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Abstract

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Keywords

Resolution, Non-Resolution, Down Syndrome, Autism, Cognitive Intervention, Qualitative Study, Grounded Theory, and Reaction to Diagnosis Interview

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A Qualitative Examination of Mothers' Resolution or Non-Resolution of Their Children's Disability of Down Syndrome or Autism Using a Cognitive Intervention

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Research has shown that the inability of some mothers to resolve their emotions when confronted with the birth of a child with a disability of cerebral palsy or epilepsy can put the child at greater risk for disruptions of attachment. This qualitative study examined mothers' emotional state of resolution or non-resolution of their children's disability of Down syndrome or autism, and mothers' perceptions of the use of a cognitive intervention. Grounded theory was used to analyze the interviews and the cognitive intervention. The results showed that in addition to the two major categories of resolution and non-resolution, a third major category called "resolving" emerged from the data. New subcategories were discovered, and parts of the cognitive intervention were helpful. Key Word: Resolution, Non-Resolution, Down Syndrome, Autism, Cognitive Intervention, Qualitative Study, Grounded Theory, and Reaction to Diagnosis Interview

Introduction

The birth of a child is normally viewed with eager anticipation. As parents make preparations for the birth of their child, they may wonder not only about the gender of their child, their child's eye color, or appearance, but they may hold expectations for who this child will become in the future. When a child is born with no complications or disabilities, this process seems to evolve naturally. However, when there are prenatal or perinatal complications, or post natal discoveries of developmental disabilities, the idealized picture of having a normal child is shattered. According to Turnbull and Turnbull (2001), parents of children with disabilities may experience a grief cycle that is similar to that of the death of a loved one (Kubler-Ross, 1969).

While this grief process includes shock, denial, guilt, anger, shame, and depression, it is important to note that the sequence of these processes may not be linear in nature or complete within each stage. These differences are due to individual and family members' coping mechanisms, cultural differences, time of diagnosis, and the manner in which they were told by professionals about their child's disability (Cook, Tessier, & Klein, 1996; Turnbull & Turnbull, 2001). Professionals working in the field of developmental disabilities have firsthand knowledge of parents' reactions to their child's diagnosis of a disability, and there are many stories regarding how a parent discovers that his/her child has a disability. Take for example the young mother who gives birth to a baby with Down syndrome (DS) in the delivery room; instead of this being a joyous

occasion, the room is filled with anxious avoiding faces. Imagine her confusion and feelings of abandonment when the physician, because of his/her own inability to cope with the diagnosis of delivering a "less than perfect baby," abruptly leaves the delivery room and the nurse ends up having to inform the parents about their child's disability. What about the mother of a baby with Noonan syndrome sitting in a support group, recalling painful stories of rejection by family members, unable to cope with the diagnosis of her child with a disability? There is also the family who realizes that their baby is not developing normally and takes their child to be examined by the neurologist to try to determine the cause of their child's developmental delays. The physician callously tells the parents that their child has cerebral palsy (CP) and not to expect the child to be able to walk or have a normal life.

These personal stories have led professionals to research mothers' abilities to accept their children's diagnoses and form strong mother-child attachments necessary for normal healthy development. Recent research has demonstrated that mothers of children with CP and epilepsy who have a difficult time accepting their child's diagnosis also have problems with their relationships with these children (Barnett et al., 1999; Knight, 2001; Marvin & Pianta, 1996; Pianta, Marvin, & Morog, 1999).

It is the intent of this paper to further examine mothers' reactions to their children's diagnosis, in different disability groups. First, I have examined the emotional reactions that mothers of children with Down syndrome (DS) and autism have with regard to their child's diagnosis. Secondly, I have developed a six-week intervention to assist mothers coping with their child's diagnosis of DS or autism. I have studied the mothers' experience of that intervention and have explored what they found to be most helpful to them. It is hoped that the information gleaned from this study will assist professionals in the field of special education or psychology who are working with families of individuals diagnosed with a developmental disability such as DS or autism.

Literature Review

Reaction to Diagnosis Interview

Pianta and Marvin (1992) developed the Reaction to Diagnosis Interview (RDI) and the Reaction to Diagnosis Classification System (RTDCS) (Pianta & Marvin, 1993) to measure and classify mothers of children with cerebral palsy into categories of unresolved or resolved with respect to the trauma of their child's diagnosis. I contacted Robert Pianta at the University of Virginia, and he was willing to share his training materials and videos for use in this study. The RDI was "based on the Adult Attachment Interview (George, Kaplan, & Main, 1985), in which parents' mental representations of relationships are assessed through probes for feelings and memories of certain relationship experiences" (Pianta, Marvin, Britner, & Borowitz, 1996, p. 246). The RDI is a qualitative interview made up of five open-ended questions that probe for feelings and beliefs about the diagnosis process, the child's condition, and parents' reactions (Pianta & Marvin, 1992). The RDI is videotaped and coded based on the RTDCS classification system of resolved and unresolved: They found three subcategories of resolved and six subcategories of unresolved (Pianta & Marvin, 1993).

Definitions of Resolution and Non-Resolution

Before reviewing the literature, on mothers' reactions to their children's diagnosis of a disability, it is helpful to understand what is meant by the terms "resolution" and "non-resolution". These definitions are used in this study to help categorize the mothers' reactions to their children's diagnosis of DS or autism. Pianta and Marvin (1993) define resolution as

...a focus on the present, and acceptance of the child's condition and reality and limitations placed on the child, a forward looking orientation to the child's condition, accurate representations of the child and the experiences of the diagnosis, no effort to bring the past into the room or to bring the interviewer into the emotional worlds of the parent, and some acknowledgement that there has been change since the period of diagnosis. (p. 9)

Pianta et al. (1996) define unresolved or non-resolution as a state that includes parental

...cognitive distortions, an active search for reasons why the experience occurred, unbalanced perceptions of the impact on the self (denial or victimization), and selective attention on past experience to the neglect of present reality. Also included are individuals whose interviews are marked by confusion and mental disorganization with respect to their discussion of the diagnostic experience. (p. 247)

Mother's Reaction to Child's Diagnosis

Pianta et al. (1996) did a study of 91 mothers of children with either cerebral palsy (CP) or epilepsy ranging in age from 15-50 months. The Reaction to Diagnosis Interview (RDI) was administered and found that half of the mothers were classified as unresolved. Marvin and Pianta (1996) did a validity study of the RDI using the Strange Situation or modified Strange Situation with 70 mothers of infants and preschoolers who had a diagnosis of CP. The Strange Situation was developed by Ainsworth, Blehar, Waters, and Wall (1978) and studied the quality of attachment between a mother and an infant in the laboratory. The Strange Situation was made up of a series of eight episodes in which the researchers observed infants' separation and reunion behavior in an unfamiliar playroom (Ainsworth, 1983). Three types of attachment were found: securely attached (Type B), insecure/resistant (Type C), and insecure/avoidant (Type A) (Ainsworth & Bowlby, 1991). In their study, Marvin and Pianta (1996) combined both the insecure/resistant (Type C) and the insecure/avoidant (Type A) into a single category of "insecure" as a basis of comparison. They found a significant relation between the RDI status and the Strange Situation attachment status. For the total sample, 82% of the mothers classified as resolved had securely attached children and 81 % of the mothers classified as unresolved had insecurely attached children.

Barnett et al. (1999) also validated the RDI and child attachment status in the Strange Situation with a group of 50 children who were diagnosed with a variety of disabilities, but most of the children had either CP or a cleft lip. They also found that resolved mothers were far more likely to have securely attached children than unresolved mothers (76% vs. 24%). Moreover, mothers of children with CP were 64% more likely to be unresolved with respect to their child's disability than those with a cleft lip (28%). This study further validates an earlier study by Marvin and Pianta (1996) and brings up the question as to why neurological impairments such as CP can lead to a greater incidence of mothers' non-resolution of their children's disability.

A study of 73 children with CP or epilepsy by Pianta et al. (1999) examined the relationships between the RDI, Adult Attachment Interview (George et al., 1985), and the child's insecure or secure attachment organization as found on either the infant Strange Situation by Ainsworth et al. (1978) or the modified Preschool Strange Situation by Cassidy and Marvin (1992). The Adult Attachment Interview is a semi-structured interview in which the mothers are asked for "descriptions and evaluations of their own childhood attachment relationships, loss of attachment figures, and effects of childhood attachment experiences on present relational functioning" (Pianta et al., 1999, p. 389). They found that the Adult Attachment Interview was not a predictor of the child's attachment organization in the Strange Situation or resolution of the child's disability in the RDI. Further, they found that resolution on the RDI was correlated to the child's organized attachment behavior in the Strange Situation for children with CP, but not for epilepsy. They found that RDI status and attachment status may depend on the child's medical condition. Pianta et al. (1999) speculated that while the developmental course of CP is often delayed, it is certainly more predictable than epilepsy, and that the unpredictability of epilepsy could serve as a chronic stressor that may interfere with resolution.

Knight (2001) further examined the RDI looking at patterns of caregiving behavior using the Maternal Behavior System in 60 mothers of children with CP and epilepsy. The Maternal Behavior System categorizes parents' caregiving behaviors into one of five patterns in the Strange Situation with preschool age children: avoidant-Alpha, secure-Beta, ambivalent-Gamma, disorganized/controlling-Delta, and insecure other Iota. The results showed that those mothers classified as resolved on the RDI were more likely to show secure caregiving patterns as assessed on the Maternal Behavior System. The results also showed an even stronger association for unresolved and insecure. According to Knight, "maternal resolution of children's medical diagnoses is not as much of a protective factor for appropriate caregiving as lack of resolution is a risk factor. At risk, ultimately, is their children's security of attachment" (p. 101). She suggested that areas of future study look at the "relation between resolution, caregiving, and different medical conditions" (p. 118). It is clear from the review of the literature, that the RDI should be further validated with disability groups in addition to CP, epilepsy, and cleft palate. It is also clear from Knight's study that research should also be carried out by examining the relation between caregiving and different coping strategies since lack of resolution is considered a risk factor.

Coping Strategies

Taanila, Syrjala, Kokkonen, and Jarvelin (2002) did a qualitative study using grounded theory looking at what kind of coping strategies families of older children (aged 8-10) with physically and/or intellectually disabled children used, and then they looked at the differences between high coping families and low coping families. They found that the coping strategies most frequently used were information and acceptance, good family cooperation, and social support. The differences between high and low coping families included, "(1) parent's initial experience; (2) personal characteristics; (3) effects of the child's disability on family life; (4) acting in everyday life; and (5) social support" (p. 73). Their findings showed that the first moments and days after being informed about their child's disability are critical in determining the family adaptation process. They said that "families' patterns of coping and functioning remain relatively consistent if there are no interventions to change them" (p. 83).

A look at the literature on the effectiveness of some of the cognitive coping strategies may help to determine which cognitive coping strategy, or combination of coping strategies, are most helpful for families of children with disabilities. The cognitive coping strategies are examined at length since Marvin and Pianta (1996) found that cognitive coping strategies predominate in mothers of children who are classified as resolved with respect to their child's disability.

Internal cognitive coping strategies

Two major internal cognitive coping strategies are cognitive reframing and passive appraisal. Lustig (2002) defines reframing as "the family's capability to redefine stressful events in order to make them more manageable" (p. 18). Boushey (2001), the mother of a 10-year-old high functioning autistic child, described the ways she used reframing over her child's lifespan. She explained that even though she knew her child was diagnosed with autism and would have certain limitations, she learned to focus on the positive things that he could do when he was growing up. For example, although she knew that her little boy would always be "quirky" (p. 29) socially, he is capable of doing math mentally, including long division and multiplication, and can remember Disney videos verbatim.

Gerber, Reiff, and Ginsberg (1996) offer the cognitive strategy of reframing as a dynamic process that can be used across the lifespan from birth to old age. Reframing can be helpful during stressful transitional periods that can occur between birth and early childhood, childhood, adolescence, adulthood, and old age or during other critical events such as when a diagnosis is made (Hanline, 1991; Turnbull & Turnbull, 2001). A number of studies have shown that parents' use of cognitive reframing can be a particularly valuable strategy (Hanline & Daley, 1992; Hastings, Allen, McDermott, & Still, 2002; Lustig, 2002; Scorgie, Wilgosh, & McDonald, 1996). Lustig used the resiliency model of family adjustment by McCubbin and McCubbin (1996) and studied 89 parents of children with disabilities. According to Lustig, the model hypothesizes that

active coping strategies such as acquiring social support, cognitively reframing events as manageable and seeking spiritual and community

support are associated with positive family adjustment, while passive coping strategies such as accepting problematic situations are associated with negative family adjustment. (p. 16)

He also found that better family adjustment, or overall family emotional health, was related to higher use of reframing and less frequent use of passive appraisal (means of trying to control the emotional toll). Hastings et al. (2002) studied 41 mothers of children with intellectual disabilities, and found that reframing also had a positive effect on the mother's personal growth and maturity. Scorgie et al. (1996) did a qualitative study and interviewed 14 urban and rural families of children with disabilities and found that nine themes related to positive life management, and of these nine themes the parents who more effectively managed their everyday lives used "reframing of thoughts and attitudes about personal circumstances" (p. 68).

Hanline and Daley (1992) studied the cultural differences in family coping strategies and strengths for families of individuals with and without disabilities, within three ethnic groups: Hispanic, African-American, and Caucasian. They found that reframing and minimizing reactivity (passive appraisal) was more predictive of family strengths than formal social supports outside the family for all groups.

Overall, the literature seems to support the use of cognitive reframing as an effective coping strategy in families of children with disabilities. How does cognitive reframing compare to passive appraisal as a coping strategy?

Another internal cognitive coping strategy used by families of individuals with disabilities is passive appraisal. Passive appraisal is defined as "the family's ability to accept problematic issues minimizing reactivity" (Lustig, 2002, p. 18). Turnbull and Turnbull (2001) described it as setting aside concerns or worries about problems and dealing with them at a later date. An example of passive appraisal is when the demands of caregiving become too stressful and the mother takes a break from her responsibilities by going for a walk or seeking some form of recreation.

Passive appraisal has not been discussed as much in the developmental disabilities literature as cognitive reframing. In fact, when it has been studied, much of the literature on passive appraisal has not been as positive as that of reframing (Hanline & Daley, 1992; Lustig, 2002; Van Hooste & Maes, 2003). Even though Hanline and Daley found that internal cognitive strategies were more predictive of family strengths in the three cultures studied than formal social supports, they also found that minimizing reactivity or passive appraisal was negatively related to family mastery in both Caucasian and Hispanic cultures. In these cultures it served more as an "avoidance" of life problems and tended to undermine the family sense of mastery (Hanline & Daley, p. 4). Van Hooste and Maes found that when parents of children with Down syndrome adopted a coping style of passive appraisal they were also more likely to have children who utilized a "passive personal coping style, i.e., learned helplessness" (p. 301). Lustig studied 92 parents of children with a variety of disabilities, many of whom were mentally retarded. He found that less frequent use of passive appraisal was found to be related to better family adjustment. To further understand the relative importance of the passive appraisal style in relation to other coping strategies, more longitudinal, multicultural, and randomized studies need to be carried out.

External family strategies

Coping strategies that are external to the family such as informal or formal social supports are also known to improve family functioning (Hanline & Daley, 1992). Informal social supports are defined as help from spouse, extended family, friends, and/or neighbors, while formal social supports are defined as coming from professionals, community agencies, and/or respite care.

Informal social supports are more effective than formal for most disability and cultural groups with the exception of the Hispanic culture (Hanline & Daley, 1992). When there is a lack of support from family or friends, formal support from parents' participation in early intervention centers can act as great resources by offering information, parent support groups, and locating respite services to reduce stress. Further, Van Hooste and Maes (2003) stated that early intervention is more effective with active parental involvement when it is related to family needs, priorities, and concerns.

Summary of Literature Review

Research to date by Barnett et al. (1999); Marvin and Pianta (1996); Pianta et al. (1996); Pianta et al. (1999); and Knight (2001) have studied only the disability categories of cerebral palsy, epilepsy, and cleft palate using the RDI. The importance of this study is that it extends their research by examining other disability groups using the RDI. It was the purpose of the current study to use the RDI to study mothers' emotional states of resolution or non-resolution with respect to their children's diagnosis of DS or autism. A review of the literature shows that there are no studies using the RDI with mothers of children with DS or autism. Since previous researchers (Knight; Pianta et al., 1999) have speculated that the medical condition of the child may affect resolution status of the mother, it is a critical next step in the research to look at other disability groups.

The study is also the first to offer an early formal intervention using cognitive coping strategies to help support the resolution process (Knight, 2001; Pianta et al., 1996). In the Pianta et al. (1996) study, the most frequently occurring subcategory in the resolved category was "thinking oriented" (p. 251). This was a surprising finding since theories on coping suggest that "emotional discharge" is necessary (Trout as cited in Pianta et al., 1996), but their studies suggest that "mental strategies that reflect the active work of cognitive processes are most frequent among mothers classified as resolved" (Pianta et al., 1999, p. 252). Even in the other two subcategories of resolved ("action" and "feeling oriented") cognitive strategies are present, although not as dominant as in the "thinking" category (Pianta et al., 1996). This finding provided the rationale for developing a cognitive intervention to assist mothers with the resolution process.

Research Questions

One purpose of the study was to understand the resolution process for mothers of children with DS or autism. The first research question was what were the mothers' emotional states of resolution or non-resolution with respect to their children's disability of DS or autism? The second purpose of this study was to understand the mothers' experience of a cognitive intervention, specifically the parts of the cognitive intervention

they found most helpful. Three research questions inquired into aspects of the cognitive intervention that were perceived as helpful or not helpful to the mothers. The three research questions were: What were the mothers' experiences of the cognitive intervention of reframing? What were the mothers' experiences of the cognitive intervention pertaining to formal and informal social support systems? What were the mothers' experiences of the cognitive intervention pertaining to informational sessions on attachment, adaptation process, child development, and child abuse?

Methodology

The research design model for this study was a naturalistic-qualitative design (Patton, 2002). The researcher did observations and in-depth structured and guided interviews using open-ended questions, to determine categories and subcategories of resolution or non-resolution. In addition, a cognitive intervention was implemented and the mothers' experiences of that intervention were examined qualitatively. The data were analyzed using grounded theory and the patterns of experiences for mothers with disabled children were identified, and the components of the intervention that were perceived to be more helpful by mothers in this study were explored (Strauss & Corbin, 1998).

Rationale for Qualitative Design

The rationale for using a qualitative design was that the range of emotions and the subtle differences among these emotions were better examined using open-ended interviews such as the RDI rather than fixed format or forced choice questionnaires or surveys (Leedy & Ormrod, 2001). This information had never been explored before for mothers of children with DS or autism. It was important to capture the full range of emotions that mothers' experience in regards to their children's disability of DS or autism, rather than relying on a measurement scale that may or may not have the proper relevance and sensitivity (Patton, 2002). This is critical because a mother's experience of having a child with DS or autism could be different from that of a mother of a child with cerebral palsy or epilepsy. While Pianta et al. (1996) found the category of resolved to include the subcategories of feeling, action, and thinking, and the category of unresolved to include the subcategories of overwhelmed, angry/preoccupied, neutralizing, depressed, distorting, and confused, it was expected that new subcategories could emerge when investigating different disability groups. This should expand the properties and dimensions of the major categories of mothers' states of emotional resolution or non-resolution. For example, it was expected that a new subcategory that could emerge in the unresolved category was that of guilt or feelings of being ashamed. Very often mothers of children with facial abnormalities, such as in Down syndrome, are hesitant to take their child into public because others may stare at their child and they are made to feel uncomfortable. Another example might be of the mother of an autistic child who is hesitant to go out into public because of her child's odd behavior. It was also important to capture the mothers' experience of the cognitive intervention, and allow them to express ways that the intervention was helpful or not, in their process of adaptation to their child's disability.

Grounded theory is used both in social science and education, and was deemed the most appropriate method for this study (Patton, 2002). Grounded theory data are collected mostly through interviews, but can also be collected through observation, videotapes, and other documents as long as it contains the voice of the participants (Leedy & Ormrod, 2001). In this study, data were collected through videotapes and observations. Grounded theory is noted for its emphasis on "systematic rigor and thoroughness from initial design, through data collection and analysis, culminating in theory generation" (p. 489). It is theory building rather than testing of theory, therefore it is inductive in nature. The information derived from this study could be used as the basis for future research.

The credibility of the researcher is an important factor in qualitative research such as grounded theory. I have 20 years of experience working in the field of special education. I have been an early childhood special educator in the classroom, an interpreter for the deaf, a published researcher in the field of Down syndrome, the coordinator of a mental retardation research center, and a university lecturer and supervisor for master students in an Early Childhood Special Education training program. My interest in understanding the emotional process of a mother's resolution of his/her child's disability as a dissertation student, combined with my knowledge of special education and connection to the disability agencies and organizations, became the foundation and stimulus for this study.

Target Population and Participant Selection

Mothers of children with DS and autism (birth to five years) were recruited from parent support groups from agencies and organizations in southern California. The age of the mothers in this study ranged from early 20s to late 40s. Eighty-three percent (15 out of 18) of the mothers were in their 30s, while only 11% (2 out of 18) were in their 20s, and another 6% (1 out of 18) in their 40s. Ninety-four percent (17 out of 18) of the mothers were married, while 6% (1 out of 18) were separated. The breakdown for ethnicity was as follows: 72% (13 out of 18) Caucasians, 17% (3 out of 18) Hispanic, and Other includes 6% (1 out of 18) Black/Caucasian and 6% (1 out of 18) Caucasian/American Indian. In terms of education, 44% (8 out of 18) had some college education, 44% (8 out of 18) had 4-year college degrees, 6% (1 out of 18) had masters, and 6% (1 out of 18) had a high school diploma. There were a variety of occupations such as preschool teacher, data processor, entrepreneur, registered nurse, accountant, office administrator, and apartment manager, but the majority of participants (56%) were homemakers.

Seventy-two percent (13 out of 18) were mothers of children with DS, while only 28% (5 out of 18) were mothers of children with autism. The children ranged in age from 4 months to 40 months. There were 11% (2 out of 18) in the birth to 12 month age range, 44% (8 out of 18) in the 13 to 24 months age range, 39% (7 out of 18) in the 25 to 36 months age range, and 6% (1 out of 18) in the 37 to 48 months age range.

Early intervention centers such as parent participation groups and organizations such as the Down Syndrome Association have parent groups that meet regularly in southern California. The parent groups were made up mostly of mothers and a few fathers. These mothers and fathers were parents of children (birth to five) with a variety

of disabilities such as DS, autism, CP, and epilepsy. I approached the parent groups at three parent participation early intervention centers in Southern California after obtaining permission from the executive directors of the facilities, and receiving Institutional Review Board approval from Capella University. At a regularly scheduled parent meeting, the leaders of the parent groups introduced the study to the mothers by reading the information found in the letters of approval and cooperation, signed by the executive directors. At the next parent meeting, the leader introduced me to the parent group and I was given the opportunity to describe the study to the parents and answer any questions they had about the study. At the end of this meeting, I passed out a sign-up list asking for volunteers for the study. The list asked for the mother's name, child's disability, child's age, and contact information. Intensity sampling, which is a form of probability sampling, was used to select the participants from this list. This involved selecting "information-rich cases that manifest the phenomenon of interest intensely (but not extremely)" (Patton, 2002, p. 234). The selection criteria for this study follows. First, only mothers were selected for participation in this study. The rationale for including only mothers rather than fathers was that the majority of participants who attended the early intervention centers were mothers. Future studies could examine fathers' resolution process and gender differences. Second, only mothers of children with autism and DS, birth to five years were selected for the purposes of this study. While children with CP and epilepsy may suffer from physical and health impairments, they do not necessarily suffer from cognitive impairment. Children with DS or autism frequently have both cognitive and physical impairment, and it is possible that the medical condition of these children could affect the resolution process in different ways. Other disability groups were excluded in order to study the phenomenon of resolution intensely with mothers of children with DS and autism. Mothers of children ages birth to five years were chosen for the study because unlike children with DS who are diagnosed prenatally or at birth, many children with autism are not diagnosed until three years of age or older. These differences in the diagnostic process could also affect the resolution process.

Thirty-six mothers indicated an interest in the study. All 36 mothers met the first two criteria listed above: However, it was decided that information from only 20 mothers would provide plentiful data for the study. Due to the possibility of participant attrition, 23 mothers (instead of 20) were randomly selected, from the list of 36 mothers, to participate in the study and were assigned study numbers. All 23 were subsequently interviewed using the Reaction to Diagnosis Interview (RDI), by Pianta and Marvin (1992), and demographic questions. Three withdrew from the study after the interviews because of scheduling conflicts, which prevented them from attending the cognitive intervention.

The remaining 20 participants were made up of 13 mothers of children with DS and 7 mothers of children with autism. These 20 participants completed the interviews and began the 6-week intervention, but only 18 completed the study. After the first few weeks of the cognitive intervention two dropped from the study. One mother left the center and went back to work full-time, placing her child in a home-based applied behavioral analysis program, and could no longer attend the parent meetings. The other mother went back for a second opinion from another neurologist after the interview and received a diagnosis other than autism within the first few weeks of the cognitive

intervention. The final 18 participants included 13 mothers with DS children and 5 mothers with autism.

Consent forms were passed out prior to the interviews. It was also decided that if interviews were found to illustrate extreme outlying cases, such as major depression or extreme disorientation, they would not be included in this study: As those cases could distort the findings or be too unusual to yield useful information. In this study there were no such extreme outlying cases (Patton, 2002).

Data Collection

The methods and procedures for data collection for the interview included a combination of a standardized open-ended interview guide and a few closed or fixed response questions (Patton, 2002). The following standardized questions for the interview were taken from the RDI by Pianta and Marvin (1992) and were mostly feeling questions with probes:

1. When did you first realize that your child had a medical problem?
2. What were your feelings at the time of this realization?
3. How have these feelings changed over time?
4. Tell me exactly what happened when you learned of your child's diagnosis. Where were you, who else was there, what were you thinking and feeling at that moment?
5. Parents sometimes wonder or have ideas about why they have a child with special needs. Do you have anything like that that you wonder about? (Prompt if necessary. For example, some parents feel that they might have done something to cause their child's condition; others believe that God must have a reason for giving them this child.)

Each interview lasted approximately 15-20 minutes in length. The interviews took place over a period of four weeks, beginning with the last two weeks of spring quarter and during the two week break before the summer session began. Each interview was videotaped. After each interview I transcribed verbatim the audio portion of the videotape. I then went back and viewed the tapes, taking notes on body language and facial expressions. The transcribed data, notes from the interviews, and the field notes from observations were analyzed using grounded theory (Strauss & Corbin, 1998). The approach for organizing the data was a "case study approach" of people (Patton, 2002, p. 439). Interview data and field notes were gathered together for one case and "sensitizing concepts" (Patton, p. 439), such as the mother's emotional state of resolution or non-resolution borrowed from the studies of Pianta and Marvin (1993), were used to organize and describe the concepts. The rationale for using these concepts was that they already have "proven relevance" (Strauss & Corbin, 1998, p. 115) in mothers of children with cerebral palsy and epilepsy, and the intention of this study was to extend the development of these concepts for mothers of children with DS or autism.

The closed questions were confined to demographic information. The demographic information included information on the mother's age, marital status, ethnicity, level of education, occupation, and the child's disability and age. Normally, this information was obtained at the beginning of the interview from the participant and served as a way of "breaking the ice" with the participants.

The six class meetings for the cognitive intervention began after the interviews were completed, and coincided with the six-week summer session at the early intervention centers. I administered the cognitive intervention for one hour per week for six weeks. The intervention included lecture, videos, and interactive discussions on issues of bonding and attachment, disruption of attachment, the grief cycle and process of adaptation and adjustment, healthy coping mechanisms, child development, child abuse, and abuse prevention. Exercises using cognitive reframing were embedded in some of the talks as well as information to help the mothers better understand their child's disability. For more detailed information regarding the cognitive intervention see Appendix A. The cognitive intervention was based on an extensive review of the literature that focused on internal and external coping strategies for families of individuals with disabilities as well as my expertise in the field of developmental disabilities, child development, child abuse, and neglect. There were five groups of parents and each group received the same information each week (as I was the only one who gave the talks and led the discussions for each of the five groups). I wrote my observations in the form of field notes after each class meeting. During the last class meeting, open-ended questions pertaining to the cognitive intervention were handed out on paper and the mothers evaluated the intervention by writing out their responses. The following questions explored the mother's experience of the cognitive intervention:

1. Did you find the cognitive intervention of reframing helpful or useful? If so, in what ways did you find it most helpful? What did you find the least helpful?
2. Did you find the information about formal or informal social support systems helpful or useful? If so, what was most helpful to you? What was least helpful to you? What would you add or change?
3. Were the informational sessions about attachment, the grief and adaptation process, child development, and child abuse helpful to you? What was the most helpful? What was the least helpful? Is there anything you would add or change about the program?

Data Analyses

The process of analyzing the data began with a microanalysis of the data, which was a "detailed line-by-line analysis necessary at the beginning of a study to generate initial categories (with their properties and dimensions) and to suggest relationships among categories, a combination of open and axial coding" (Strauss & Corbin, 1998, p. 57). Therefore, each individual case was coded in a line by line fashion. Next, I began "thinking comparatively" (Strauss & Corbin, p. 89) across other cases, according to properties and dimensions. Properties were defined as "general or specific characteristics or attributes of a category, dimensions represent the location of a property along a continuum or range" (Strauss & Corbin, p. 117). These properties varied dimensionally. The first time the transcripts of the interviews and the field notes were read, categories were coded with different colored pencils or pens (Patton, 2002). Later, shorthand codes were written next to the different color codes. For example, the color code for cognitive reframing was green, feelings were coded in violet, informal family support in orange-red, and formal professional support in light blue. Reflective memos were written for each participant after the color coding was completed (Strauss & Corbin, 1998). These

memos included when and how each mother found out about her child's diagnosis, whether the feelings changed over time, if the mother ever wondered why she has a child with a disability, and video notes on the body language of the participant during the interview. Each participant was then assigned to the major category of resolved or unresolved, by comparing each memo to Pianta and Marvin's (1993) definition of resolution or non-resolution. Data were also analyzed by discovering what data fit together (convergence) and what data did not (divergence) (Patton, 2002). During the process of categorizing into major categories, I found several cases that did not fit into the definitions of the two major categories, and it became apparent that a new major category was emerging; resolving. It was important to find the meanings and not to just apply labels to these categories (Strauss & Corbin, 1998).

The next step, axial coding, was the "process of relating categories to their subcategories" (Strauss & Corbin, 1998, p. 101). It was speculated that for various disability categories such as autism or DS, different subcategories of resolution or non-resolution would be discovered, other than what Pianta et al. (1996) found in their study of mothers of children with CP and epilepsy. Different disability categories offer different challenges and may require different coping strategies, thus resulting in different states of emotional resolution. Subcategories should answer the questions of "when, where, why, who, how, and what" (Strauss & Corbin, 1998, p. 125). For example, within the major category of resolution three cases were found in which the participants made use of cognitive reframing throughout their interviews. They varied as to when, where, why, who, and how they used this strategy. Participant 31 used this strategy when talking about what her daughter's future life would be like. She said, "I do realize that she will live, she will grow up, you know she will probably have a job, she may get married, and that is much better than what could of happened." Participant 21 used cognitive reframing when she talked about her every day approach to life: "So that's kind of the approach I take, he is gonna be the best he can be and today is gonna be better than yesterday type of thing." Participant 08 used cognitive reframing when talking about her expectations for her child: "He is what he is, and he is gonna be what he is gonna be and that's it, and we were ok with it." This same approach was used to develop each subcategory of other major categories of non-resolution or resolving, by comparing the properties and dimensions of a concept within that category. In this way, the range of variability within a category was examined until the point of "theoretical saturation" occurred and there were "no new properties, dimensions or relationships" that emerged (Strauss & Corbin, p. 143).

The third step of analysis was selective coding and involved forming a "story line" that explained the phenomenon from the categories and their relationships (Leedy & Ormrod, 2001, p. 155). The relationship between the categories and the subcategories was best described using a visual diagram, and therefore an integrative diagram was developed that included the three major categories and their respective subcategories. The last step was the development of a formal theory that was offered to explain the phenomenon in question (Leedy & Ormrod).

The data pertaining to the open-ended questions of the cognitive intervention were analyzed using grounded theory and followed the four-step procedure, which included open ended coding, axial coding, selective coding, and development of theory as described above (Strauss & Corbin, 1998).

The following is one example of the process of analysis for one mother found to be resolved (subcategory feeling oriented) by combining interview transcripts, video notes, observation notes, respondent validation, and participant summary.

Participant 03 Interview Transcripts

This mother discovered that her child had DS four months after he was born: He was having trouble breast feeding and she had gone to a lactation consultant for help. The consultant pointed out that there were soft signs such as short stubby fingers and tongue thrust that indicated DS, and she urged the mother to talk to her doctor. After that meeting she recalls that she was in shock and "got on the freeway going the wrong way, and I think because I knew, I knew something was wrong. It just made sense to me." Once she got the results back from doctor, she was "completely devastated" and was initially "very, very angry" with the doctor and with the thought of having a child with a disability because she had not planned for this.

And I was really, really mad. I wanted to sue the doctors. I rejected M and I had these feelings of rejection, I didn't want to nurse him, I didn't want to hold him. I just thought our happiness, our joy is over, it's done. We're never going to smile again; we're never going to laugh again. And I thought of my other son he is going to have this mentally retarded brother. I mean I was just brutally honest with my feelings. No, I didn't hold back at all. Very, very angry.

She does admit that her feelings have "changed tremendously" over time and she cannot believe she said the things she said. At the time of the interview her child was 26 months old and now she thinks "he is pure joy" and that "it is not at all what we thought." She says that "he is this vibrant, wonderful child" and that she feels "really good about that."

She describes her husband and mother-in-law as "very supportive." Her husband said that he "waited 40 something years to be married and have my children, this is my son, we'll figure it out." She describes her in-laws and the physician as "fantastic." She said that the physician said that her son is still her son, "and if it comes back positive that he has DS, he is still the same child, you are still going to love him." He provided them "immediately with all the support."

She admits to having wondered why she has a child with a disability, but now she just thinks it is a "genetic defect" and that it is the "luck of the draw." She feels that she has "really processed it" and that it is "really important to get all of your feelings out." She describes this process during the first year as follows:

Several moms came up to me during the first year in group and said you know after, because a lot of them were quiet during the discussions, because you are sitting there feeling and you can deny it, but a lot of them feel that rejection or just angry. It is very difficult to say, I am pissed that I have this child because it is your flesh and blood. If you feel it then you need to say it then once you hear yourself say it, then you can let it go.

Participant 03 Video Notes

Participant 03's body language is relaxed. She shows good eye contact and smiles appropriately. As she describes the moment she found out about her child's diagnosis she just relays the information as it happened and is not solicitous even though she found out about her child's diagnosis of DS 4 months after her his birth. She is no longer angry about the diagnosis or blaming the doctor.

Participant 03 Observation Notes

During the first week of the intervention the participants were asked to do a visual metaphor exercise (Yuan, 2003) and describe in pictures or words their experience of having a child with a disability in their family. Participant 03 shows her family walking down a winding path with different colored swirling clouds above and below the path. The beginning of the path is early in their life together. The single green lines are decisions that the both of them made including getting married, buying a house, and working at their jobs. Her husband and she are wearing backpacks signifying the baggage that they carry with them through life. The second scene along the path signifies the birth of their first child, and other aspects of their life including moving and working. Above the path are swirling pink lavender and yellow clouds. The third scene is the birth of their second child with DS and the solid green line is now broken, which signifies her inability to make her own decision about having a child with DS, since she found out 4 months after he was born. There were many decisions that had to be made after her son's birth illustrated by eight green lines along the path. The clouds at this point are brown and black in color and swirling both above and below the path, and represent the sadness that she felt during this time. The path curves steeply downward at this point, but later the path turns upward illustrating that life down the road is looking up. The clouds above the path at this point are pink, yellow, and green with only streaks of black.

Participant 03 Respondent Validation

Participant 03 read over the findings and I asked for her feedback on the results. She said that it was a "true" account and that I captured her process perfectly: She would not change a thing. She thought that reading certain parts of the verbatim transcript was really amazing, and she laughed and said that she wished she had used better grammar during the interview.

Participant 03 Summary

This mother is able to easily identify her feelings and was very comfortable expressing her feelings throughout the interview and in her drawings, and "there is no effort to bring the interviewer into the emotional worlds of the parent" (Pianta & Marvin, 1993, p. 9). She showed that her feelings changed over time since the initial diagnosis. Her drawing showed she has moved on with her life. She does not search for further reasons and says simply that was a genetic defect, plain and simple. She has been offered and has accepted support from her husband and in-laws as well as her doctor. This

mother is resolved with respect to the diagnosis of her child's disability, and has processed this by being "brutally honest" with her feelings along with the help of supportive comments and actions of her husband, extended family, and physician.

Validity

Issues of validity and reliability take on different meanings in quantitative and qualitative methodology. Winter (2000) discussed internal validity in qualitative methodology as it relates to data collection, the design of the study, and the technical analysis. Validation strategies included various forms of triangulation such as triangulation of data sources, respondent validation, expert review, and negative case analysis (Leedy & Ormrod, 2001; Patton, 2002). The first step of validation included the triangulation of data sources by comparing observations with interviews (Patton). Observations were made during each week of the six-week cognitive intervention. After each class, reflective memos were written about each class session. For example, in the first week of the visual metaphor exercise, Participant 31 used cognitive reframing by saying that "when she finds herself feeling sorry for herself she reminds herself that her daughter could be very sick, but she is not." This was then combined with the interview data that also illustrated frequent use of cognitive reframing. The second step of validation was to obtain respondent or expert review validation. The chair of my dissertation committee decided that respondent validation by 9 participants and expert review by the committee of 5 different cases was sufficient validation. In other words, 14 out of 18 cases (Three-quarters of the cases) were validated by either respondent or expert review. Nine out of the 18 participants were given their findings in person or by postal mail, and they were asked to read over their results and give their feedback. Follow-up meetings or calls were made with each of these 9 participants to discuss her individual findings and for each participant to validate her results. Dissertation committee members reviewed the data analysis and findings for five different case studies in order to further enhance validity. Written feedback was given on each of the five cases, and there was agreement on participant classification for categories of resolution, non-resolution, or resolving. Finally, negative case analysis was used, and this was a process that involved looking for cases that do not fit into the categories found in the study (Leedy & Ormrod, 2001; Patton, 2002).

Reliability

Multiple coders and the calculation of inter-coder consistency were not used in this study. However, the researcher was supervised by a dissertation committee who was able to judge the appropriateness of the coding process. In addition, the researcher reliably adhered to the rigorous and systematic coding system found in grounded theory, discussed earlier in this paper.

Credibility

According to Patton (2002), credibility of qualitative inquiry is related to rigorous methods, the credibility of the researcher, and the belief in the value of qualitative analysis. The rigorous methods of grounded theory have already been discussed above and were adhered to in this study.

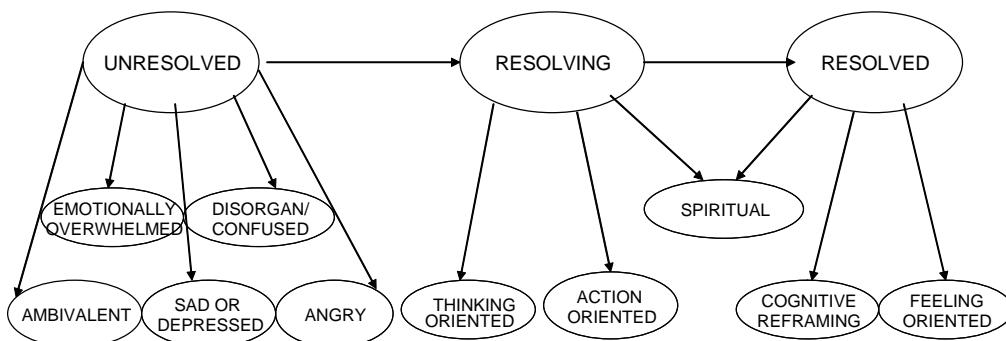
The credibility of the researcher was equally important because she is the tool of qualitative inquiry (Patton, 2002). As stated previously, the researcher has 20 years working in the field of special education. The researcher maintained a belief in the value of qualitative analysis and demonstrated integrity and fairness in the interpretation of the results of this study.

Results

Major Categories and Subcategories

An integrative diagram illustrating the resolution process for mothers of children with DS and autism is presented in Figure 1. The process of resolution is viewed as a continuum rather than as a dichotomous category of unresolved and resolved, as found in studies of mothers of children with cerebral palsy or epilepsy (Knight, 2001; Marvin & Pianta, 1996; Pianta et al., 1996; Pianta et al., 1999). The diagram shows that this continuum progresses from unresolved to resolving to resolved. The new category of resolving emerged from the interviews and observations during the data analysis: This helps to explain an intermediary process that can occur in mothers of children with disabilities of DS and autism. These mothers are neither resolved nor unresolved, but are in the process of resolution, and these parents may have utilized some of the elements of resolution. They may be able to identify their feelings and there is some evidence that their feelings have changed over time in a positive direction rather than worsening or remaining in the past with the emotional pain. They are making progress towards resolution of their child's disability, but have not quite achieved resolution as yet.

Figure 1. Continuum of resolution.



The three major categories in the process of resolution for this sample are unresolved, resolving, and resolved. The subcategories of unresolved include emotionally overwhelmed, disorganized/confused, ambivalent, sad or depressed, and angry. The subcategories for the new major category of resolving are thinking oriented, action oriented, and spiritual. The subcategories of resolved include spiritual, cognitive reframing, and feeling oriented.

Resolved

The mothers who were categorized as resolved were found to use several strategies to achieve resolution. The three subcategories that emerged from the data include cognitive reframing, feeling oriented (Pianta & Marvin, 1993), and spiritual beliefs/supports. Two new subcategories, cognitive reframing and spiritual beliefs/supports, emerged from the analysis using grounded theory, for those classified as resolved. Cognitive reframing has been identified in the literature as an effective coping strategy in families of children with disabilities (Hanline & Daley, 1992; Hastings et al., 2002; Lustig, 2002; Scorgie et al., 1996). Lustig defines cognitive reframing as "the family's capability to redefine stressful events in order to make them more manageable" (p. 18). In this study, mothers were found to use this strategy in the resolution process of their children's disability of DS or autism. The mother of a DS child who was resolved knew from the information she had received from the doctors and family friends, soon after her baby's birth that, "this isn't a bad thing. This is just, he is what he is, and he is gonna be what he is gonna be and that's it." Another mother of a child with DS said something similar and wanted to "celebrate her life and it is not that bad, I heard a saying, the grass is always browner on the other side and it is true things could be a heck of a lot worse." The mother of an autistic child said, "so that's kind of the approach I take, he is gonna be the best he can be and today is gonna be better than yesterday type of thing." Each mother made use of cognitive reframing and informal support from family and friends as well as the information from doctors and therapists.

Mothers' use of spiritual beliefs or support has also been documented in the literature as an effective coping strategy and was also used by the mothers who were resolved in this study (Hanline & Daley, 1992; Lin, 2000; Mahoney & O'Sullivan, 1992; Turnbull & Turnbull, 2001). When this young mother was informed by the doctors that her child had DS, she used her spiritual beliefs to cope with the diagnosis.

I think that only God gives special kids to special people, that is what I've been told, and you start to believe it. I am not bragging or anything, but certain people just can't handle a situation like that, and he obviously knows that we can. So he doesn't give me more than I can handle, so just trust that.

This same mother had to face a complicated and life-threatening heart surgery for her four month old daughter with DS and enlisted the help of her spiritual support group.

We had this huge big prayer chain in our waiting room, and the doctor was like, we don't care how many people you have as long as we don't have to set up bleachers. We had tons of people coming in and praying with us and staying with us through the whole thing. They said five hours and it took them three and one-half.

Further, mothers who were resolved in this study utilized informal support from husbands, family, and friends as well as formal support from professionals such as physicians, doctors, nurses, early interventionists, and therapists. Use of formal and

informal support systems is also well-documented in the literature as a coping strategy (Boyd, 2002; Dunst, Trivette, & Jodry, 1997; Hanline & Daley, 1992; Van Hooste & Maes, 2003).

Resolving

Pianta and Marvin (1993) describe three subcategories within the major category of resolved: thinking oriented, feeling oriented, and action oriented. In this study, the major category of resolving contained two of Pianta and Marvin's subcategories, thinking and action oriented, and a new subcategory, spiritual beliefs/support. The subcategory of spiritual beliefs and support is shared by both the major categories of resolved and resolving (see Figure 1). While Pianta and Marvin acknowledged that parents who are thinking oriented use "beliefs, thoughts, philosophy" (p. 14) and acknowledged that "religious beliefs" can be a part of those beliefs, in this study, spiritual beliefs/support were elevated to a separate subcategory based on the number of recurring themes in the qualitative interviews and observations in this study.

Unresolved

Five subcategories of unresolved emerged from the qualitative data in this study of mothers of children with DS and autism. Four subcategories were found to be similar to Pianta and Marvin's (1993) subcategories of emotionally overwhelmed, disorganized/confused, sad or depressed, and angry. The fifth and new subcategory that emerged from the data was ambivalent. The properties and dimensions of the subcategories of unresolved in this study have been expanded for the mothers of children with DS and autism.

While the subcategory of emotionally overwhelmed in this study is similar to that of Pianta and Marvin's (1993), in that the participant often "evokes a very sympathetic reaction in the interviewer" (p. 15), the properties and dimensions of this subcategory varied for mothers of children with DS and autism. Emotionally overwhelmed in this study was connected to McCubbin and McCubbin's (1996) description of a "pile-up of family stressors" (p. 17). For mothers of children with DS this pile up of stressors varied dimensionally due to numerous severe medical conditions of the child or the mother, as a result of a pile-up of other family stressors surrounding family illness, death and divorce, or job loss. In the interviews, those mothers who were emotionally overwhelmed sometimes cried frequently throughout the interview, while others seemed to be cut off from the emotion of the experience. In the former case, the mothers' feelings were right on the surface and often enlisted sympathy from the interviewer, while in the latter case the mothers' feelings were often buried and difficult to access by the interviewer.

The subcategory of disorganized/confused also varied dimensionally for mothers of children with autism compared to Pianta and Marvin's (1993) definition. Pianta and Marvin noted that "this subtype is marked by incoherence in the content of the story (at times it is not logical or does not make sense) and by appearance of confusion and disorganization in the story" (pp. 17-18). Confusion could result for mothers of children with autism if they had either too much or too little information about autism. Physician shopping frequently resulted in too much information causing confusion about the

diagnosis, just as too little information resulted in a lack of understanding regarding what a diagnosis of autism meant or what type of autism their child had. One mother was confused because she did not know much about autism and did not know if it was severe or mild. She went to a support group, but it did not provide her with enough information.

I know that there is something with the autism, but I don't know much about it because I haven't like gotten a lot of information on it and even when I went to the support group I didn't feel like I got enough information on it and even when I went to the support group I didn't feel like I got enough information for somebody who just got the diagnosis, you know, most of the parents there you could see, I think there was like three new parents there, but the other parents had been there for a while, and you could just notice that there wasn't enough information for a person that is just walking into the group.

According to Pianta and Marvin (1993), mothers who appear sad or depressed are "sad, listless, very passive, requiring lots of probes and effort on the part of the interviewer. Their report is minimal. They appear depressed, or their affect may be flat and accompanied by a very passive style of interaction" (p. 17). This was found to be true for the mothers in this study. For example, one mother of two children with autism displayed a feeling of hopelessness and uncertainty regarding the future for her children. When asked if her feelings changed over time, she said they had "worsened," and she felt the "heavier burden of both children, comparing them, feeling that (her younger son) is worse and wondering what the future would be for him."

Mothers of children with DS or autism who were categorized as angry often directed their anger at the medical system or diagnosis, similar to the mothers of children with cerebral palsy and epilepsy in Pianta and Marvin's (1993) study, but there were a number who also directed their anger at the public's reaction to their children. Some mothers of children with DS became angry at people when they were out in public because they did not want to see "the look" or answer questions regarding their children's physical differences. One mother described her reaction as

You don't want to see that look on their face. You want them to say congratulations! And people who look uncomfortable, and you feel bad, you feel like crying, and then you are like just don't look at my kid because I don't want to see the look.

Some mothers of children with autism had difficulty in public because although their child might look normal on the outside, a standard of behavior was expected that was not realistic for their child's level of social emotional development. They were often judged as "bad parents" because they couldn't control their child's behavior. When one unresolved mother of a child with autism was asked if her feelings have changed over time she said that "it's still going up and down" and said

Well, there are so many unknowns. It's because the behaviors change and they are different and people accept a child who looks like they have a

disability. People are so much less accepting of a child who looks like they should be able to behave, and they can't.

The new subcategory of ambivalence found in this study reflected a mother's conflicted feelings about the diagnosis of her child. On the one hand she might view her child as a blessing, but then immediately describe how difficult it was having a child with a disability.

It's still hard, you know, she is going to be two and I still have moments, but now I can't imagine not having her in our life. She has been such a blessing, she's added so much, and I can't imagine not having her in our life now. But it is still hard, 'cause my other two typical kids I didn't have to come here three days a week and it started at seven weeks, you know it has been a lot, it has been a huge adjustment. It is not like you take this baby home, no one tells you all the tests, therapy you have to do with these children. No one tells you that (laughs), no one says anything about that, you just kind of call regional center and that was one of the hardest calls I ever had to make; calling her was another hard call. It seems like it was so long ago, yet it really wasn't.

Examples of this type of ambivalence were evident as the circumstances varied and could be exacerbated by a pile-up of stressors. This ambivalence towards the diagnosis could prevent the mother from moving towards the resolution of her child's diagnosis.

Two threads ran through the subcategories of those mothers categorized as unresolved. Many of these mothers did not have adequate informal or formal support systems. As noted previously, the literature tells us that strong support systems can enhance coping abilities for families of individuals with disabilities. While spiritual beliefs and supports seem to enhance the resolution process, negative use of spiritual beliefs may hinder the resolution process. One unresolved mother of a child with DS said that she still wondered why God chose her daughter and she felt it was unfair to her. She also felt that God somehow punished her for liking her life so organized.

...that is why God threw me for a loop, because I like my life so organized and this was something you know that was out of the ordinary that I wasn't expecting. And my friends kind of tease me now, that's why God did it just to show you that life doesn't go always the way you want it to go. Um it sure doesn't.

In this way, spiritual beliefs were used negatively rather than positively: This could impede the process of resolution rather than enhance it.

Differences in the Diagnostic Process

There are unique differences in the way mothers of children with DS and autism learn of the diagnosis that may affect the resolution process. Mothers of children with DS typically learn of the diagnosis prenatally through alpha fetoprotein (AFP) screening,

amniocentesis, or post-natally through genetic testing. It is common for these mothers to learn of the diagnosis before, at the time of birth, or very soon thereafter, and they can begin the process of resolution sooner than mothers of children with autism. A Swedish study of 165 parents of 86 children with DS by Hedov, Wikblad, and Anneren (2002) found that parents were informed about their child's condition between "...0h and more than 5 d of age. The vast majority of the parents (75%) were informed within 24 h" (p. 1348). They found that "information given immediately after delivery might disturb the bonding and recovery of a fragile new family. On the other hand, the information cannot wait too long after the birth, leaving the parents in anxiety and loneliness" (p. 1348). Not only is the timing important, but the way the parents are told can have a profound effect on the parents. Hedov et al. found that parents were often dissatisfied with the communication skills of professionals, too much negative information was given about DS, and they felt that professionals needed more training in these areas.

The diagnostic process for mothers of children with autism in this study typically took a longer time than for mothers of children with DS, and the process was more complicated. To date there is no genetic testing available to diagnose autism, and often times the parents do not receive a diagnosis of autism until the child is much older, around the age of 3 (Nissenbaum, Tollefson, & Reese, 2002). Even though they may have suspected that something was wrong much earlier, due to delays in language or difficulties with social behavior, the diagnostic process may include the evaluation by several different professionals, over an extended period of time. Nissenbaum et al. did a qualitative study of 17 parents of children with autism, which looked at how professionals share a diagnosis of autism with families. They made a number of recommendations for practice based on the results of the study, which included that professionals should "become knowledgeable about autism, establish a family-friendly setting, understand the family's needs, use good communication skills, provide a list of resources and interventions, provide follow-up, discuss prognosis and provide hope" (p. 9).

The difference in the diagnostic process may also be reflected in the resolution process in this study. Although there were only 5 mothers of children with autism in this study, only 1 was categorized as resolved, while the other 4 were categorized as unresolved. The mother who was categorized as resolved was sub-classified as using cognitive reframing. Of the 4 mothers of children with autism who were unresolved, 2 were classified as disorganized/confused, 1 had too much information, while the other had too little information about autism. One participant was the mother of 2 autistic children and was classified as sad or depressed, having a difficult time maintaining a sense of hope for the future of her 2 children. Another classified as emotionally overwhelmed was the mother of 5 typical children and 2 children with disabilities, 1 autistic and 1 with DS. Since the diagnostic process took a lot longer for all of these mothers, it is possible that they needed a longer or more intense cognitive intervention and more time to process the cognitive intervention, as well as behavioral interventions for their child with autism.

There were 12 mothers of children with DS. Five were classified as resolved, 3 were categorized as resolving, and 4 were unresolved. In the resolved category, 2 were classified as using cognitive reframing, while 3 were classified in the subcategory of spiritual beliefs/supports. In the resolving category, 1 was subcategorized as thinking

oriented, 1 was action oriented, and the other was in the subcategory of spiritual beliefs/supports. In the unresolved major category, 2 mothers of children with DS were subcategorized as emotionally overwhelmed, 1 was subcategorized as angry, and the last was subcategorized as ambivalent.

Comparison of Percentages of Rates of Resolution

In Marvin and Pianta's (1996) study of children with cerebral palsy, 47% were classified as resolved, while 53% were classified as unresolved. The study of mothers of children with cerebral palsy and epilepsy by Pianta et al. (1996) found that roughly half of these mothers were classified as unresolved. Of the total number of mothers in the Pianta et al. (1996) study that were resolved, 46% of the mothers of children with cerebral palsy and 56% of the mothers of children with epilepsy were resolved. Knight (2001) found similar rates in her study of mothers of children with cerebral palsy and epilepsy; 45% were resolved, while 55% were unresolved.

In the current study, three major categories were used instead of the two major categories in previous studies. Thirty-nine percent of the mothers were classified as resolved, 17% were classified as resolving, and 44% were classified as unresolved. Of the 39% found to be resolved, 33% were mothers of children with DS, while only 6% were mothers of children with autism. Of the 17% classified as resolving, 17% were mothers of children with DS and there were no mothers of children with autism in this category. Of the 44% found to be unresolved, 22% were mothers of children with DS and 22% were mothers of children with autism.

It is important to note the lower percentage of mothers of children with DS or autism (39%) who are resolved compared to previous studies of mothers of children with cerebral palsy or epilepsy (45%-56%) who are resolved. Certainly the creation of three major categories could account for the drop in the percentage of mothers who are resolved in this population: However, if one combines the resolving and unresolved categories into a single category of unresolved, the results equal 61% unresolved. It is hypothesized that these differences might be related to a more complicated diagnostic process as found in autism or a more severe medical diagnosis such as that found in severe autism or life-threatening medical conditions of DS. The latter condition was mentioned previously by Morog (1996) in terms of the chronic stress of reoccurring seizures experienced by mothers of children with epilepsy. This "ongoing crisis" (p. 93) may hinder the process of resolution. The same may be true for mothers of children with DS or autism. In the population of mothers of children with DS or autism, it could also be related to what McCubbin and McCubbin (1996) described as "pile-up of family stressors" (p. 17). Further studies will have to be carried out to understand the significance of this relationship.

Cognitive Intervention

The results of the analysis using grounded theory revealed what seems to be most helpful to the mothers in the cognitive intervention were the reframing exercise, the information on informal and formal support systems, the talk on the grief and adaptation process, participating in the visual metaphor exercise (Yuan, 2003), and the child

development information, especially the video on raising a child with DS. It is less clear if the information on attachment, child abuse, and abuse prevention was helpful because the feedback was so mixed. Finally, it cannot be determined if the prevention strategies for child abuse were helpful or not since there was no feedback given about this material.

The reframing exercise is an exercise that can be used throughout a child's developmental stages and particularly during transitional periods when the family may be experiencing high levels of stress. One mother who was resolved said, "This information was a helpful reminder to reframe the focus of our experiences with our child, and that I will have to 'reframe' often as our experiences change." Another mother who was unresolved said, "It gave me a chance to see a more healing way to deal with issues about my child and how to turn it to a positive for my mental health."

The visual metaphor exercise (Yuan, 2003), which is a type of reframing exercise, was viewed by the majority of mothers as helpful, and it was a way to reframe their experience of having a child with a disability by using their own words or drawings. This exercise was seen as "therapeutic" or "cleansing" by many of the mothers in the study. One resolved mother said, "The activity we did drawing pictures of our experiences having a child with disabilities was one of the best thing(s) we did. It helped me see my experiences even more objectively." Another mother who was resolving said, "I thought the picture exercise was a good way to express our feelings." Several examples of the mothers' drawings and descriptions of these drawings can be found in Appendix B.

Mothers of children with disabilities need to be kept informed and be reminded of the informal or formal supports systems that are available, which can help with the process of resolution. Mothers in group situations can also be valuable sources of information for other mothers of children with disabilities, and they should be encouraged to share their resources with one another. One unresolved mother said that the information about formal or informal social support systems was helpful and said, "yes, to know all the support is out there. I just have to reach out." Another mother who was resolving said, "All the resources were helpful," while another mother who was resolved said that "this also was a helpful reminder to use the support systems available to me, i.e., my husband and family."

Information on child development in terms of language, cognition, social-emotional, and gross and fine motor skills was viewed as helpful, as it gave the mothers the opportunity to understand what typical development was and when to expect changes in their own children. One unresolved mother of an autistic child said it was most helpful "knowing the different stages our child goes through and when to expect or see the change (of socializing)." The video on raising a child with DS was viewed as encouraging, as it gave the mothers the opportunity to see the developmental changes that occur across the lifespan. One mother said she "really enjoyed the video—'Raising a Child with Down syndrome.' It gave us hope for the future."

Although information on child abuse and neglect in children with disabilities was considered important information, the reality that child abuse can occur at twice to three times the rate of that of normal children may have been too upsetting for the mothers to contemplate and overshadowed the intended message. While there is no easy way to deliver such information, perhaps it would be more useful to place more emphasis on prevention strategies instead of information and statistics on child abuse.

Limitations of the Study

The limitations of the study include the fact that the results of the study can only be transferred to similar settings, in terms of the demographics of the study. In this study, with the exception of one mother, most of the mothers had at least some college education and many had four-year college or masters degrees. On the whole, they were a fairly well-educated group. Other studies, with less educated participants, may yield different results when using this cognitive intervention.

All of the mothers were married with the exception of one mother who was recently divorced. One mother who was married was also an adoptive mother. Studies that include more single or adoptive mothers could yield different results. Single mothers face different challenges financially and in terms of managing their busy schedules. It is possible that these mothers may experience more stress raising a child with a disability than mothers of children who are married. Some mothers who intentionally chose to adopt a child with a disability may have a very different outlook than a mother who unexpectedly gives birth to a child with a disability. It is possible that initially they could be more resolved about raising a child with a disability because they knowingly chose this option. Their attitude about adopting a child with a disability could result in a different resolution process.

In this qualitative study, the random selection of 18 mothers of children with DS or autism resulted in 12 mothers of children with DS and only 5 mothers of children with autism. A larger sample of mothers of children with autism may offer more in-depth information about the resolution process in this population.

Another limitation of this study is that only parent participation centers were used versus drop-off centers or home-based services. Studies at drop-off centers or home-based services could yield very different results than parent participation centers. Finally, the intervention in this study was six weeks in length and studies that are longer or shorter in length could also result in different outcomes.

Recommendations for Future Research

There are some unresolved mothers who may need a different type of intervention than the cognitive intervention used in this study. Some unresolved mothers may need individual therapy or a combination of individual therapy and group classes. This may be particularly true for mothers who are sad, depressed, or angry. They may also require more time to process the information or need more opportunities to socialize with other mothers. Mothers of children with autism may need a combination of both cognitive and behavioral intervention.

Groupings for the cognitive intervention should be carefully considered. Once the interviews have been completed and the mothers have been categorized into the major categories, it is recommended that groups be made up of no more than six to a group, with a mixture of mothers who are categorized as resolved, resolving, and unresolved. Mothers who are unresolved should not be grouped together by themselves, but should be placed in groups with other mothers who are resolved. In this study I noticed that resolved mothers could assist mothers who were unresolved with the process of resolution, by sharing their stories of success or offering suggestions or support. It is

recommended that mothers of children with DS or autism be kept in separate disability groups so that specific information about their children's disability of DS or autism can be presented.

It is recommended that the time allotted for the cognitive intervention be at least one hour for lecture and another one-half hour for discussion per week, for six weeks, rather than just one hour per week. This allows more time for group reflection and discussion, which can be an important part of the intervention process. I recommend that the group not be run at the same time as other support groups at the center as this could create conflict and affect attendance rates, thus the efficacy of the intervention.

Future studies could be done with fathers only or with both parents as participants. Couples may resolve their children's disability at different rates and in different ways. Knight (2001) suggests that a father's secure caregiving may make up for a mother's lack of secure caregiving, thus assisting with the resolution process. Future recommendations would be to do a quantitative study using a pre-post experimental design, implementing the cognitive intervention for mothers or fathers who are identified as unresolved. Validity studies could also be carried out to examine mothers' resolution and its relationship to attachment in children with DS and autism. Validity studies of this type were done previously with mothers of children with cerebral palsy by Marvin and Pianta (1996) and with mothers of children with neurological and non neurological problems by Barnett et al. (1999).

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Appendix A

Six Week Cognitive Intervention

One hour talks were given to moms in small groups once a week for 6 weeks at 3 parent participant early intervention centers in Southern California.

Week 1: Grief and Adaptation Cycle. Grief cycle and disabilities (Cook, Tessier, & Klein, 1996) and four stage adaptation model by Miller (1994). Do visual metaphor exercise (Yuan, 2003). Family Life Cycle and transitions (Turnbull & Turnbull, 2001). After class reflect on drawings and observations of moms.

Week 2: Attachment. Give talk and handouts on attachment. Show video on "Attachment" (Diach, n.d.) Go over attachment in DS and autism. Write up class observations.

Week 3: Child Development and DS and Autism: Handouts on developmental milestones for language and motor. Use overhead information on DS and autism. For moms of children with DS show video "Like Any Child: Raising a child with DS" (Sheridan, n.d.). For the moms of children with autism show video: "Autism: The Child Who Couldn't Play" (Canadian Broadcasting Company, 1996). Homework assignment: Design a developmentally appropriate toy for their child that enhances either cognitive, motor, language, socio-emotional or visual development. This is due week 6. Reflect on class observations and type up.

Week 4: Positive Coping skills: Internal cognitive coping strategies of reframing and passive appraisal. Go over class exercise for reframing and have mothers identify a challenge or problem that they are currently dealing with concerning their child and have them use reframing strategies. Go over informal and formal support systems as well as spiritual support. Hand out information on UCP Family Support Services: The Respite Connection (UCP of Orange County, 2004), Down Syndrome Association of Orange County—Circle of Friends Parent Group (DSAOC, 2004), and Parent Support Groups from Regional Center of Orange County (RCOC, 2000). Share Community Resources

Handbook (Orme, 2000). Talk about developmental milestones for cognitive development. Reflect on observations after class and type up.

Week 5: Child Abuse and Prevention. Child Abuse Prevention Handbook (California Attorney General's Office, 2000) and prevalence of abuse and neglect in children with disabilities. Go over prevention strategies and pass out Educational Coloring and Activities Books on "Good Touch, Bad Touch" (Liptak & Mandel, n.d.) and "Be Smart, Say No to Strangers" (Weber & Berry., n.d.). Talk about developmental milestones for social emotional development. Reflect on observations after class and type up.

Week 6: Go over homework assigned in week 3. Do evaluations on 6 week program.

Appendix B

Visual Metaphor Exercise Drawings and Descriptions

Drawing of Participant 21



Description of Visual Metaphor Exercise – Participant 21

This is a drawing of a resolved (cognitive reframing) mother of a child with autism. The visual metaphor consists of the road of life at the top of the paper where other people live and at the bottom of the drawing are steep stairs leading down to a beach. She considers this beach to be her life with her family. The waves come in and out washing away the sand and revealing other facets of life. The tide pools on the left and right of the beach reveal the gems of their life. On the beach is an umbrella and chair which provides a place of respite for her. She feels that the changing sea is like her own life, and sometimes the sea is turbulent and stormy and other times it is calm.

Drawings of Participants 24 & 25

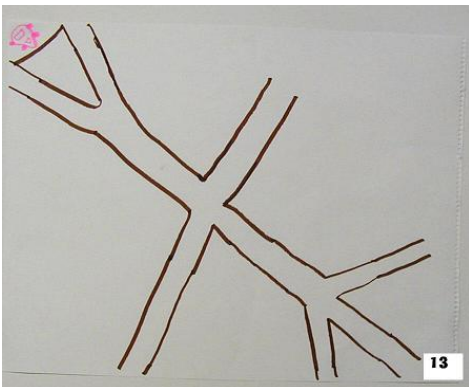


Description of Visual Metaphor Exercise – Participants 24 & 25

Participants 24 and 25 were found to be in the process of resolving their child's diagnosis of Down Syndrome (DS). They decided to combine their efforts and do the exercise together. The overall visual metaphor is presented as mountains and valleys, with river rapids running alongside the mountains. Participant 24 described the ups and downs of the mountains as representing her family life with a child with a disability of DS. The low area to the left of range represents the birth of her child with DS and represents a more constricted time in her life. Further along the mountain range to the right are several highs and lows in the form of hills and valleys. The sun is shining between the first and second peaks of the drawing. Further to the right of the drawing the highs and lows level off, and this represents a more stable time in her life, however this level area is higher than the beginning of the mountain range. She commented that she found this exercise very relaxing and therapeutic, and the other mothers agreed with her.

Participant 25 chose to describe her experience as a ride in a raft down the river rapids. She is in the raft with her child and husband. The beginning of the river ride is turbulent and she says that this represents her husband's family and how they reacted to the diagnosis, whereas further down the river the water is calmer and this represents her family, which has been more accepting of the diagnosis of DS for her child.

Drawing of Participant 13



Description of Visual Metaphor Exercise - Participant 13

Participant 13 was found to be unresolved (disorganized/confused) in regard to her child's diagnosis of severe autism. She was really stumped by this exercise when asked to draw her experience of having a child with a disability. Eventually she drew a car in front of a road block, and then a road with several different crossroads. The first road has two choices, but the two roads end up merging into one, and then in the center of the paper there is an intersection that would allow her to go in three different directions. She notes that this is the time when her daughter was about a year and she had to make many decisions about her life. Further up the road is another cross road that will allow her to once again go into three different directions, signifying the actual diagnosis of autism with her child. She remarks that she doesn't know where all these roads will lead her.

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