his father's standpoint, I was thinking that [chronic sorrow] could be something that he goes through . . . I think that whole having a son and not being able to do those things you want to do with a son, and I think possibly he could have some of these feelings.

**Extended family support and support outside of the family do not appear to be present.** All of the participants in this study reported that extended family and friends did not seem to understand the ways in which their daily lives and emotions were affected by their children's disabilities. This meant for them that the number of people who might have served as confidantes was limited. Further, because others outside of the immediate family in the household could not conceive of all that went into care-giving and therapies for the children, they also did not rejoice with mothers in the celebration of reaching a hard-earned milestone. Through tears, Denise described an incident when during a gathering with extended family, her daughter took her first steps. She was seven years old.

I believe it was close to Christmas . . . and my husband's parents were over and his sister and the whole family . . .and she took like 7 or 8 steps all by herself and I was like "Oh my God, Oh my God, look she's walking!" Everybody kind of stopped, I was screaming and hugging her, and it was one of the most chronically hurtful moments in my life because there was like no reaction from anybody else. . . There was no congratulation. They had no idea how hard won that single moment was.

Since extended family members and friends did not seem to fully understand the daily impact of care-giving on the family and especially the lives of mothers who served as the primary caregivers, they were not able to validate mothers' feelings of sorrow. In the following quote, Lorraine discusses how people on the outside only see the positives and don't see what mothers really have to go through.

You're supposed to be thankful for all your blessings and thankful Matthew's here and you just feel like you can't complain about stuff, and you're not supposed to complain about it. It's like I'm not supposed to feel this way . . . and you know, "oh but he's a miracle," you know... and he is so happy. I think sometimes because he is so happy, he's such a loving person, people don't see the negative. They don't see him throw tantrums, but they're not the ones who have to brush his teeth. They don't have to take care of him day in and day out . . . I'm like "sure he's cute and wonderful, but YOU don't have him 24/7."

In these cases, with extended and even immediate family offering seemingly little support, it was especially interesting to note mothers' lack of use or involvement in local family support group networks. When asked about their past or current involvement in family support groups, all mothers who had tried them reported that they did not find them useful. The main reason for this was that the support groups seemed to be designed for mothers of children with specific disabilities, and these mothers did not feel that they could relate with the other family members. Another reason mothers found support

groups to be ineffective for them were reports that their experiences at them had shown that other families were too negative.

It was just very negative, very, very, negative. And a lot of people all they do is complain about their kids, and I just wasn't there. I'm so grateful. I mean it got to the point where, yeah I have this sick kid, but I'm just so blessed to have him because he's the miracle I get to hold in my arms every day.

Five of the seven mothers reported finding support through online friendships, but none of these were with other families of children with disabilities. Melissa, for example, found support through talking to friends she made through a blog she had designed for people interested in Photoshop designs. Stephanie found support through new and old friends she had reconnected with via the social network Facebook.

I have a lot of Facebook friends, friends from high school and other people I've met and that's my support group really. You know, everybody in my little click or group is just really positive and we're always encouraging each other, and that's my therapy.

Without being prompted, several of the participants offered that they had at one point in their lives sought professional mental health to help them cope more effectively with the demands of constant care-giving and feelings of grief and loss associated with those demands. None of them found counseling helpful. Karen explained why she believes mental health providers are unable to provide support to families of children with disabilities.

It's hard to go to a counselor because they can't fathom this. I think if you get a counselor and you go in and you've been raped, they have so much

research out there on the normal reaction of a person who's been raped. They have all these resources and all these data, so they can draw from that. They don't have a lot of data on us. So I've found when I have gone to a counselor ... I kinda look at these guys as having a toolbox. So you get raped, for example, you come in and they have a toolbox, tools they can give you to help you deal with it. You come in and you're a battered wife, they have a toolbox, they teach you those tools and they send you on your way. Where is their toolbox for us? They don't have one. They don't know what to do with us, they don't know how to deal with us.

**Mothers' are able to function effectively despite feelings associated with chronic sorrow.** One of the key components of chronic sorrow is the understanding that a person may be affected by it but not show any signs of depression because they are still able to function effectively in their daily lives (Roos, 2002). Mothers in this study shared their own perceptions of this piece of the definition, especially when reflecting on their feelings of sadness, their role of advocates for their children, and their coping strategies in times of sadness and stress. Stephanie explained how she is able to function by turning her emotions off at whim, and as each of the other parents reported, simply maintaining that attitude that one has no choice but to function because they have so many responsibilities toward the child: "But you become that, in charge, like okay I can do this. and you don't even think about the emotions. You just cut the emotions off...do what you have to do."

None of the mothers claimed to be or feel clinically depressed, and in fact they seemed to be rather indignant to the suggestion by other people or professionals that they were. Denise, who had been to see a psychologist for herself, talks briefly about the experience and how she felt when the doctor suggested she take antidepressant medication to deal with her feelings of sadness.

In talking to the psychologist, they were very classic. Here are some antidepressants, and I said no, I am not depressed. In any given day I can be at my lowest low and at my highest high. That's not depression. It doesn't fit....This is not something you can fix and it's not something that's going to go away, so popping pills isn't going to do anything, nor is telling me to get over it.

Lorraine reiterated this sentiment with the statement, "I'm not a depressed person. I'm actually a very happy person."

In order to be able to function effectively, mothers used coping strategies. When asked directly about what some of those coping strategies were, several of the mothers mentioned their advocacy work, as mentioned above, while all of them identified crying and talking with others as the most effective. Lorraine actually cried as she explained how crying was helpful to her as was being able to talk to her mother and praying: "I cry. I'm very emotional, I cry, and I do get it out. And then honestly I do feel better. Yeah definitely crying . . . I talk to my mom a lot. And prayer."

Though all of the mothers indicated that they were spiritual or religious, only Renee and Lorraine suggested that their faith helped them to cope. Renee talked about how her belief in God has helped her and her family through:

I really feel like that God has really helped me and my husband as well as Ryan through that experience because we go to church on a regular basis, we believe in that, and um, he's shown us that yeah there's gonna be difficult times but there's also gonna be good times.

The exhaustive nature of care-giving was an underlying theme found throughout each of the interviews of participants. Due to the children's multiple needs, mothers

found themselves constantly providing care and becoming fatigued by doing so. There was a burden related to that in that there was frequently little time to give to siblings and spouses, and frequently there was not outside understanding and support available to help mothers address their own needs. Still, despite the pervasiveness of feelings consistent with grief and loss, mothers did not feel overly consumed by sadness, and reported that they were able to function effectively in their primary roles.

#### **Theme 4: Perceptions that Society Stigmatizes People who have Disabilities**

Each of the mothers in the study reflected in some way their beliefs that society still stigmatizes people who have disabilities. They felt this stigmatization in their residential communities, health care and educational settings, social settings, and even within their extended families. Several subthemes fit into this theme of mothers' perceptions of society stigmatizing people who have disabilities. These are 1) avoidance of social situations, 2) worry for the child's future, and 3) feeling like society doesn't validate mothers' feelings of grief.

**Avoidance of social situations.** Living with the disabilities resulted in feelings of social isolation for all of the families. Though they tried to engage in social activities, participation in community events, such as trips to the museum or even to the store or church, was reportedly more trouble than it seemed worth.

Some mothers indicated a lack of energy for engaging in social events, but more than that, most indicated a sense of other people's discomfort, fear, and ignorance as the reason for their avoidance of situations. Participants described in detail a multitude of

experiences in which they could feel people's uneasiness or simply their disinterest in being around them and their children.

Lorraine explained how it sometimes felt that people did not want to take the time to spend with her and talk with her or to hear about her sorrow: "[It's] just either too much for them to process and deal with, or they just don't have time to deal with my grief and my sadness, so I just keep it to myself."

Most of the discomfort of others seemed to be specifically in relation to the child who had disabilities. Denise described it as a type of fear, talking about the obstacles that she faces when trying to find social activities or summer camps for her daughter.

Everybody's afraid of the liability of Catherine. They have this fear, whether it's lawsuit fear or I don't know exactly what the fear is but you can sense it. I mean you could almost smell it. It's strong. Just a barrier a constant barrier.

Even trained professionals were known to show discomfort when faced with the sorrow or just the experiences described by parents of children who have disabilities. Karen described her therapeutic sessions with psychologists trained in grief counseling when she sought their expertise years ago to talk about the death of her one daughter and the disabilities of the other.

I still think there's some ignorance even around the medical profession, and your psychologists and psychiatrists, because when I start talking about Christa and all the weird stuff she does...I can see them, watch them physically in all their discomfort. And I'm going you're uncomfortable with what I'm talking about but you're supposed to help me? That's funny. So I mean going to counseling hasn't been effective...it was effective for the grief of my daughter who died, but not effective for the grief of my daughter who is disabled. Because they're frightened. People have too many fears associated with children with disabilities.

Denise talked about her experience in trying to bring her whole family back into the church, hoping to find support and a renewed sense of faith there, but in the end, feeling unwelcomed.

I think the hardest thing was knowing that they would welcome me, they would welcome my typical child, but they would not welcome my other family member...And it makes me angry because the church is supposed to welcome... you know who you are, where you are, what you are. And if a church doesn't welcome you then good God who does?

Even participation in family gatherings was a challenge for several of the mothers. Melissa explained her family's attempted participation in an extended family Fourth of July celebration.

I do dread situations happening. And I'll be the first to tell you that I'll avoid a situation in a heartbeat if I know I can avoid it. The 4<sup>th</sup> of July, we had a cookout over there and Trent didn't understand why he couldn't have ... little wiggly stars [a little girl] had on her head. So I could see the tension building up with Trent... I knew he was fixing to just go off on this little girl because he couldn't have her little wiggly things. So in a round about way, I've learned how to handle situations . . . I just led him on and I said we have to go home. I forgot what I said. But I got him out of there and we came home.

**Worry for the child's future.** All of the participants in this study expressed their worry for their children's future. Some of this was based on realities like frequent cuts in state budgets and the instability of funding which might provide services and resources for their children as they became adults with disabilities. Primarily though, worries for children's futures were influenced by society's stigmatization of individuals living with

disabilities. Mothers wondered about whether or not the world would be kind to their children and determined that likely it would not.

Stephanie discussed her recognition of the fact that her son does not have any friends now, and this exacerbated her worry for her son when she and her husband have passed away, thinking that he would have nobody to treat him well or who would be a real friend to him.

He deserves to be typical and have all the friends his sister has. But he doesn't have friends. You know he has acquaintances at school and they're great to him, but nobody wants to come over. And I just, I think what's going to happen when we're gone? What's the world going to treat him like?

Melissa shared a similar sentiment in recognizing the lack of other people present in her son's life who can support her son in the ways that she and his father have and the pain she feels associated with that.

When you go through all the heart aches and stuff of people not accepting them for who they are, which is definitely what I'm going through right now with him, that's what hurts. My husband and I support him for who he is, we believe in him and but... it's the other people that don't know about what's going on with him that we have the problems with . . . It's just really, really, really, frustrating and aggravating to where you . . . just want to shield them from the world because you know that they are being mistreated when they are not with you.

Denise talked in greater detail about her thankfulness that her daughter is not aware of how people see her and discussed her own fears of what will happen to her daughter after she is no longer able to care for her.

I still struggle with a combination of just deep sadness and an appreciation of sorts that Katelyn is cognitively involved enough that she doesn't know how other

people think. I think the hardest thing that I do, is I have to look at her every day and I have to almost lie to her face, every day, that it will be okay, whatever it is. Because I'm not at all sure. Particularly in this day and age, with all the cuts and everything. I have no confidence even in what tomorrow brings, really.

**Feeling like society doesn't validate mothers' feelings of grief.** Parents reported that they don't feel their feelings of grief are validated by society as having sustained a "real" loss of any kind. This seems to stem from the perception that people who have not lived their experience cannot possibly understand the experience or the feelings associated with it. Karen explained the difference as she perceives it between her life and the lives of people who do not live with disabilities:

Sometimes I think [of people] if they only knew how lucky they were. They can get up in the morning and they can get ready for work and they don't have to fight with someone who doesn't know how to put underwear on straight. And they don't have to fight someone to take their medicine in the morning. They don't have to worry about if CAP services ever got removed what would they do. Trying to find someone... you know they don't have all these fears and these worries in their life that go on on a daily basis, or monthly, weekly, yearly basis. You know. They don't have \$100,000 worth of medical bills.

Most of the participants spoke of being told by well-intentioned friends or family members that they had "been blessed" or "been chosen" or they were admired for "being so strong." None of them found this to be helpful. Instead, it seemed to multiply their sense of guilt for having any negative feelings about their situations.

Lorraine briefly discussed her feelings about being told that her child was "a miracle" and being made to feel like she should be thankful he was alive instead of sorrowful.

“I know in a sense that they’re right, cause there’s nobody else like him and he is something special, but um, it doesn’t really feel like a miracle to me. It just feels like something went terribly wrong (crying) and you really just don’t understand it. But you’re expected to just be happy, to be able to accept it and go on. Which I’ve tried to do. But I mean honestly, the only way I can describe it, is your whole world just comes crashing down, and it changed my world completely.”

Though all of the participants reported feeling that society didn’t validate their feelings of grief, they each agreed that the term chronic sorrow seemed validating for experiences of families of children who have multiple disabilities. Stephanie stated very clearly how just having knowledge of the term and finding that she identified with the concept of chronic sorrow made her feel less alone.

“The term itself is validating. Because it’s like that is exactly what I’ve been waiting for. For somebody to validate that yes what I’m feeling is really a real feeling. It’s not just me reacting. It’s actual, it’s real. And I’m not alone. And that’s probably a big part of it. I’m not alone.”

In talking about her own overall perceptions of the chronic sorrow phenomenon, Denise weighed the joys with the sorrows she had experienced in her own life in relation to raising a child who has multiple disabilities.

It’s very accurate and I think it’s very prevalent. Yeah, I mean, that is what I deal with, chronic sorrow. It is that combination of like I said, it’s always bittersweet, it’s not like you never have joy, but there is that constant, it will never be a complete joy...Every beautiful moment is associated with that nagging loss. I think chronic sorrow will be a part of my entire life.

The way in which mothers tried to make meaning of their life events, namely the unexpected event of giving birth to a child who would be diagnosed as having multiple

disabilities, was influenced a great deal by the realization that society has certain expectations of people for fitting into a norm and that their children, and now they themselves, do not fit that norm. Even though mothers reported avoiding social situations because of lack of energy or sometimes the lack of opportunity, they primarily seemed to think of their avoidance as a guard for themselves and their children against a sense of feeling rejected. The way in which society appears to stigmatize those affected by disabilities seems to play a significant role in the continual worry for their children's future. Finally, without having sustained a loss in the ways in which society might define it, therefore not falling into that typical time-bound model of grief, mothers find that this society does not validate their feelings of grief associated with raising a child who has multiple disabilities. Instead, mothers are expected to be thankful and grateful that their children live. Their perceived inability to openly express feelings of grief, in turn, isolate them more.

### **Variances in Mothers' Perceptions**

Shauna's circumstances were different from the other participants in the study in that her son had been diagnosed with a degenerative condition and at 13 years old, he was quickly approaching his life expectancy of 15 years. Though she indicated feelings of "highs and lows," feelings of frustration and fatigue related to care-giving, and a sense that her grief was not socially validated, feelings which are all consistent with chronic sorrow, she still did not completely identify with the term of chronic sorrow. Specifically, in reference to the terms a living loss or unending loss, she indicated that she did not feel

a sense of sorrow associated with that concept. Rather, she was mentally preparing, or felt she had prepared herself already, to accept the biological death of her son.

I don't know if some of the reason I don't totally relate to it is because my whole thing is thinking about when there is going to be an end and how that's going to be dealt with, as opposed to thinking about things like, okay what am I going to do with him as I get older and I can't care for him, because I don't expect him to be around that long. So um maybe that's kind of why I get a different view of it.

Melissa, reported identifying somewhat with the term but did not appear to fully understand the concept, or rather not in ways that it could only represent what she was feeling herself. Rather, she primarily discussed experiences of loss as something that her son with disabilities experiences, even though she believes he is not cognitively capable of recognizing any personal loss of his own in terms of comparison to an otherwise typical life.

He loses every day. He loses the chance to live normal. I don't think he'll ever be on his own so he's lost...I guess he loses the chance everyday of being independent. But that's how I look at that term. I mean, we've lost too because he's our son, and I don't think he would know what that term means. But I think he notices things he can't do, like toys that his brother plays with that he wants but he can't have.

While six of the seven mothers immediately responded positively to the term chronic sorrow, indicating that they understood it perfectly well and identified with it, one mother did not. When first given the definition of chronic sorrow at the end of the first interview, Renee's immediate response was one of disagreement. She said that it was too negative. However, as she took several quiet minutes to re-read the definition, she began to nod her head and said that she could see how it describes her feelings in a way.

After having several weeks to process the definition (two scheduled times for the second interview had to be canceled due to child illness and weather conditions), Renee began the second interview with the following statement:

Originally when I read this, at the last interview, I came right out and I said it's very negative. But then I thought about this thing and I tried to put myself in there. And I thought ... I have this chronic sorrow feeling... a lot of times, but it just doesn't affect my everyday things.

### **Recommendations by Mothers for Professionals**

One of the final questions asked of mothers was whether or not they had any recommendations that they would offer professionals working with children who have multiple disabilities. Their responses were directed at a variety of professionals including health care providers, system administrators, and educators and primarily on the need for professionals to work together with other professionals and with parents to address the needs of the child, rather than just each professional focusing on his or her own professional discipline.

Denise delivered the following recommendation which addresses the need for considering the whole child.

“Because children or individuals with multiple disabilities are complex and you cannot divide them into their individual little problems because they're whole. They are not little component parts, they are complex, whole human beings. And for whatever reason they are taught not to see them like that. I don't understand it. But I would try to tell them to look at the whole – not the parts.”

Lorraine based her recommendations for professionals on her need to feel like she was part of the team and that considerations could be made for the amount of time and energy she had available. This reflects other mothers' responses.

Take the time to listen, ask me the questions. Take time to listen to my experiences. It helps me so that they'll know where I'm coming from...I mean you sometimes feel like doctors and nurses, and teachers they're all the time telling you what you need to do and it's like they don't listen to hear you say what you *can* do...It would just make me feel more part of the team, being listened to.

### **Mothers Suggesting what New Mothers Might Experience**

The final question asked of mothers was what they would tell a mother of a newly diagnosed child who has multiple disabilities that she might expect in terms of the feelings she is likely to have throughout life with that child. It was interesting that Lorraine who had not spoken of the joys she experienced with her son, even when asked, had this to say:

I would definitely say the happiness and the joy. You're definitely going to love this child even though you don't think you will. Because I was afraid of that honestly, that I wouldn't be able to love him. I don't know why I felt that way. Because I really wanted to be a mom, I did. But I was scared that I wouldn't love him like I would a typical child or a healthy child. But I love him even more probably.

Renee said that telling mothers what they might experience in terms of feelings related to raising a child who has multiple disabilities was not something she was comfortable doing because everybody experiences things differently.

I would try not to say you will feel like this or you won't feel like this. Because I don't know what they're gonna experience personally, so I would try not to tell other mothers. You know if they do come to me with a specific question, then I try to answer it kind of for the time, and kind of as generically as I can, but not say, every mother feels that way.

Other mothers described other types of feelings a new mother might experience over the course of life with her child. Lorraine added the following to her suggestions for a mother of a child newly diagnosed with multiple disabilities would experience, reflecting the answers of most of the other mothers in this study.

I would tell her you're definitely gonna feel overwhelmed, stress, anxious. I would definitely say you're gonna have times when you're gonna feel sad, angry, probably . . . any emotion that you would ever feel, you're gonna have with having this child and raising him.

### **Summary**

Four central themes emerged from the analysis of this qualitative data: 1) the fluctuation of emotions as experienced by mothers from the time of diagnosis on through to the present day; 2) mothers' tendencies to turn sadness into anger and anger into advocacy; 3) effects of the exhaustive nature of care-giving; and 4) mothers' perceptions that society stigmatizes people with disabilities. In this chapter, these themes were supported by selected quotes from the interviews of participants. In addition, this chapter provided an analysis of the variance among several of the participants and reported participant recommendations for professionals and suggestions for mothers of children who have been newly diagnosed with multiple disabilities. In the following chapter, the

themes that emerged from the data will be discussed in the context of the theoretical frameworks of stress and coping and grief and loss.

## **CHAPTER V**

### **DISCUSSION**

Chronic sorrow is described as a normal reaction to a living or ongoing loss of self or other due to permanent injury, disability, or illness for which there is no public recognition that legitimizes the grieving process (Roos, 2009). The phenomenon of chronic sorrow has not been explored in the field of education and since some parents may experience it, educators will be better prepared for their efforts in establishing meaningful partnerships with families if they are familiar with the phenomenon and its meaning.

This chapter will discuss the personal experiences described by seven mothers of school-age children who have multiple disabilities and their perceptions of the chronic sorrow phenomenon within the theoretical frameworks of stress and coping, grief and loss, and chronic sorrow. A brief discussion on professionals' tendencies to focus mainly on family strengths and how this may be balanced with their recognition of chronic sorrow where it exists is also included. Specifically, a discussion of the balance of joy and sorrow as part of the chronic sorrow phenomenon will be discussed, drawing from mothers' own words and emotional reactions to the interview questions. It will further discuss recommendations by mothers for professionals working with families of children who have multiple disabilities, as well as recommendations by mothers for mothers of

children who are newly diagnosed with multiple disabilities. Finally limitations of the study and implications for further research will be discussed.

## **Theoretical Frameworks**

### **Stress and Coping**

Having come to the realization that significant stressors, like those associated with raising a child who has multiple disabilities, mothers in this study developed an outlook of “this is our life now and we have to keep moving” which has seemed to serve them quite well. This outlook matches Lazarus’ and Folkman’s (1984) final stage of the stress and coping model in which adaptational outcomes are recognized. Not to be confused with a “final stage of acceptance” as in the grieving process identified by Kubler-Ross (1969), since there is no sense of finality when a living loss is present, the adaptational outcomes do bring forth a level of acceptance of the role in which the disability plays in the lives of these mothers. Essentially, the mothers in this study seem to “accept” that the grieving process will continue for them, and they have developed coping strategies to help themselves, their children, and their families through it.

Using the stress and coping model of Lazarus and Folkman (1984), one might typically define the stress-causing environmental event for these mothers as the time in which the child who has multiple disabilities was diagnosed, and indeed, that was a highly stressful event and time. Each of them reported experiencing feelings of shock and sadness, mostly because the diagnosis of their children with disabilities meant their dreams of motherhood and family, if ever realized, would be significantly altered. At the time, none of the mothers had in place resources or strategies to help them cope, and most

of them admitted to feeling overwhelmed. Lorraine who was embarrassed, she said, to admit that she had never heard of a Neonatal Intensive Care Unit (NICU) before the birth of her son, said that she felt very naïve during this time. Most of the mothers also admitted to feeling that sense of “why me?” Stephanie reported a feeling of numbness and a disbelief that this was happening, which eventually, for her and the others, settled into a sense of loss that would apparently never go away. Still, with the need to keep functioning for the sake of their children all of the mothers reported that they simply could not allow themselves to be consumed by sadness. Renee explained how when another parent said to her, “I don’t know how you do it,” her response was “I don’t have a choice.” The realization of the lack of any choice but to keep on moving ahead was recognized in each of the mothers in this study.

It is important to note though that throughout the course of their lives, new unpredictable stress-causing events have arisen, which triggered feelings similar to those experienced at the time of diagnosis. When directly asked about stress-causing or “trigger events” since the initial diagnoses were given, a few of the mothers in this study indicated that these trigger events occur only once in a while, sometimes a year or more apart. While others maintained that trigger events were almost a daily occurrence. Commonly mentioned were birthdays, a time in which parents typically look at their children and reflect on their growth and development over the years. The mothers in this study did not experience the birthdays of their children in this way. Rather, birthdays seemed to serve as a reminder of how far behind their children were, especially when compared to siblings or peers. As the children aged, birthdays became even harder for several of the

parents. Lorraine and Shauna both said that they are reluctant to even have birthday parties anymore for their sons because they know that their children do not really understand the purpose of the celebration and it is simply too hurtful for them to take the time to stop and reflect on the milestones that have *not* yet been reached. Stephanie defined trigger events as things that happened unexpectedly, such as middle of the night emergency room visits, but also occurrences that could be predicted after a while, like upcoming IEP meetings. Denise and Melissa both confirmed that just the anticipation of school meetings or scheduled doctor visits could serve as a stressful time because prior experience had taught them that these events could turn out badly. Establishing coping strategies that could help them deal with these stressful events became a priority for mothers so that they could continue to function as they needed to for their children.

Lazarus and Folkman (1984) discuss the necessity for making primary appraisals and secondary appraisals of stressful events in order to be able to cope effectively. Primary appraisals are those which help an individual make meaning of the stressful event, while secondary appraisals are conscious thought processes which help individuals draw upon available resources to minimize the potentially harmful effects of the stressful events. After the shock of the initial diagnosis dissipated, mothers appeared to move through the stages of the stress and coping model identified by Lazarus and Folkman (1984) by making a primary appraisal of the situation and trying to make some meaning of it. For all of the participants in this study, this seemed to be the most difficult part, and in fact they still seem to be trying to make meaning of it. Denise sought her faith in God to help her make meaning of the experience but when she returned to the church, she felt

that she and her daughter were rejected. After this experience, she noted sadly and with lowered expectations, that if a person is not welcome in church, how could they expect to be welcomed anywhere. Since mothers find themselves still, years later, trying to find a place in society where they and their children fit, it is no wonder they have, for the most part, been unable to make meaning of the situation.

Still, secondary appraisals were necessary for mothers to make in the beginning to determine how they would let their lives be affected by the diagnosis and to seek and find resources which would decrease the stress. These secondary appraisals appeared to be, in most cases, subconscious decisions, as each of the mothers described more of “going through the motions” rather than any real planning or decision-making. Part of this seemed to stem from their lack of prior experience or knowledge about disabilities and so not knowing what they could possibly do or where to turn for assistance. When Lorraine was connected by the hospital with an early intervention service program she was hesitant to meet for the first time because she had no idea what it was they wanted. Even though resources were in fact in place for them, the fact that mothers had no prior experience with those services and no immediate knowledge of their purposes left them feeling confused. Further, though a number of services are in place in the beginning (e.g., early intervention services, family support networks) to assist parents in the adaptation of having a child who has multiple disabilities, there do not appear to be similar services available as the child ages to assist parents in what appears to be for them a process of continual re-adaptation. Because of this, nothing prepared these mothers for the continuance of the daily stressors they would experience, and making secondary

appraisals was a challenge. This may play a significant role in the onset of chronic sorrow in families of children with disabilities.

For people affected by chronic sorrow, Hainsworth, Eakes, and Burke (1994) suggest that individuals use “action strategies” for coping and feeling a sense of maintaining control of their lives. Specifically, these researchers suggest that parents of children who have disabilities should remain actively involved in personal interests and activities so as not to become consumed by the effects of the disability. However, this is a challenge for the mothers in this study. Because of the constant demands of care-giving, they cannot seem to find the time to fulfill their own interests, and some even reported forgetting over time what their personal interests ever were. Though all of the mothers in this study reported finding some sort of relief from care-giving through Community Alternatives Program (CAP), a program designed to support individuals with disabilities in their communities, it seemed that this time in which they did not have to provide direct care to their child with a disability was usually given to their other children or spent running household errands or attending to personal needs like bathing. In fact, this was not time in which they could re-coup or engage in activities that personally interested them. Only Melissa received respite services in addition to the CAP services, and found that she was able to take advantage of the opportunities to rest or go out and do things that she enjoyed, such as spending time with her best friend or going shopping. Most of the parents indicated that they felt they would be unable to function without the assistance of community supports. Denise, however, expressed concern in the turnover rate and unpredictability of community service providers for her daughter and considered

it another stressor in their lives. Karen expounded upon this when she noted that families of typically developing children do not have to worry about things like what they will do if the CAP provider chooses not to show on any given day. For mothers who seemed to be struggling to gain some sense of control over their lives, it seemed a bittersweet necessity to them to rely on these outside persons for support.

Hainsworth and colleagues (1994) stress the importance of maintaining interpersonal relationships and having others to talk to, especially those who are sympathetic and understanding, when stressful events occur. Professionals may assume that because family support groups are available, parents of children who have disabilities will seek each other for support there. However, all of the mothers in this study had tried joining support groups either face-to-face or online, but did not appear to find these groups helpful. A few indicated not being able to find enough time to participate in these groups, while others said that they did not identify with the parents who were present at them. It seems that the sense of difference and isolation mothers feel from others who have children who are typically developing extends even to mothers who are in similar situations to their own. This may be due to the fact that these mothers have children with multiple disabilities and so do not feel that they fit in entirely with disability-specific support groups. Their overall responses to the question about family support group involvement overwhelmingly indicated that their initial experiences with those had been too negative. Karen explained that the negativity of other parents present at such meetings left her feeling despondent and even somewhat angry. It appeared that mothers initially sought out these types of support groups in an effort to find hope, but

instead found other mothers who were drowning in self-pity. This is valuable information for coordinators of support groups to consider as they design and implement such programs for families. It was clear that all of these mothers wanted to attend, and they may have benefited if facilitators were in place who would keep groups focused on specific topics and who made an effort to keep discussions more balanced.

Probably one of the most effective coping strategies that mothers in this study identified was learning to advocate for their own and other people's children. Wang, Mannan, Poston, Turnbull, and Summers (2004) suggest that parents who engage in advocacy efforts, despite the time and stress associated with it, develop a greater sense of self confidence. In addition, developing advocacy skills opens doors for families to learn more about specific disabilities, legal rights and resources, which in turn can decrease their stress level. This may give mothers a sense of regaining some control of their lives, when most reported feeling that the direction their lives had taken was not something that they had planned or hoped for. Itkonen (1997) discussed how parents in advocacy roles are typically very motivated because of the personal nature. All of these mothers described intense advocacy efforts to obtain appropriate educations and community services for their children. Karen, Denise, and Melissa each made it clear that they felt there was a gap between their own level of dedication to their child and the level of dedication to their child on the part of professionals. Denise wondered aloud why professionals who do not appear to have the passion to help children who have multiple disabilities would go into the field in the first place.

Other coping strategies that were frequently identified in this research were crying and talking about feelings with other people. These are two strategies that are referred to as helpful for persons who are experiencing grief as it relates to a biological loss. However, one must be cautious in prescribing generic grief-related therapeutic practices for individuals who are experiencing chronic sorrow due to a living loss. As mentioned earlier, chronic grief and chronic sorrow are two different phenomena. Therefore, the type of therapy prescribed for one may be quite useless for the other. This is discussed further in the following section.

### **Grief and Loss / Chronic Sorrow**

As mentioned in Chapter 2, society plays an important role in helping a person to move through the stages of grief, making the experience actually a social event (Klass, 1988). Rituals are performed, sympathies are expressed, and individuals are given a certain period of time to come to terms with the loss and move on with their lives. When a person experiences the biological loss of a loved one, they typically experience feelings of intense sadness, but it is expected by society that the whole grieving process will finally conclude, within a certain amount of time, with acceptance of the loss (Doka, 1988). This is a time-bound model for grieving that society appears to have deemed appropriate and non-pathological (Doka, 1988; Andereg, Vergason, & Smith, 1992). When individuals take too much time to go through this grieving process they are considered to be suffering “chronic grief.” Counseling services are usually helpful in getting a person to work through the pain of loss so that they might learn to accept it and move on with life.

Chronic sorrow differs from this time-bound model of grief in that the emotional responses to a loss reoccur for as long as the cause of the grief is still present (Olshansky, 1962). These grief-related feelings do not have to be continuous, but they are known to peak due to specific trigger events in life and lead a person to re-experience stages of grief. Unfortunately, probably because the two terms are so similar, professionals confuse the definition of chronic sorrow with chronic grief (Roos, 2002). Chronic grief is a pathological response to a single loss or event, usually the biological death of a loved one, in which individuals continue to feel intense sadness over an extended period of time, beyond that which is recognized by society as appropriate (Doka, 1989). Chronic sorrow consists of an underlying sadness that is always present, but it is in response to multiple losses over time, or losses that are living and offer no finality as with biological death (Roos, 2002).

Because the phenomenon of chronic sorrow has not received a lot of attention in research, the term is relatively unfamiliar to professionals, even those in counseling services. The researcher for this study registered for and attended as a full-time student two classes which focused on grief and loss and never found the term chronic sorrow even mentioned. When it was brought up by the researcher to the professors of those classes, it was categorically fitted into the area of “chronic grief” or “complicated grief.” It does seem appropriate to categorize chronic sorrow as a type of complicated grief, and yet, doing so does not seem to bring further attention to the unique phenomenon, at least in terms of the experiences of people living with disabilities. One could surmise that the stigma associated with disabilities leaves a level of discomfort in discussion of the topic

at all. Further, there appears to be some sort of moral dilemma about whether or not it is acceptable to experience grief in relation to a living child, disabled or not, and this may be what leaves society, including counselors, feeling most uncomfortable. Mothers in this study who had sought counseling to address their feelings in relation to raising a child who has multiple disabilities did not find the experience to be helpful. Denise and Karen both said that they could sense the psychologists' discomfort with the things they were trying to openly discuss. Finally, they found that the strategies they were being given were not at all suitable for people experiencing a living loss, but rather were more appropriate for people who were being encouraged to "let it go" and "move on" as with those experiencing chronic grief instead of chronic sorrow. For example, they may be asked to try to disengage, reflect on memories, or to "cry it all out." Unfortunately, it would not be suitable for a mother to disengage from her child, there are no memories necessarily to reflect upon since memories continue to be made, and crying could never be finished as further losses continue to occur. Karen, who had lost one daughter to biological death already recognized immediately that these strategies would not help her in dealing with her other daughter's disabilities. Denise suggested that professionals who maintained the attitude of how to "fix the problem," usually with medication, simply did not understand that the sense of sorrow was not something that could be repaired. What these mothers needed, simply, was an empathetic ear.

The mothers in this study indicated not only the inability to, but the unwillingness to detach themselves emotionally from the child with a disability. Therefore, a better model for assisting families from a counseling perspective may be one which focuses on

personal growth, rather than letting go (Roos, 2002; Wolfelt, 1988). From a clinical therapeutic perspective, it is also important to note that two mothers in this study mentioned associating their feelings to post-traumatic stress disorder, having never heard the term chronic sorrow before and not knowing how else to define what they were experiencing emotionally. Further research into the similarities between chronic sorrow and post-traumatic stress disorder may be helpful for coming to better understand the emotions that mothers of children who have multiple disabilities feel.

**Disenfranchised grief.** As mentioned above, the grieving process is something that is facilitated by social interactions (Klass, 1988). A public recognition of a loss is essential to an individual's final acceptance of it. However, if a person grieves the loss of something or someone that is stigmatized or simply misunderstood by society, such as someone with AIDS (Roos, 2002), their grief historically has gone unrecognized (Doka, 1989, Roos, 2002). Whether this is because of society's discomfort or distaste varies depending upon the type of loss and the incidents from which it evolved. The type of grief that is experienced in which there is an absence of social recognition and validation of a person's loss is known in the literature as disenfranchised grief (Doka, 1988) and is associated with chronic sorrow (Roos, 2002). This appears to be similar to the type of grief experienced by mothers in this particular study, as none of them felt their feelings of grief were validated by society because they had not, in fact, sustained a real biological loss. Rather than acknowledge any feelings of grief, for example, extended family and friends of participants in this study provided mothers with feedback that implied high expectations of their abilities to cope effectively with their otherwise stressful situations.

Statements such as “you are so special,” “your child is a gift from God,” or “you are so strong...I could never do what you do” left mothers feeling that they were not expected, or even allowed, to grieve. Roos (2002) suggests that these kinds of statements, however well-intentioned, actually sets parents farther apart from others than they may have been feeling in the first place. Many of the mothers in this study indicated that they preferred not to let their sorrow show because they would be perceived as weak, supporting Roos’ theory that being perceived as strong implies to a person that they cannot show any weakness. In essence, these well-intended responses do nothing to support families and actually isolate them more. Lindgren, Burke, Hainsworth, and Eakes (1992) said it best when they said “failing to recognize a person’s chronic sorrow may actually contribute to it.”

**Anticipatory loss.** In the literature on grief and loss, anticipatory loss is a term that refers to how individuals may come to expect a loss to occur, either for real reasons or imagined ones. For instance, if a child has been diagnosed with terminal cancer, the expectation that the biological death of that child will come is very real. For mothers of children who have disabilities, such as these in this current study who have already experienced feelings of multiple losses, it seems reasonable for them to anticipate additional ones. Roos (2002) suggests that parents of children with disabilities sometimes remain in a state of denial when a loss has occurred as a method of defending themselves against further trauma, what she deems re-traumatization.

One participant in this study, Renee, who seemed uneasy about admitting her identification with chronic sorrow still openly admitted experiences that continued to

cause her great sadness. However, when directly asked about this, she maintained that she had “accepted” the disability, though her acceptance of the multiple losses associated with her child’s disability seemed far off. Roos (2002) would likely characterize this as an example of someone who is defending themselves against re-traumatization. It may also actually be a helpful coping mechanism to prevent the onset of depression.

Though participants in this study were not directly asked about their anticipation of additional losses, it was recognized by the researcher consistently. Melissa, for example, described feelings of re-grieving just before the annual CT scans of her son who has tubero sclerosis. She expressed her fear each time that the scans would show further damage to her son’s organs due to the tumors, and explained how she cried weeks ahead of the scheduled scans. Lorraine reflected on the early years of her son and described how she cried before each medical check-up because she always expected them to tell her about “something else that was wrong.” Karen felt a sense of anticipatory loss whenever anything happened to her son who did not have disabilities. She described a time after a sports injury when a bone growth was found on her son’s chin, and talked about her level of fear probably being higher than that of a parent of a child without disabilities because she “knew what could go wrong.” These examples are indicative of anticipatory losses that may or may not have gone unfounded. However, Shauna’s anticipated loss was very real and may be the reason that she did not personally identify with the terms associated with chronic sorrow. Shauna’s son has been diagnosed with a degenerative disease, Hunter’s syndrome, and is not expected to live more than another year or two. Currently she readies herself emotionally for a loss that she knows without a doubt will occur.

### **Mothers' Life Experiences and Their Perceptions on Chronic Sorrow**

The overall grief-related feelings expressed by mothers in this study seemed to evolve around multiple losses including the loss of the dreamed-of child, the loss of self, as well as the loss of their expectations associated with motherhood. These multiple losses combined, appeared to leave them with, in one mother's words, "a pervasive sense of emptiness." A theme of sadness ran throughout, leaving the impression that the diagnosis of their children with multiple disabilities had done a type of damage that simply was not something that could ever be repaired. Nor did it seem that mothers expected it would be. Rather, mothers seemed to be making continual adjustments to their lives and the lives of their family members in response to continual stressors and to the rebuilding of their dreams. The identification of meaningful coping strategies, such as talking with others and allowing themselves to grieve, even when it seemed that others would not, was purposeful in their attempts to continue functioning in their daily lives.

It is especially interesting that at this later stage in the lives of participants, when asked about their feelings around the time of their children's diagnoses, each of them were able to reflect back and remember in vivid details. They not only recalled the feelings they had, they recalled the effects of the event on the entire family and the realization that it would be life-changing. Further, they were able to recall specific things that were said to them by professionals, family and friends around them at the time, especially the things that were the least helpful and most hurtful. For instance, being told of the diagnosis in a callous and non-hopeful manner by physicians, or in one case, being told by a friend that her daughter would do nothing but "masturbate her entire life" –

these were things that mothers carried with them for many years and still do today. These kinds of negative statements had an impact on mothers and seemed to define for them a new reality, a new world in which they no longer felt they would fit.

As mentioned in Chapter 2, Roos (2009) describes the phenomenon of chronic sorrow as somewhat of a disparity between reality and fantasy, that is the recognition of the initial loss and then the dreams of what might have been. Mothers in this current study described being consumed by care-giving responsibilities that sometimes left them with not even enough energy to think far into the future. Lorraine explained, for example, how thoughts of her sons' future and his place in the world really occurred to her for the first time one morning when she watched him from the window outside waiting for the school bus. This is consistent with Roos's notion that the extent of a loss may not even be fully realized for years, until a person begins to recognize the re-occurrence of feelings of grief (Roos, 2009). For the mothers in this study, after the initial emotional reactions to the diagnosis of their children who have multiple disabilities, there appeared to be a slow and steady realization of the lost dream they had only thought about in the beginning. As their children grew and mothers began to recognize the things that their children could not do, the ways in which their children do not fit in, the struggles that their children face against a world that seemingly doesn't offer a viable place for them, the reality of the lost dream became abundantly and often painfully clear for the first time.

### **The Joy-Sorrow Concept**

Chronic sorrow is thought to have the elements of both joy and sorrow as individuals who experience chronic sorrow typically describe episodes of joy and

happiness, even satisfaction (Kearney & Griffin, 2001). The presence of these positive emotions appears to prevent a person's feelings of grief from becoming incapacitating (Eakes, Burke, & Hainsworth, 1998). The joy-sorrow concept as described by Kearney and Griffin (2001) is one of the more interesting pieces of the chronic sorrow phenomenon, and if it were frequently enough discussed would likely be the most controversial. There appears to be among researchers and parents an unwillingness to suggest that an abundance of joy is not present or that it is not at the very least balanced with feelings of sorrow. That noted, an interesting theme evolved in the process of the explication of the data which indicates that despite mothers' reports that there was indeed an equal balance of joy and sorrow in the experiences of raising a child who has multiple disabilities, their other words and their emotional expressions told a different story.

In the small number of research studies that examined parental joys (Scornaienchi, 2003; Kearny & Griffin, 2001; Eakes, Burke, & Hainsworth, 1998), parents of children who have disabilities expressed feelings of being torn between joy and sorrow from one moment to the next. Indeed several of the mothers in this study reminded the researcher that had she come to interview them at a different time, their feelings and therefore their responses to questions may have been quite different. Some indicated that the time frame between the fluctuations in their feelings might be just a day or two, while others suggested that years might pass before they would experience sorrow again, as if every day between this and those years were joyful. As an example, Lorraine said that if she had been asked the question about the joys and sorrows five years ago when her son was hospitalized for a life-threatening illness, she would have felt and

therefore expressed much more sorrow in this interview. For now, she says that her experiences of joy far outweigh her feelings of sorrow. She went on to say that she is a happy person, but said that she would have to “really sit down and think about it” before determining that she is indeed “blessed” and her life is a “joyful” one. While she cried with tissues in hand through much of the current interviews she also laughed simultaneously, in almost an effort to dismiss her own sorrow. When asked what she would tell a mother of a child newly diagnosed as having multiple disabilities about the types of feelings she might experience, she went on about the joys and happiness she could expect to know. Her answer to this question, however, seemed more to focus on the love she has for her own child with an unprovoked explanation about how she had worried before that she would not be able to love him. Again, she cried while talking about this. The magnitude of her words and her emotion might lead one to believe that it is her strong love for her son that makes it difficult for her to admit that there is far less joy present than she would like to have – as if saying “there is little joy” would equal “I do not love him.”

Renee indicated that if the researcher had come to interview her just a few days ago, she might have found her sad instead of joyful. She was fighting back tears when she said this, again as if unwilling to admit to feelings of sorrow. Each time that the researcher probed Renee with questions relevant to the experiences of sorrow, Renee made an obvious effort to turn the question around to one of joy as if excusing her sorrow, and yet her answers inevitably came back to the sorrowful feelings she experienced and she would find herself in tears again. Also, when initially given the

definition of chronic sorrow to read, her response was that it was something negative, and she quickly explained that she did not feel those things. However, taking one week to ponder the definition, at the time of the second interview, she began by acknowledging that her initial reaction was not accurate. She then said that she did in fact have feelings that were consistent with chronic sorrow, but quickly made it perfectly clear that she was not depressed or incapable of or unwilling to take care of her child.

Kearney and Griffin (2001) learned from parents of children who have disabilities that their experiences of joy tend to be associated with their personal interactions with their children, while the experiences of sorrow tend to stem from their interactions with people outside of the family. This was found to be the case in this study as well, as a consistent theme of other people's lack of understanding was recognized in each of the interviews and seemed to contribute significantly to mothers' experiences of sorrow. The sense of joy that mothers may have gotten from their interactions with their children, however, was limited due to communication disabilities. Renee, for instance, talked about feeling like just another caregiver rather than a mother, because in thirteen years she had never even heard her son call her "mom." Lorraine spoke also of a longing to have meaningful interactions with her son who was unable to communicate effectively with her. Shauna reflected on her son's degenerative condition and the loss of the ability he once had to speak and communicate with her. She relished those rare moments when he would express love for her through just a simple smile. Denise talked about her relationship with her daughter and trying to make meaning out of "unreciprocated love." If the joys of parenting a child who has disabilities is derived from interactions with the

child, then mothers of children who have multiple disabilities, which frequently include an inability to communicate effectively, face greater challenges in finding that joy.

Mothers in this study also discussed their interactions with people outside of the family and their concerns with being seen as sorrowful people. Lorraine and Stephanie each openly shared their concerns about being seen as depressed. When asked about this, each of them indicated that they really did have happiness in their lives and they did not want to appear to be depressed people or poor company for others. In further discussion, both of them alluded to interactions they had had with other people who appeared to be uncomfortable when they mentioned problems they were currently having or stress or sadness they were currently feeling. Stephanie referred to a woman who she works with who is also the mother of a child who has disabilities. She indicated that she could plainly see that this mother has chronic sorrow, but that she is sad and angry all the time, and she hopes that people do not see *her* that way.

Lorraine talked about her middle son who wanted to have friends over for a play date, but when she tried to arrange it with another mother, that mother agreed it would be best to have the play date at her house instead. Lorraine expressed her confusion about this incident by considering out loud the variety of reasons why this other mother would say that and finally concluded by saying she believes that the other mothers must think she already has too much on her with her son who has disabilities. This and similar kinds of incidents have left her feeling isolated and feeling like other people do not really understand what she goes through. In an effort to fit in better with the other moms, she says she makes a concentrated effort to let them only see her happy side.

Denise, whose interviews carried on for as long as three hours each and provided much more detail and expression than any of the others, cried almost the entire time the researcher was present in her home. Still, despite her tears, her responses to questions about joy and sorrow were eloquent and profound. Unlike any of the others, she appeared to want to make a point for the sake of this research that she feels consumed with sorrow and that the joys are few and far between. Her sorrows, she believed, were brought upon not by her daughter's disabilities, but by the lack of adequate support from systems supposedly designed to assist her in providing her daughter with a purposeful life. She recognized and was deeply hurt by her daughter's poor quality of life. The following statement delivered through uncontrollable sobs sums up this emotion: "I have sat on the floor with Catherine seizing every 30 minutes, and just go, 'God, why do typical, healthy incredibly smart children die of cancer, and she lives?'"

When Denise did mention joy, she would go on to describe how those joys were made bittersweet by the realization that there was no one to share them with, no one who understood the sacrifices made by both her and her daughter to reach a milestone, and no one else who would define, as she did, the sun in her daughter's hair as a joy. She described the effort needed to find joy and discussed her belief that a mother must actively seek joy in order to survive. She made no claims that she did not love her daughter – quite the opposite. After eighteen years of constant care-giving, she is still adamant about not placing her daughter in a group home because she says she would simply miss her too much.

With the expression of emotions that swelled in the study participants when asked about their joys and the obvious attempts to redirect the conversations when asked about sorrows, it seemed very much that their sorrows do outweigh the joys. The obvious struggles they had in naming those joys was apparent when they could say nothing other than to provide the generic statements of “there is lots of joy” or “there is lots of happiness” without being to expound upon those statements. The level of discomfort they felt, with the exception of Denise, in being able to openly say that joy was limited is understandable, but disconcerting. One wonders how much sorrow a person can hold within before confounding factors of that sorrow, such as isolation and detachment (Roos, 2009), lead them into depression. Though some studies suggest that parents grow from the experience of raising children who have disabilities and become stronger and more cohesive families, there is still a reality of sorrow that should be recognized, not dismissed. Indeed that element of the presence of sorrow, however pervasive, does not mean that joy is not present and happiness is not experienced. Pearl Buck (1950), the mother of a child with severe mental retardation once said: “Sorrow fully accepted brings its own gifts. For there is an alchemy in sorrow. It can be transmuted into wisdom, which, if it does not bring joy, can yet bring happiness” (p. 5).

### **Focus on Family Strengths with Recognition of Chronic Sorrow**

In the literature of present day, there is a strong push for researchers and professionals to focus on family strengths, highlighting the joys that families experience with their children who have disabilities, and the positive coping skills they utilize (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Risdal & Singer, 2004). These are

noble pursuits and necessary to learn what works best for families in terms of ways in which professionals can continue to provide support. However, for families experiencing chronic sorrow, this consistent recognition of *only* the positives can leave them feeling more isolated. One of the reasons for this is that parents find themselves feeling negative things that are not addressed by professionals and so they feel like they must be the only one, which in turn makes them feel guilty as if they are wrong somehow to even have these feelings. As an example, in both interviews with Lorraine, she repeatedly said things like “I know this sounds terrible...,” “I’m kind of embarrassed to admit this...,” “You must think I’m just awful...,” and “I’m probably the only one who feels that way.” In fact, everything that she said in her interviews was repeated by the other mothers in the study.

Though it is instinctive for many professionals to want to try to “fix” families, sometimes just by giving them hope, there is a certain value in recognizing that some things just cannot be repaired. Understandably, it must be difficult for professionals to serve in supportive roles for families while recognizing that in many cases, hope simply cannot be restored. As an example, one of the mothers, Denise, directly mentioned a book which is popular among parents of children with disabilities. It is a compilation of encouraging stories, tales of hope, a sort of guide for parents in recognizing and accepting the loss of the child they had dreamed of while building new dreams for their child and their family and is frequently recommended by professionals for parents to read. Denise commented that even though a person can build new dreams, for her it feels like even those new dreams are continually “re-shattered” for one reason or another. Her

experiences reflect that of most of the other mothers, that there appears to always be a reason, despite their best efforts, that their children do not “fit in.” This is likely a reality for many parents who feel like they are consistently battling one system or another to make way for their child. Denise’s comment may surprise some professionals, but outlines perfectly well how the experience of so many lost dreams can evolve into chronic sorrow.

### **Recommendations by Mothers for Professionals**

When given the opportunity to share what recommendations they would offer professionals who might work with mothers of children who have multiples disabilities, most of the mothers in this study said that professionals should listen more to parents. Lorraine recommended that professionals ask her questions about her experiences and try to understand what life is like for her and her son and her entire family. This was important to Lorraine because, as she said, professionals tend to tell you what to do instead of asking you what you *can* do. This sentiment is reflected in the responses of Denise and Karen who each recommended that professionals see their child as a whole child rather than focusing on developmental domains specific to their individual disciplines. When working with children who have multiple disabilities, professionals need to understand that mothers are feeling like they have to coordinate and plan and follow the instructions of each and every therapist, doctor, and teacher with whom they interact. The participants in this study reported how exhausting this can be, and that sometimes they simply do not have the energy to carry through on everything. Lorraine said that when her son’s teachers tell her that she should be working on something

specific at home with her child, she will tell them “okay” even though she knows she will likely not find the time or energy to do it. When asked by the researcher why she tells teachers that she will do something if she knows she will not, Lorraine responded that she did not want to be seen as a bad parent.

Several of the mothers in this study also reported their distaste for being made to feel like “difficult parents” when they tried to advocate for their children in schools, and at least one of them has said she has now just given up and allows the teachers to do what they want to do. She has been made to be fearful that if she continues to be “difficult” the teachers will make her son suffer. Denise described a time when she was talking to her daughter’s physical therapist about an experience she had at the hospital earlier and sharing her feelings about it, when the physical therapist asked, “Why are you telling me all this?” Denise reported feeling like the therapist did not want to listen either because it was not about her specific domain or because she simply did not care. Whatever the reason, Denise responded by, in her own words, “shutting down.” She went on to explain how that therapist worked with her daughter for another three years but they never got any where because she did not have a relationship with her any longer. These kinds of experiences do nothing to build or maintain partnerships with families. If professionals really want to understand and work closely with families to provide support and assistance for their children, these mothers recommend that they listen more closely, ask questions about family life and experiences and try to understand how the entire family is affected by the disability.

### **Mothers Suggesting what New Mothers Might Experience**

Finally, participants in this study were asked what they would say to mothers of children who have been newly diagnosed with multiple disabilities about the types of feelings they might expect to have throughout their lives with those children. All of the mothers agreed that new mothers could be expected to have feelings related to grief such as sadness and anger. In addition, they included feelings of being overwhelmed, anxious, and stressed. Renee, however, made the profound suggestion that perhaps mothers should not be told what they might expect to feel since individuals are known to adjust to and cope with stressful situations differently. When probed for clarification, she did go on to say that if a parent approached her crying and asked if feelings of sadness were normal, she would tell her yes.

Interestingly, Lorraine, who could never definitively say what specific joys she found in raising her son who has multiple disabilities though she reported joys were indeed present, was the only one who suggested that new mothers should expect to feel great joy and happiness. She talked a great deal about how much they could expect to love the child, despite any initial feelings they would likely have in the beginning that they possibly would *not* be able to love him. Lorraine's comments take us back to the above mentioned joy-sorrow concept and the ways in which mothers in this study seemed to be adamant about explaining that joy was present, even though defining what those joys were was a challenge. However, returning to what Denise suggested, that joy is something that should be actively sought in order to compensate for the sorrow, it seems

reasonable, even prophetic, to suggest to new mothers that feelings of joy will indeed be actualized.

### **Limitations of the Study**

There are three significant limitations to this study which must be considered. The first limitation of this study was in the selection of participants from those who had been connected in one way or another with the Exceptional Children's Assistance Center, which is a non-profit organization providing educational advocacy services to parents of children who have disabilities. It is possible then that mothers who were ultimately selected to participate in this study had encountered more problems in educational settings, requiring the assistance of an advocacy service, than other mothers might have, thus the descriptions of their negative experiences in educational settings may have been unique.

The current study examined the perspectives of seven mothers of children who have multiple disabilities, only one of which was not Caucasian. This is recognized as a second limitation of this study. Since the culture of European-American families tends to place a great deal of importance on a child's development of independence and self-reliance (Burden & Thomas, 1986), the level of sorrow experienced by these families may be greater than that which we might see across other cultures. Because different cultures have different meanings for the birth of a child with disabilities, and their belief systems frequently effect the direction of their responses and the ways in which they adjust (Rogers-Dulan, 1998), this current study cannot be generalized across cultures. Participants were not asked in this study how they felt their cultural backgrounds may

have affected their experiences or their perceptions, and none, including the one African-American offered any such information. It would have been interesting to examine if there was a difference in the perceptions of the Caucasian mothers and the African-American mother, and yet the unequal ratio would have made this unfair. Indeed, as it turns out, there did happen to be a difference between the Caucasian mothers and the African-American mother, but this difference in perceptions of the chronic sorrow phenomenon was based on a different type of child diagnosis, rather than on ethnicity.

Finally, it is important to note that though families experiencing chronic sorrow appear to be functioning well, the onset of major depression is certainly a complication of chronic sorrow, and that people with chronic sorrow are at risk for developing post-traumatic stress disorder, problems in identity development, and disordered intimacy and attachment (Roos, 2009). For this study, mothers were asked before being recruited to participate whether or not they had been diagnosed with a serious mental health disorders. If they said yes, they would not have been included in the study. Each of them reported that they had not. However, as one of the mothers pointed out after her first interview, just because a person has not been officially been diagnosed with clinical depression, does not mean they do not have it. With this said, there is the very real possibility that any of the mothers interviewed may well have been experiencing signs consistent with depression or other mental health disorders. From the researcher's perspective and field notes, it was clear that two of the mothers interviewed for this study articulated feelings that might have been founded by a psychologist or healthcare professional to meet the criteria for depression. If this were indeed the case, the

experiences of these parents may go beyond that which is experienced as chronic sorrow, however likely it may be that depression stemmed from years of living with chronic sorrow unrecognized.

### **Strength of researcher bias**

Given that the researcher is a biological mother of a school-age child who has multiple disabilities, it would be irresponsible to suggest that a bias was not present. However, this bias, her personal experiences, likely strengthened this study. For one, the researcher revealed to participants in the beginning of the study that she too is a mother of a child who has multiple disabilities, and so it is highly probable that they felt more comfortable opening up and sharing their thoughts and feelings with her than they might have with someone else. Indeed, informal conversational responses from mothers to the researcher indicated that this was the case. In addition, during the interviews, most of the mothers said things to the researcher like, “of course I know you understand what I am talking about.” The researcher’s personal experiences also meant that she was able to recognize specific participant responses and knew when to probe for deeper meaning from them.

Many of the experiences participants shared were quite simply heart-breaking. Since it was clear from the beginning that the researcher has lived many of the experiences described by mothers in this study, and because there is no doubt that she shares a reality with them that sets them apart from the majority, it is no wonder that when participants cried, she cried with them. In most cases, the researcher brought those tears home with her. On the other hand, as mothers in this study tried hard to describe the

most basic of joys in the most extravagant terms, the research was also able to identify with this, even celebrate with them where it seemed that others had not. Indeed, it was difficult for this researcher to don two hats: one as a professional and capable researcher and the other as a mother. The perspective as a mother, however, allowed a passion not typically seen or even welcomed in this type of research, but a passion necessary to bring out a level of depth in the participants that is not frequently shown to others. It was a challenge not to engage in discussion, to share her personal experiences, and to provide a sympathetic ear, but it was a challenge met and overcome for the important purpose of gathering this very valuable information on mothers' experiences and their perceptions of the chronic sorrow phenomenon.

### **Implications of the Study**

The current study introduces a relatively unheard of phenomenon and terminology into the field of education, which may serve to assist professionals in better understanding the experiences of families of children with multiple disabilities. The information provided for this study by mothers of children with multiple disabilities should serve as a reminder to professionals that there is inherent value in listening to the perspectives of families and truly including them as part of teams, in order to learn how they can best support families. In addition, this study serves in some capacity to introduce the terminology specific to the phenomenon of chronic sorrow to families who may be experiencing feelings that they have been unable to identify. The researcher will attempt to reproduce study results in a format which is more accessible to families for this

purpose, for example through publication in journals that families may be more likely to read, like *Exceptional Parent*.

### **Implications for Future Research**

The prevalence of chronic sorrow is something that professionals will likely see rise in parents of children who have multiple disabilities, as the numbers of these children who years ago may not have survived is ever-increasing due to advances in medical technology (Roos, 2009). Research has been scant on the topic of chronic sorrow since its introduction by Simon Olshansky in 1962, but appears to be increasing, especially in the fields of medicine, social work, and psychology. Educators, however, have not been given the term to even ponder and are still being taught that families experience what is essentially characterized as the time-bound model of grieving. The current study is Phase 1 in a line of research that hopes to more closely examine the unique experiences of families of children with multiple and severe disabilities over time. Other studies will include the perspectives of biological fathers, adoptive families, siblings, grandparents, other family members and finally, educators who work with these family members. In addition, it would be important to consider ways in which chronic sorrow as experienced by one family member has an effect on the way in which the family functions, for example, how are marriages affected when one parent experiences chronic sorrow and the other does not. There are also families who are raising children with degenerative conditions who appear, based on this study, to be experiencing feelings that are not defined by chronic sorrow. It would be valuable to the field, in terms of determining best ways to support these families, to understand their perspectives regarding the education

of their children and the ways in which they make meaning of their unique circumstances.

Obviously individual people and families will handle similar life circumstances very differently, and so it is unwise to generalize how families experience their lives after a child has been diagnosed with having disabilities. There are many variables which can affect how families adjust, including cultural backgrounds and family belief systems (Burden & Thomas, 1986), individual personality characteristics, experience with prior losses, and life-long expectations of family life (Roos, 2009). Therefore, future research may also examine more closely these and other contributing factors when looking at the effects of chronic sorrow in families of children who have multiple disabilities.

Future research might also consider the level of readiness in early childhood education settings to include children with multiple disabilities and their families, and examine longitudinally how families' feelings of chronic sorrow may be affected by these early childhood experiences.

Finally, the question was posed to this researcher whether or not chronic grief and chronic sorrow can be mutually exclusive. This is indeed a topic worthy of future research, especially as one considers the complicating factors of chronic sorrow and whether or not the severity of it might determine whether or not assistance of some sort through counseling services might be helpful to families.

## REFERENCES

- Ali, Z., Fazil, Q., Bywaters, P., Wallace, L., & Singh, G. (2001). Disability, ethnicity and childhood: A critical review of research. *Disability & Society, 16*(7), 949-967.
- Americans with Disabilities Act (2008). Definition of the term disability [Section 902.1(b)(A)]. Accessed online at <http://www.eeoc.gov/policy/docs/902cm.html>.
- Anderegg, M. L., & Vergason, G. A., & Smith, M. C. (1992). A visual representation of the grief cycle for us by teachers with families of children with disabilities. *Remedial and Special Education, 13*(2), 17-23.
- Belsky, J., & Barends, N. (2002). Personality and parenting. In M. H. Bornstein (Ed.), *Handbook of Parenting: Being and Becoming a Parent* (2<sup>nd</sup> Ed.) (pp. 415-438). Lawrence Erlbaum Associates Publishers, London, UK.
- Blacher, J. (1984). Sequential stages of parental adjustment to the birth of a child with handicaps. Fact or artifact. *Mental Retardation, 22*, 55-68.
- Brett, J. (2004). The journey to accepting support: How parents of profoundly disabled children experience support in their lives. *Paediatric Nursing, 16*(8), 14-18.
- Bristol, M. M., Gallagher, J. J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. *Developmental Psychology, 24*(3), 441-451.
- Brown, D. R., Ndubuisi, S. C., & Gary, L. E. (1990). Religiosity and psychological distress among Blacks. *Journal of Religion and Health, 29*, 55-68.

- Burden, R., & Thomas, D. (1986). Working with parents of exceptional children: The need for more careful thought and more positive action. *Disability, Handicap, & Society* 1(2), 165-171.
- Burke, M. L. (1989). Chronic sorrow in mothers of school-age children with a myelomeningocele disability (Doctoral dissertation, Boston University, 1989). *Dissertation Abstracts International*, 50, 233-234B.
- Cameron, S. J., Snowdon, A., & Orr, R. R. (1992). Emotions experienced by mothers of children with developmental disabilities. *Children's Health Care*, 21(2), 96-103.
- Cass, H., Price, K., Reilly, S., Wisbeach, A., & McConachie, H. (1998). A model for the assessment and management of children with multiple disabilities. *Child: Care, Health & Development*, 25(3), 191-211.
- Chadwick, O., Beecham, J., Piroth, N., Bernard, S., & Taylor, E. (2002). Respite care for children with severe intellectual disability and their families: Who needs it? Who receives it? *Child and Adolescent Mental Health*, 7(2), 66-72.
- Cooke, T. (1996). The changing epidemiology of cerebral palsy. *Archives of Disease in Childhood*, 75, 169-173.
- Cox, A. H., Marshall, E. S., Mandelco, B., & Olsen, S. F. (2003). Coping responses to daily life stressors of children who have a sibling with a disability. *Journal of Family Nursing*, 9, 397-413.
- Damrosch, S. P., & Perry, L. A. (1989). Self-reported adjustment, chronic sorrow, and coping of parents of children with Down syndrome. *Nursing Research*, 38(1), 25-30.

- Dellve, L., Samuelsson, L., Tallborn, A., Fasth, A., & Hallberg, L. R. (2006). Stress and well-being among parents of children with rare diseases: A prospective intervention study. *Journal of Advanced Nursing*, 53(4), 392-402.
- DeNeve, K. M., & Cooper, H. (1998). The happy personality: A meta-analysis of 137 personality traits and subjective well-being. *Psychological Bulletin*, 124, 197-229.
- Doka, K. J. (1989). Disenfranchised grief. In K. J. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow* (pp.3-12). Lexington, MA: Lexington Books.
- Dyson, L. L. (1993). Response to the presence of a child with disabilities: Parental stress and family functioning over time. *American Journal on Mental Retardation*, 98(2), 207-218.
- Eakes, G., Burke, M. L., & Hainsworth, M. A. (1998). Middle-range theory of chronic sorrow. *Image: Journal of Nursing Scholarship*, 30, 179-186.
- Erickson, D. V., & Lynne, D. R. (2004). Children with chronic continence problems. *Journal of Wound, Ostomy, and Continence Nursing*, 31, 215-222.
- Flaherty, E. M., & Glidden, L. M. (2000). Positive adjustment in parents rearing children with down syndrome. *Early Education & Development*, 11(4), 407-422.
- Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American Psychologist*, 55(6), 647-654.
- Fraleay, A. M. (1990). Chronic sorrow. A parental response. *Journal of Pediatric Nursing*, 5, 268-273.
- Freedman, R. I., Krauss, M. W., & Seltzer, M. M. (1997). Aging parents' residential plans for adult children with mental retardation. *Mental Retardation*, 35, 114-123.

- Friedrich, W. N., Greenberg, M. T., & Crnic, K. (1983). A short form of the Questionnaire on Resources and Stress. *American Journal of Mental Deficiency*, 88, 41-48.
- Gallagher, J. J., Beckman, P., & Cross, A. H. (1983). Families of the handicapped children: Sources of stress and its amelioration. *Exceptional Children*, 50, 10-19.
- Giangreco, M. F., & Cloninger, C., Mueller, P., Yuan, S., & Ashworth, S. (1991). Perspectives of parents whose children have dual sensory impairments. *Journal of the Association for Persons with Severe Handicaps*, 16, 14-24.
- Glidden, L. M. (1993). What we do not know about families with developmentally disabled children: The Questionnaire on Resources and Stress as a case study. *American Journal on Mental Retardation*, 97, 481-495.
- Grant, G., Ramcharan, P., McGrath, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: Towards a refined model of caring and coping. *Journal of Intellectual Disability Research*, 42(1), 58-71.
- Graungaard, A. H., & Skov, L. (2006). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child care, health and development*, 33(3), 296-307.
- Greenberg, J. S., Seltzer, M. M., & Greenley, J. R. (1993). Aging parents of adults with disabilities: The gratifications and frustrations of later-life care-giving. *The Gerontologist*, 33, 542-50.
- Hainsworth, M. A., Eakes, G. G., & Burke, M. L. (1994). Coping with chronic sorrow. *Issues in Mental Health Nursing*, 15(1), 59-66.

- Hamlett, K.W., Pellegrini, D.S., & Katz, K.S. (1992). Childhood chronic illness as a family stressor. *Journal of Pediatric Psychology*, 17(1), 33-47.
- Hartshorne, T. S. (2002). Mistaking courage for denial: Family resilience after the birth of a child with severe disabilities. *The Journal of Individual Psychology*, 58(3), 263-278.
- 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.
- Haveman, M., van Berkum, G., Reijnders, R., & Heller, T. H. (1997). Differences in service needs, time demands, and care-giving burden among parents of persons with mental retardation across the life cycle. *Family Relations*, 46, 417-25.
- Helff, C. M., & Glidden, L. M. (1998). More positive or less negative? Trends in research on adjustment of families rearing children with developmental disabilities. *Mental Retardation*, 36(6), 457-64.
- Hoare, P., Harris, M., Jackson, P., & Kerley, S. (1998). A community survey of children with severe intellectual disability and their families: Psychological adjustment, carer distress and the effect of respite care. *Journal of Intellectual Disability Research*, 42(3), 218-227.
- Ho, K. M., & Keiley, M. K. (2003). Dealing with denial: A systems approach for family professionals working with parents of individuals with multiple disabilities. *The*

- Family Journal: Counseling and Therapy for Couples and Families*, 11(3), 239-247.
- Hobdell, E. (2004). Chronic sorrow and depression in parents of children with neural tube defects. *Journal of Neuroscience Nursing*, 36, 82-88.
- Hodapp, R. M. (2007). Families of persons with Down syndrome: New perspectives, findings, and research and service needs. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 279-287.
- Hodapp, R. M., Ly, T. M., Fidler, D. J. & Ricci, L. A. (2001). Less stress, more rewarding: Parenting children with Down syndrome. *Parenting: Science and Practice*, 1, 317-337.
- Hughes, R. S. (1999). An investigation of coping skills of parents of children with disabilities: Implications for service providers. *Education and Training in Mental Retardation and Developmental Disabilities*, 34(3), 271-80.
- Ievers, C. E., & Drotar, D. (1996). Family and parental functioning in cystic fibrosis. *Journal of Developmental and Behavioral Pediatrics*, 17(1), 48-55.
- Itkonen, T. (2007). Politics of passion: Collective action from pain and loss. *American Journal of Education*, 113, 577-604.
- Jackson, A. C., Tsantefski, M., Goodman, H., Johnson, B., & Rosenfeld, J. (2003). The psychosocial impacts on families of low-incidence, complex conditions in children: The case of craniopharyngioma. *Social Work in Health Care*, 38(1), 81-107.

- Jarzab, A. (2004). Attack it with humor and make it as wonderful as you can. *Exceptional Parent*, 34(4), 38-40.
- Johnsonius, J. (1996). Lived experiences that reflect embodied themes of chronic sorrow: A phenomenological pilot study. *Journal of Nursing Science*, 1, 165-173.
- Jones, D. W. (2004). Families and serious mental illness: Working with loss and ambivalence. *British Journal of Social Work*, 34(7), 961-979.
- Kasari, C., & Freeman, S. F. N. (2001). Task related social behavior in children with Down syndrome. *American Journal of Mental Retardation*, 106, 253-264.
- Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with a developmental disability. *Journal of Advanced Nursing*, 34, 582-592.
- Kensit, D. A. (2000). Rogerian theory: A critique of the effectiveness of pure client-centred-therapy. *Counselling Psychology Quarterly*, 13(4), 345-342.
- Kerr, S. & McIntosh, J. (2000). Coping when a child has a disability: Exploring the impact of parent-to-parent support. *Child: Care, Health & Development*, 26, 309–21.
- Klass, D. (1988). *Parental grief*. New York: Springer.
- Kubler-Ross, E. (1969). *On Death and Dying*. London: Tavistock.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.
- Land, G. H. (1998). Reconstructing motherhood in the age of “perfect” babies: Mothers of infants and toddlers with disabilities. *Journal of Women in Culture and Society*, 24(1), 69-99.

- Langridge, P. (2002). Reduction of chronic sorrow: A health promotion role for children's community nurses? *Journal of Child Health Care, 6*, 157-170.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York: Springer.
- Lloyd, C. M., & Rosman, E. (2005). Exploring mental health outcomes for low-income mothers of children with special needs: Implications for policy and practice. *Infants & Young Children, 18*(3), 186-199.
- Luescher, J. L., Dede, D. E., Gitten, J. C., Fennell, E., & Maria, B. L. (1999). Parental burden, coping, and family functioning in primary caregivers of children with Joubert syndrome. *Journal of Child Neurology, 14*(10), 642-8, 669-72.
- Mallow, G. E., & Bechtel, G. A. (1990). Chronic sorrow: The experience of parents with children who are developmentally disabled. *Journal of Psychosocial Nursing and Mental Health Services, 37*(7), 31-35.
- Mandell, D. S., & Salzer, M. S. (2007). Who joins support groups among parents of children with autism? *Autism, 11*(2), 111-122.
- Marshak, L., & Seligman, M. (1993). *Counseling persons with physical disabilities: Theoretical and clinical perspectives*. Austin, TX: Pro-Ed.
- McConkey, R., Truesdale, M., & Conliffe, C. (2004). The features of short-break residential services valued by families who have children with multiple disabilities. *Journal of Social Work, 4*(1), 61-75.
- McCubbin, H. I., Thompson, A. I., & McCubbin, M. A. (1996). Resiliency in families: A conceptual model of family adjustment and adaptation in response to stress and

- crisis. In H. I. McCubbin, A. I. Thompson, & M. A. McCubbin (Eds.), *Family Assessment: Resiliency, Coping, and Adaptation – Inventories for Research and Practice* (1<sup>st</sup> ed.) (pp. 1-64). University of Wisconsin Publishers, Madison, Wisconsin.
- Melnyk, B. M., & Feinstein, N. F. (2001). Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatric Nursing*, 27(6), 548-558.
- Mussatto, K. (2006). Adaptation of the child and family to life with a chronic illness. *Cardiology in the Young*, 16 (Suppl. 3), 110-116.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 43, 190-192.
- Patterson, J. M., & Garwick, A. W. (1994). Levels of meaning in family stress theory. *Family Process*, 33, 287-304.
- Petry, K., Maes, B., Vlaskamp, C. (2004). Domains of quality of life of people with profound multiple disabilities: The perspectives of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities*, 18, 35-46.
- Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research*, 51(2), 109-124.
- Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life: A qualitative Inquiry. *Mental Retardation*, 41(3), 313-328.

- Powell, T. H., & Gallagher, P. A. (1993). *Brothers and Sisters: A Special Part of Exceptional Families* (2<sup>nd</sup> ed.). Baltimore: Paul H. Brookes.
- Quine, L., & Pahl, J. (1986) First diagnosis of severe handicap: A study of parental reactions. *Developmental Medical Child Neurology*, 29, 232-242.
- Read, J. (2001). There never was really any choice: The experience of mothers of disabled children in the U.K. *Womens' Studies International Forum*, 14(6), 561-571.
- Retzlaff, R. (2007). Families of children with Rett syndrome: Stories of coherence and resilience. *Families, Systems, & Health*, 25(3), 246-262.
- Risdal, D., & Singer, G. H. S. (2004). Marital adjustment in parents of children with disabilities: A historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities*, 29(2), 95-103.
- Rieger, A. (2004). Explorations of the functions of humor and other types of fun among families of children with disabilities. *Research & Practice for Persons with Severe Disabilities*, 29(3), 194-209.
- Risdal, D., & Singer, G. H. S. (2004). Marital adjustment in parents of children with disabilities: A historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities*, 29(2), 95-103.
- Robinson, C., & Stalker, K. (1993). Patterns of provision of respite care and the Children Act. *British Journal of Social Work*, 23, 45-63.
- Rodriguez, D., Smith-Canter, L. L., & Voytecki, K. S. (2007). Freedom from social isolation for young students with disabilities. *Childhood Education*, 83(5), 316-320.

- Rolland, J. S. (1994). *Families, illness & disability*. New York: Basic Books.
- Rolland, J. S. (2004). Helping families with anticipatory loss and terminal illness. In F. Walsh & M. McGoldrick (Eds.), *Living beyond loss: Death in the family* (2<sup>nd</sup> ed.) (p 213-236).
- Rolland, J. S. (2006). Living with anticipatory loss in the new era of genetics: A life cycle perspective. In S. M. Miller, S. H. McDaniel, Rolland, J. S., & S. L. Feetham (Eds.), *Individuals, families, and the new era of genetics: Biopsychosocial perspectives* (p. 139-172). New York: W. W. Norton.
- Rogers-Dulan, J. (1998). Religious Connectedness Among Urban African American Families Who Have A Child With Disabilities. *Mental Retardation*, 36(2), 91-103.
- Roos, S. (2002). *Chronic Sorrow: A Living Loss*. New York: Brunner-Routledge.
- Roos, S. (2009, in press). Chronic sorrow. In C. D. Bryand & D. L. Peck (Eds.), *Encyclopedia of death and the human experience*. Thousand Oaks, CA: Sage Publications.
- Scorgie, K. (1998). Transformational outcomes associated with parenting children with disabilities. *Ethics and Intellectual Disability*, 3, 4-6.
- Scorgie, K., Wilgosh, L., & McDonald, L. (1996). A qualitative study of managing life when a child has a disability. *Developmental Disabilities Bulletin*, 24, 68-90.
- 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.

- Scorgie, K., Wilgosh, L., & McDonald, L. (1999). Transforming partnerships: Parent life management issues when a child has mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities, 34*(4), 395-405.
- Scornaienchi, J. M. (2003). Chronic sorrow: One mother's experience with two children with lissencephaly. *Journal of Pediatric Health Care, 17*, 290-294.
- Seligman, M., & Darling, R. (1997). *Ordinary families, special children: A systems approach to childhood disability*. New York: Guilford Press.
- Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation, 106*(3), 265-286.
- Seltzer, M. M., & Heller, T. (1997). Families and care-giving across the life course: Research advances on the influence of context. *Family Relations, 46*, 395-405.
- Shultz, R., & Quittner, A. L. (1998). Care-giving for children and adults with chronic conditions: Introduction to the special issue. *Health Psychology, 17*, 107-111.
- Solnit, A. J., & Stark, M. H. (1961). Mourning and the birth of a defective child. *The Psychoanalytic Study of the Child, 16*, 523-537.
- Stainton, T., & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. *Journal of Intellectual & Developmental Disability, 23*, 57-70.
- Stein, R. E., & Reissman, C. K. (1980). The development of an Impact-on-Family scale. *Medical Care, 18*(4), 465-472.

- Tannila, A., Kokkonen, J., & Jaervelin, M. R. (1996). The long-term effects of children's early-onset disability on marital relationships. *Developmental Medicine & Child Neurology*, 38(7), 567-577.
- Teel, C. S. (1991). Chronic sorrow: Analysis of the concept. *Journal of Advanced Nursing*, 16, 1311-1319.
- Trapp, A. (1994). Support for the family. In A. Goldman (Ed.), *Care of the Dying Child*. Oxford University Press.
- Treneman, M., Corkery, A., Dowdney, L., & Hammond, J. (1997). Respite-care needs – met and unmet: Assessment of needs for children with disability. *Developmental Medicine and Child Neurology*, 39, 548-553.
- Turnbull, A. P., Blue-Banning, M., Behr, S., & Kerns, G. (1986). Family research and intervention: A value and ethical examination. In P. R. Dokecki & R. M. Zaner (Eds.), *Ethics of dealing with persons with severe handicaps: Toward a research agenda* (pp. 119-140). Baltimore: Brookes.
- Turnbull, H. R., Guess, D., & Turnbull, A. P. (1988). Vox populi and Baby Doe. *Mental Retardation*, 26, 127-32.
- Turnbull, A. P., Patterson, J. M., Behr, S., Murphy, D. L., Marquis, J. G., & Blue-Banning, M. J. (1993). *Cognitive coping, families, and disability*. Baltimore: Brookes.
- Turnbull, A. P., Turnbull, R., Erwin, E., & Soodak, L. (2005). *Families, professionals, and exceptionalities: Positive outcomes through partnerships and trust*, (5<sup>th</sup> ed.). Upper Saddle River, NJ: Prentice Hall.

- 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, & Development*, 34(5), 665-674.
- Vermaes, I. P. R., Janssens, J. M. A. M., Bosman, A. M. T., & Gerris, J. R. M. (2005). Parents' psychological adjustment in families of children with spina bifida: A meta-analysis. *BMC Pediatrics*, 32, 1-13.
- Vondra, J., Sysko, H. B., & Belsky, J. (2005). Developmental origins of parenting: Personality and relationship factors. In T. Luster & L. Okagaki (Eds.), *Parenting: An Ecological Perspective* (2<sup>nd</sup> ed.) (pp. 35-71). London: Lawrence Erlbaum.
- 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 & Practice for Persons with Severe Disabilities*, 29(2), 144-155.
- Warda, M. (1992). The family and chronic sorrow: Role theory approach. *Journal of Pediatric Nursing*, 7(3), 205-210.
- Welman, J. C., & Kruger, S. J. (1999). *Research methodology for the business and administrative sciences*. Johannesburg, South Africa: International Thompson.
- Wikler, L. (1986). Periodic stresses of families of older mentally retarded children: An exploratory study. *American Journal of Mental Deficiency*, 90, 703-706.
- Wikler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parent vs. professional depiction of the adjustment of parents of mentally retarded children. *American Journal of Orthopsychiatry*, 51(1), 63-70.

- Wolfensberger, W. (1967). Counseling the parents of the retarded. In B. A. Baumeister (Ed.), *Mental Retardation: Appraisal, Education, and Rehabilitation* (pp. 329-400). Chicago: Aldine.
- Yau, M. K., & Li-Tsang, C. W. P. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes. *British Journal of Developmental Disabilities*, 88, 38-51.
- Zeitlin, S., Williamson, G. G., & Rosenblatt, W. P. (1987). The coping with stress model: A counseling approach for families with a handicapped child. *Journal of Counseling and Development*, 65, 443-446.

## APPENDIX A

### INVITATION SCRIPT

(To be used by the Assistant Director of the Exceptional Children's Assistance Center for invitation to mothers to share their name and contact information with the researcher)

“Rosalie Parrish, a mother of a child who has multiple disabilities, is seeking permission to contact other mothers about the possibility of participating in a research study she is conducting to fulfill the requirement of a doctoral degree in Special Education. I am helping her to identify mothers to assist her with her research. She is interested in interviewing mothers to learn about their experiences raising children who have multiple disabilities.

Rosalie has to keep her current study very narrow and so is only looking to interview biological mothers who are Caucasian and English-speaking. The children should have multiple disabilities (meaning children with intellectual disabilities *and* physical disabilities or special healthcare needs that significantly affect at least one major life function), be of school-age (7 to 21 years of age) and be at least two years post-diagnosis. Rosalie plans to do more research in the future with fathers, adoptive/foster parents, siblings, and other full-time care providers as well as those who represent other ethnicities and cultural backgrounds.

Do you think you would be interested in letting her contact you about the possibility of participating in this study? No one at the Exceptional Children's Assistance Center will know whether you decide to participate and your decision as to whether to let Rosalie call you will not affect your relationship with The Arc or your services in any way. The Arc is not affiliated with this project, but has agreed to assist in inviting people to participate. [IF INTERESTED]...

Okay, I'm going to give your name and number to her and she'll call you within a week. When she calls, you can ask her whatever questions you want to ask her about the project, and if you decide then that you do not want to do it, that's completely fine. If you decide to do the interview, you and she can set up the date/time that works best for you, and she'll give you her contact information then, too.”

APPENDIX B

**RECRUITMENT / INITIAL CONTACT SCRIPT**

Study #: 09-0388

(To be used by Researcher 1 during first telephone contact with potential participants)

Hello. My name is Rosalie Parrish, and I am calling from the University of North Carolina Greensboro where I am currently a doctoral student. I was given your name and phone number by a staff member at Exceptional Children's Assistance Center (ECAC). This person mentioned that they spoke to you about your possible interest in a research project addressing mothers' experiences raising children with multiple disabilities. Are you still interested in hearing more about this project?

**[If no: Thank you for your time.]**

**[If yes, proceed as follows:]**

Thank you for your interest. Before you decide to participate, I will tell you a little bit about myself, the project and the expectations there would be for your participation. But first, may I ask you a few questions to verify that you meet the criteria for participation in the study?

Are you your child's biological mother? YES NO

Do you have a child with multiple disabilities? YES NO

What are your child's disabilities? \_\_\_\_\_

How old is your child? \_\_\_\_\_

Has it been at least 2 years since your child was diagnosed with these disabilities? YES  
NO

I realize this is rather personal, but I need to ask: Do you have a history of mental illness or a diagnosis of clinical depression? YES NO

**[If YES to #7, participants cannot be included in the study. Say: "Thank you for your interest in the study and for your time. Unfortunately, you do not meet the criteria for this study."]**

**[If NO to #7, continue with the following...]**

I have just a few more questions to ask to determine eligibility. These questions might feel sensitive and I want to remind you that you do not need to answer them if you are not comfortable.

Okay, now I would like to ask you several questions about some of the thoughts and feelings you have experienced as the mother of a child with multiple disabilities.

1. What were some of the feelings you had when you first learned that your child was diagnosed with a disability? (What went through your mind?)
2. Thinking back to how you reacted at first to the news of \_\_\_\_\_'s disability, has there been a time since then when something happened and you had those same feelings of \_\_\_\_\_ (use mother's words in her response to #1) all over again?
3. Were other people aware that you were having these feelings? (If yes, how did they know?)
4. What feelings do you have right now when you think about his/her disability?
5. Do you ever perceive the circumstances related to the disabilities as a loss? Why or why not? Explain.

**[If they DO NOT indicate recurring feelings of grief (shock, sadness, fear, anger, anxiety etc.) and if they DO NOT indicate that they perceive the circumstances as a loss, they do not fit the criteria. Say: "Thank you for your interest in the study and for your time. Unfortunately, you do not meet the criteria for this study."]**

**[If they DO indicate recurring feelings of grief (shock, sadness, fear, anger, anxiety etc.) or if they indicate that they DO perceive the circumstances as a loss, they fit the criteria associated with chronic sorrow, and you should go on and explain the rest of the study as follows to see if they are willing to participate.]**

Okay, thank you so much for answering those questions. I also want to answer any questions you have about the project. You may have been told from someone at ECAC that this research project is my doctoral dissertation. They may have also told you that I, too, am a parent of a child with multiple disabilities, thus I have an obvious interest in this area of study and I want to make sure that families' voices are heard and reflected in the professional research. That is why I am calling you.

The purpose of this project is to learn more about the experiences of mothers of children with multiple disabilities (which I am defining as intellectual delays or disabilities *with* physical disabilities or special health care needs that significantly affect at least one major life function). For this study, I am only looking at the experiences of mothers of school-age children with multiple disabilities who are at least 2 years post-diagnosis, and mothers who are 18 years of age and older and who are English-speaking. I do plan to do future research with other populations such as fathers, siblings, and foster or adoptive families as well as families who may speak other languages.

If you agree to volunteer for this study you would participate in two audiotaped interviews, each lasting approximately 1-2 hours and spaced approximately 1 week apart. These interviews would take place in your home or wherever you would feel more

comfortable. You would be asked questions regarding your beliefs about life before and after your child's diagnosis, your experiences raising a child with multiple disabilities and how you feel these experiences have affected your life and your family's life. After each interview, a transcriptionist will transcribe the audiotapes, and a summary of the interviews will be written by me and provided to you for you to review to assure accuracy. You would be paid \$25.00 for each interview in the form of a \$50 gift card upon the completion of review of the second interview. If you are unable to remain in the study or choose to withdraw your participation after the first interview, you would still be paid \$25.00 for your participation in the first interview.

I also want to assure you of confidentiality. If you agree to participate in the study, I will create a file that has your name and a random number that I will assign to you. I will use that number to label digital audio recordings and transcripts as well as any other information for data collecting, so your name will not appear on any data, and the file linking your name to the number will remain on my computer under password protection. Only a hired transcriptionist will hear your voice on the digital audio file and this person has signed a confidentiality agreement, a copy of which will be provided to you if you agree to participate. After the interviews have been transcribed, the digital audio recordings and transcripts will remain on a password protected computer. All other data, such as typewritten transcripts and consent forms will remain in a locked file cabinet in my supervisor's office for 3 years after from the ending date of the study. After three years, all electronic data relevant to this study will be permanently deleted and paper transcripts and consent forms will be destroyed by shredding. All information obtained in this study is strictly confidential unless disclosure is required by law.

Finally, I want to share with you the risks and benefits to you if you choose to participate in this study. Because the topic we will be discussing may cause you to feel sadness, I want to provide you with the name and number of an agency you could contact to help you address any mental health needs that may arise including feelings of depression or anxiety 1-800-233-6834. If you have a history of mental illness or have been diagnosed with clinical depression you should not participate in this study. Overall, your participation should pose minimal risk to you. In fact, many parents who participate in studies in which they are asked to share their experiences in raising children with disabilities indicate that talking about their child and their feelings is therapeutic for them. If at any time during the study you wish to withdraw your participation, you may do so just by letting me know. Any information you have provided up to that point will be destroyed and not used in the study.

Do you think you would like to participate in this research study?

**[If no: Okay, I understand. Thank you for your time.]**

**[If yes, proceed as follows:]**

Great! Let me verify some information before we set up the first interview.

Okay, thank you! Now let's set up a time for the interview on a day and time that is convenient for you.

**[AGREE TO MEETING DATE, TIME, LOCATION.]**

I'm looking forward to meeting you! See you then! Good-bye.

## APPENDIX C

### DEMOGRAPHIC SURVEY

1. What was your age on your last birthday? \_\_\_\_
2. What is the highest grade you completed in school or college? \_\_\_\_\_
3. What is your religious/spiritual preference? \_\_\_\_\_
4. Are you employed outside your home? \_\_\_\_\_
5. What type of job do you have? \_\_\_\_\_\*
6. In what range is your annual family income? \*  
Less than \$10,000 \$10-20,000 \$21-35,000 \$36-50,000 \$50-75,000  
\$75,000 or higher
7. What is your present marital status?  
Single Married Widowed Separated Divorced In a Relationship
8. How many children do you have, including \_\_\_\_\_? \_\_\_\_\_
9. What birth position does \_\_\_\_\_ have in the family?  
Youngest Middle Oldest
10. Does anyone besides your husband or significant other and children live in the household? \_\_\_\_\_
11. How many times does \_\_\_\_\_ visit a doctor or clinic each year, on an average? \_\_\_\_\_
12. How many times has \_\_\_\_\_ been hospitalized since he/she was discharged after birth? \_\_\_\_\_
13. Does \_\_\_\_\_ attend school?
  - a. What type of school program is he/she enrolled in:
    - i. Regular public school class
    - ii. Public school, special class
    - iii. Regular private school class
    - iv. Special school \_\_\_\_\_
  - b. What grade is \_\_\_\_\_ in at the present time?
14. Does his/her disability include a communication disorder? \* YES NO
15. Does he/she have: \*
  - a. Bladder control? YES NO SOMETIMES
  - b. Bowel control? YES NO SOMETIMES
16. How does \_\_\_\_\_ move about? Does he/she:
  - a. Walk unaided?
  - b. Walk with braces?
  - c. Walk with crutches?
  - d. Walk with a walker?
  - e. Use a wheelchair?

Thank you very much for taking the time to answer these questions. I really appreciate your participation in this study.

## APPENDIX D

### INTERVIEW #1A

ID Number: \_\_\_\_\_

I would like to ask you some questions about some of the thoughts and feelings you have related to your experience as the mother of a child who has multiple disabilities. I am interested in what you have to say because I think it is important for educators to become more knowledgeable about mothers individual and collective experiences.

1. How did you first learn about your child's disabilities?
  - a. What types of feelings did you have when you first learned about it? (What went through your mind?)
  - b. What was most helpful to you in adjusting to the news about his/her condition?
  - c. Was there anything in particular that happened that was not helpful (If yes, please give me an example.)
  
2. Thinking back to how you reacted at first to the news of \_\_\_\_\_  
\_\_\_\_\_ 's disability, has there been a time since then when something happened and you had those same feelings of \_\_\_\_\_  
(use mother's words in her response to #1) all over again?
  - a. Please tell me about one time when you felt this way. (What were the circumstances? Describe your feelings?)
  - b. Did it seem to you that other people aware that you were having these feelings? (If yes, how do you think they knew?)
  - c. When you were experiencing those feelings, what was most helpful to you?
  - d. What was least helpful? In what way?
  
3. Do you participate in family support groups? Why or why not?
  - a. If no, why not?
  - b. If yes, is it online or in-person? How long? Is it specific to your child's disability? In what ways has the support group been helpful?

Adapted from Burke's (1989) Chronic Sorrow Questionnaire and Roos (2009) model of chronic sorrow.

## APPENDIX E

### INTERVIEW #1B

As we come to a close, I'd like for you to take a minute to read this description of a term I have come across.

**Give the 3 x 5 note card with the chronic sorrow description to the participant. The note card reads:**

Chronic sorrow is a term used to describe the feelings some people have when they are living with unending losses, usually specific to life with a disability. The feelings of chronic sorrow are usually brought upon by specific trigger events experienced in daily life. Chronic sorrow is a normal response and contains the elements of both sorrow and joy. Chronic sorrow does not typically affect a person's ability to function effectively in normal daily routines. Chronic sorrow is also reportedly related to the fact that feelings of grief are not validated because a person does not appear to have sustained a real loss as with the death of a loved one.

**After the participant has had a few minutes to read it and think it over, ask the following:**

Is there any part of what you have just read that you would like for me to clarify?  
Based on what you have just read, what are your thoughts about this definition of the phenomenon of chronic sorrow?

## APPENDIX F

### INTERVIEW #2

ID Number: \_\_\_\_\_

1. The last time that we met, I gave you a card with a definition on it. Have you had time to think about that definition?

**[The interviewer should have a copy of the card with the following definition:** *“Chronic sorrow is a term used to describe the feelings some people have when they are living with unending losses, usually specific to life with a disability. The feelings of chronic sorrow are usually brought upon by specific trigger events experienced in daily life. Chronic sorrow is a normal response and contains the elements of both sorrow and joy. Chronic sorrow does not typically affect a person’s ability to function effectively in normal daily routines. Chronic sorrow is also reportedly related to the fact that feelings of grief are not validated because a person does not appear to have sustained a real loss as with the death of a loved one.”*]

2. What does the term “chronic sorrow” mean to you?
  - a. How does the term reflect or not reflect your own life experiences?
3. How do you feel about the term “unending loss?”
  - a. Another term that has been used to mean the same thing is “living loss.” How do you feel about the term “living loss?”
4. How do you feel about the term “trigger events?”
  - a. Describe any experiences you may have had that you might define as “trigger events.”
5. How do you feel about the description of chronic sorrow having both elements of sorrow and joy?
  - a. Describe any experiences of the feelings of joy that you may have had as the mother of a child who has multiple disabilities.
  - b. How do you feel this is, or is not, in balance with any feelings of sorrow you may have experienced?
6. How do you feel about the description of chronic sorrow as not affecting a person’s ability to function effectively in normal daily routines?
  - a. Describe how you function in normal daily routines?

- b. Do you ever feel incapacitated with feelings of sorrow? Explain.
  - c. What kinds of coping strategies do you feel work best for you in stressful situations?
- 7. How do you feel about the description related to feelings of grief not being validated?
  - a. Describe some experiences you might have had in which you felt your grief was not validated or was misunderstood? How has that made you feel?
- 8. What would you tell a new mother of a child with disabilities that she can expect in terms of her own feelings?
- 9. What would you tell professionals about how they can be helpful to mothers of children who have multiple disabilities?

Adapted from Burke's (1989) Chronic Sorrow Questionnaire and Roos (2009) model of chronic sorrow.

## APPENDIX G

### CONSENT TO ACT AS A HUMAN PARTICIPANT: LONG FORM

Project Title: Mothers' Experiences Raising a Child with Multiple Disabilities

Project Director: Rosalie N. Parrish

University of North Carolina at Greensboro

rnarris@uncg.edu, (919) 599-9267 or (919) 732-8762

Participant's Name: \_\_\_\_\_

#### **What is the study about?**

The purpose of this research project is to learn about the experiences of mothers of children with multiple disabilities (physical disabilities *with* intellectual disabilities). This information will be obtained through interviews of mothers.

#### **Why are you asking me?**

You have been chosen to participate in this study because you are a biological mother of a child with multiple disabilities who is of school-age and who is at least two years post-diagnosis. In addition, you have been chosen because you are 18-years of age or older and English-speaking. Since the study of mothers' perspectives raising school-age children with multiple disabilities is limited in the field, your feedback will be very valuable. I am currently limiting my study to biological mothers, but I do hope to do future research on this topic with a more diverse group, including fathers, adoptive/foster parents, siblings and other full-time care providers representing extended family and different languages.

#### **What will you ask me to do if I agree to be in the study?**

If you agree to participate in the study, you will be asked to participate in two interviews approximately one week apart, each lasting approximately 2 hours. The interviews will take place at a time and place of your convenience, but should be in a place which is quiet and free of distractions. Questions will be asked regarding your experiences raising a child with multiple disabilities and how you feel these experiences have affected your life and your family. The interviews will be audiotaped and transcribed. You will be asked to review a typed summary of each of the interviews to assure accuracy. You will be paid \$25.00 for each interview in the form of a \$50 gift card upon the completion of review of the second interview. If you are unable to complete the second interview or withdraw from the study before the second interview, you will still be paid \$25.00 for the first interview.

**What are the dangers to me?**

If you have a self-history of mental illness or have been diagnosed with clinical depression you should not participate in this study. Though parents who are given the opportunities to discuss their experiences raising children with disabilities typically report an enhanced overall outlook, including experiences of joy, you may also experience sadness while talking about your experiences raising a child with multiple disabilities. If you feel you are becoming depressed and you feel like you need mental health services at any time during or after your participation in this study, please call 1-800-233-6834.

Overall, participation in this study should pose minimal risk to the study participants.

If you have any concerns about your rights or how you are being treated please contact Eric Allen in the Office of Research and Compliance at UNCG at (336) 256-1482.

Questions, concerns or complaints about this project or benefits or risks associated with being in this study can be answered by Judith Niemeyer at 336-334-3447 or Rosalie Parrish who may be contacted at 919-599-9267 or rnparris@uncg.edu.

**Are there any benefits to me for taking part in this research study?**

Parents who participate in studies in which they get to share their experiences in raising children with disabilities typically indicate that the experience is therapeutic for them, partly because there are few people who they can talk to, especially people who truly understand what they are feeling.

**Are there any benefits to society as a result of me taking part in this research?**

There is limited research available on mothers' experiences of raising school-age children with multiple disabilities. Your participation in this research study will provide professionals (e.g., teachers, administrators, medical providers, community service providers) with firsthand knowledge about mothers' experiences and help them learn what they can do to make a profound difference in the lives of families of children with multiple disabilities.

**How will you keep my information confidential?**

Because the interviews will be audiotaped, your voice will be potentially identifiable by anyone who hears the tapes. Your confidentiality for things you say on the tape cannot be guaranteed although the researcher will try to limit access to the tape. The researcher, a hired transcriptionist, and the faculty supervisor will be the only ones with access to these tapes.

Random numbers will be assigned to individual names and these numbers will be used to identify all data (including audiotape labels and computer filenames for transcripts).

However, a file will exist which links your name to this random number. This and all other files will be stored on the researcher's computer under password protection.

Audiotapes will be stored digitally on a password protected computer. All information obtained in this study is strictly confidential unless disclosure is required by law. All data

and signed consent forms will be stored for a period of 3 years from the ending date of the study in a locked storage cabinet located in the office of the researcher's faculty supervisor and only she and the student researcher will have access to it. Three years after the end of the study, all interview data in paper form and signed consent forms will be shredded and electronic data will be permanently deleted.

**What if I want to leave the study?**

You have the right to refuse to participate or to withdraw at any time, without penalty. If you do withdraw, it will not affect you in any way. If you choose to withdraw, you may request that any of your data which has been collected be destroyed unless it is in a de-identifiable state.

**What about new information/changes in the study?**

If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you.

**Voluntary Consent by Participant:**

By signing this consent form you are agreeing that you read, or it has been read to you, and you fully understand the contents of this document and are openly willing consent to take part in this study. All of your questions concerning this study have been answered. By signing this form, you are agreeing that you are 18 years of age or older and are agreeing to participate, or have the individual specified above as a participant participate, in this study described to you by Rosalie Parrish.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_