

ABSTRACT

Title of Thesis: PARENTAL COPING METHODS FOR MANAGING STRESSES EXPERIENCED FOLLOWING OUT-OF-HOME PLACEMENT OF A CHILD WITH DEVELOPMENTAL DISABILITIES

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A model describing the process of parental adaptation to life after voluntarily placing a child with developmental disabilities in out-of-home care was generated by utilizing grounded theory to analyze 20 qualitative interviews. The resulting model provides an organized understanding of how parents adapt to post-placement stressors. The cognitive appraisals of parents were categorized by their associated emotions: guilt, sadness, fear and worry, anger and frustration, and uncertainty (emotional stresses); and relief (an emotional advantage). Problematic and desirable adaptive responses to placement of both the child with developmental disabilities and his or her siblings, and the critical or supportive messages from others were determined as contextual factors affecting the emotional stresses of the parents. The primary coping methods employed by the parents to manage the emotional stresses consist of reappraisals regarding the necessity of placement, involvement in the child's life, therapy, and the passage of time.

PARENTAL COPING METHODS FOR MANAGING STRESSES EXPERIENCED
FOLLOWING OUT-OF-HOME PLACEMENT OF A CHILD
WITH DEVELOPMENTAL DISABILITIES

by

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CHAPTER 1

INTRODUCTION

Statement of the Problem

Bringing a child with developmental disabilities (e.g., autism, blindness, cerebral palsy, dyslexia, hydrocephalus, mental retardation, Down's Syndrome, Turner Syndrome) into the world has life-changing implications and lasting effects not only for the child, but also for his or her family (Blacher, 1994; Dunst, Cooper, & Bolick, 1987; Martin & Colbert, 1997). As if parenting is not already demanding and stressful enough, parents of children with special needs and limitations usually face significant additional difficulties (Martin & Colbert, 1997). Raising a child with disabilities can be exceedingly arduous and challenging, as well as rewarding. Even though there has been legislative progress toward providing for the needs of children with special needs and improved services are becoming increasingly available (Martin & Colbert, 1997), parents of these children still have many challenges with which they must contend. Studies indicate that as many as 12.1% of adolescents have developmental disabilities, with 3.2% reporting severe developmental impairments (*U.S. Census Bureau, 1995*).

A large body of literature has examined issues relating to parenting a child with special needs, giving specific attention to stresses, resources, and coping. Often the demands of raising a child with developmental disabilities become such that parents may consider placing their child in some form of out-of-home care (e.g., adoption, foster care, residential care, group homes, assisted living). Such a decision is not an easy one; yet as many as 40% of children with severe or profound mental retardation are placed by the end of adolescence (Meyers, Borthwick, & Eyman, 1985). The decision to place usually

occurs as a means of relieving the stressors that the parents associate with their child, and for the perceived benefit of the entire family (i.e., parents, siblings, and the child with disabilities) (Marin & Colbert, 1997). Most of the literature on out-of-home placement investigates the factors leading up to placement (Allen, 1972; Blacher, 1990; Bromley & Blacher, 1989; Bruns, 2000; Cole, 1986; Kobe, Rojahn, & Schroeder, 1991; Llewellyn, Dunn, Fante, Turnbull, & Grace, 1999; Sherman, 1988; Sherman & Coccozza, 1984), describes and evaluates the various forms of placement (Barsh, Moore, & Hamerlynck, 1983; Brown, 1988; Bryant & Snodgrass, 1991; Campbell, 1997; Coyne & Brown, 1986; Erickson, 1990; Grayson, 1985; Lightburn & Pine, 1996; Meyers & Marcenko, 1989; Myers, 1989, 1992; Ott & Langer, 1987; Petr, Murdock, & Chapin, 1995; Richardson, West, Day, & Stuart, 1989; Rosenau, 1990; Webb, 1988; Wimmer & Richardson, 1990), considers parental satisfaction with placements (Blacher & Baker, 1994; Bruns, 2000; Cole, 1986; Westling, 1997), and explores the effects that this decision may have on the child with special needs (Hodapp & Zigler, 1985, Paquin & Braden, 1990). In contrast, the question of how families adapt to the changes stemming from placement *after* placement has occurred has received noticeably little attention.

Purpose of the Study

A review of the literature on out-of-home placement for children with developmental disabilities indicated an absence of research exploring (a) how parents are affected by their decision to place a child with developmental disabilities in out-of-home care, (b) how parents adapt to life after placement, and (c) how parents manage the effects of their decision *after* placement has occurred. This study attempts to address that void in knowledge by explaining the advantages and stressors perceived by parents, in

addition to increasing understanding of how parents cope with the changes resulting from placement. The research questions used to guide the analysis of the data were designed to bridge the gaps in understanding post-placement parental adaptation and are as follows:

1. *What are the prevalent advantages and stressors that parents experience **following** the voluntary placement of a child with severe or profound developmental disabilities in some form of out-of-home care?*
2. *What are the general parental coping methods for managing the stressors and adapting to the changes associated with life **after** placing a child with severe or profound developmental disabilities in some form of out-of-home care?*

These questions directed the researcher in discovering the advantages and stressors experienced by the families after placement, and the coping methods that parents employed to ameliorate them. Grounded theory qualitative research designs and methods were utilized to recognize and categorize prevalent themes in the types of advantages and stressors perceived by the parents and the coping strategies that the parents employ to reduce the negative impacts of stressors in post-placement family life associated with the decision to place their children. The *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities*, a model that visually represents the results and describes how parents adapt to post-placement life, was subsequently developed from the themes identified in the data.

It is expected that the results of this study will be of assistance to families who are facing, or who will eventually face, the difficult decision of placement. The results of this study could help parents both directly and indirectly. Parents may be assisted directly by providing them with information about managing the effects of a placement decision by

increasing their understanding of the stresses and related coping processes. Potential benefits to parents who receive this information include: (a) facilitating the normalization of experiences, (b) helping anticipate stresses, and (c) providing examples of a variety of potential coping strategies.

Furthermore, parents of children with disabilities may be benefited indirectly, should the results of this study influence future legislation and/or the administration of relevant services for parents who have placed, or who are considering placing a child with developmental disabilities. As an exploratory qualitative study, the results will likely increase the depth and diversity of the current body of literature on out-of-home placement decisions. It is anticipated that these additions to the field will be achieved by focusing on how parents manage the effects of placement decisions for children with severe or profound developmental disabilities, the population most likely to be placed (Blacher & Baker, 1994; Borthwick-Duffy, Eyman, & White, 1987; Dunst et al., 1987; Eyman et al., 1972; Kobe et al., 1991; Martin & Colbert, 1997; Sherman, 1988; Westling, 1997). Finally, findings of this study will be disseminated to service providers, field professionals, and families of children with developmental disabilities who are facing or who may eventually face the difficult decision of placement, in hopes of increasing awareness of the overlooked experiences of parents after they have placed a child with developmental disabilities in some form of out-of-home care.

Review of Literature

Developmental Disabilities

Definitions

Due to the lack of a clear operational definition, the conceptualization of *developmental disabilities* varies from source to source, making the term difficult to define and elusive to measure. However, for the study at hand, the following definition of developmental disabilities will be utilized: “a condition of someone who has had one or more mental or physical impairments from an early age that are likely to continue indefinitely” (Lenhart, 2000, p. 171). Thus, the age of onset and permanency are the unique factors that set developmental disabilities apart from other disabilities. The terms *child with developmental disabilities* and *child with special needs* are used synonymously throughout this thesis.

Etiology

Different types of developmental disabilities vary in etiology. The origins of the disability may be classified in two distinct categories: (a) genetic makeup and (b) environmental factors (i.e., accident, illness, poisons, pregnancy complications, and teratogens) (*The Arc of the United States*, n.d.). It is important to note that these two categories are not mutually exclusive (e.g., a disability may have both genetic and environmental components). In contrast, the field of developmental psychopathology studies developmental disabilities from a contextual approach in terms of normal development, placing emphasis on the following three developmental domains: community, home, and school (Berger & Thompson, 1995; Oltmanns & Emery, 2001).

Types and Forms

Lenhart divides developmental disabilities into the following four categories: (a) cognitive impairments (e.g., communication disorders; learning disorders like dyslexia, dyscalcula, and attention-deficit hyperactivity disorder [ADHD]; and mental retardation), (b) sensory (e.g., blindness and deafness) and other physical impairments (e.g., mobility and motor skills), (c) genetic disorders (e.g., Down syndrome, fragile-X syndrome, and Phenylketonuria [PKU]), and (d) neurological disorders (e.g., autism, cerebral palsy, and epilepsy). These categories are not mutually exclusive; for instance, PKU (a genetic disorder characterized by hyperactivity and mental retardation) would be considered both a cognitive impairment and a genetic disorder.

Prevalence

Because the U.S. Census Bureau measures disability by collecting data on only a few specific impairments, and due to inconsistent operational definitions for developmental disabilities, it is difficult to give precise statistics. That being said, a 1995 sample collected by the Census Bureau yielded the following prevalences for developmental disabilities of the following specified age groups: children under 3 years of age (2.6%), children ages 3-5 (5.2%), children and adolescents ages 6-14 (12.7%), and adolescents and young adults age 15-21 (12.1%). Within the 15-21 year-old group, a staggering 3.2% reported having severe developmental disabilities. However, contrasting findings by Dell Orto and Marinelli (1995) indicate only 1.6% of school-age children and 1.5% of adults in U.S. have developmental disabilities. Still, these more conservative statistics indicate that developmental disabilities affect the lives of millions of people in the United States.

Parenting Children with Developmental Disabilities

Parental Stresses and Adaptation

Raising a child with disabilities usually results in multiple stresses to which families must cope. These stresses usually disrupt family functioning (Cole, 1986; Gabel, McDowell, & Cerreto, 1983; Martin & Colbert, 1997; McCubbin, Cauble, & Patterson, 1982). However, considerable variance exists among families' abilities to make the necessary adaptations to not only rear the child with special needs, but also to function successfully as a family (Cole, 1986; Crnic, Friedrich, & Greenberg, 1983; Dunst et al., 1987). A considerable amount of literature has been dedicated to understanding how families adapt to raising a child with developmental disabilities; nonetheless, the body of literature and related theoretical models lack coherency and consistency (Cole, 1986; Crnic et al., 1983). The following section seeks to organize and summarize the findings of key studies regarding parental adaptation to the stresses associated with raising a child with developmental disabilities.

Child-Related Stresses

Many of the stresses faced by parents of children with developmental disabilities result from their child's disabilities. Such child-related parental stresses include: (a) initial diagnosis; (b) identities and roles; (c) caregiving; (d) level of disability; (e) availability of, and access to, necessary services; (f) education; (g) financial stresses; (h) decisions about guardianship; and (i) family functioning and relationships.

Initial diagnosis. Dunst et al. (1987) state that a significant amount of research has indicated that family integrity and individual well-being are frequently profoundly affected by the birth and/or raising of a child with special needs. Shock, denial, and

disbelief are common reactions to the sudden or unexpected discovery that a child has a disability (Martin & Colbert, 1997; Turnbull & Blacher-Dixon, 1980). However, parents may actually experience a sense of relief in situations where the diagnosis confirms suspicions and provides answers (Martin & Colbert, 1997). Following these widespread reactions, parents usually grieve for their child—the shattering of dreams, possibilities, and potentials (Martin & Colbert, 1997). This painful process of loss often results in an emotional roller coaster where feelings of anger, depression, denial, grief, guilt, physical distress, resentment, and sadness are not uncommon (Gabel et al., 1983; Martin & Colbert, 1997; McCubbin et al., 1982). Although accepting the impairment(s) faced by their children typically becomes easier with time, the emergence of new challenges, incongruities between child achievement and parent expectations, and unmet developmental milestones (e.g., walking, talking, dating, launching, marriage, etc.) often bring renewed feelings of grief and sadness throughout the life cycle (Wikler, 1981).

Identities and roles. Parental roles are often altered or adjusted to provide the necessary care (Martin & Colbert, 1997). Ambivalence about their new identity as parents of a child with disabilities and anxieties about the uncertainty of their child's future (Waisbren, 1980) only add to the parents' stresses. In addition, due to the nature of their disabilities, children with developmental disabilities often must rely upon others to champion their special needs. Parents are usually the ones to step up and become their child's advocate (Karp & Bradley, 1991; Martin & Colbert, 1997).

Caregiving. Perhaps it is not surprising that parents attribute most of the stresses they experience to caregiving (Beckman-Bell, 1981). Many children affected by impairments are unable to do things on their own that are typically taken for granted (e.g.,

bathe, dress, eat, move, follow directions, communicate); consequently, caregiver demands are often challenging, persistent, and prolonged (Kobe et al., 1991; Martin & Colbert, 1997). Parenting a child with developmental disabilities not only affects the intensity of caregiving, but may also result in extending the period of parental caregiving, as the development of autonomy for children with disabilities is often compromised and/or delayed (Martin & Colbert, 1997). Special medical and educational training for parents, in addition to routine meetings and visits with various professionals, creates additional time demands and stressors (Martin & Colbert, 1997). Leisure and recreational activities (e.g., vacations and outings) and everyday activities (e.g., shopping and running errands) are also greatly affected (Cole, 1986). Consequently, exhaustion and burnout are common among parents (Martin & Colbert, 1997).

The characteristics of the child with disabilities can drastically increase the stresses associated with caregiving. Challenging child behaviors (e.g., biting, hitting, getting into cupboards and refrigerators, running away, self-stimulation such as poking eyes, head banging, picking nails off), can be a major source of stress to parents and a powerful predictor of out-of-home placement (Allen, 1972; Borthwick-Duffy et al., 1987; Cole, 1986; Eyman, O'Connor, Tarjan, & Justice, 1972; Hodapp & Zigler, 1985; Kobe et al., 1991). These dangerous behaviors frequently require constant supervision to insure the safety of the child and other family members. The age and the size of the child is also a factor in that the older a child becomes, the more physically demanding care may become (Blacher & Baker, 1994; Bromley & Blacher, 1989; Hodapp & Zigler, 1985; Kobe et al., 1991; Martin & Colbert, 1997; Sherman, 1988). Crnic et al. (1983) and Dunst

et al. (1987) add challenging temperaments and unresponsiveness to the list of stressful child attributes.

Level of disability. Although there are standard operationalized definitions for mild, moderate, severe, and profound mental retardation (American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 2000, text revision), no standard measure exists for determining the severity of developmental disability. There has been a recent shift in terminology from focusing on level of disability to intensities of needed supports (i.e., intermittent, limited, extensive, and pervasive needed supports replace mild, moderate, severe, and profound levels of disability) (Oltmanns & Emery, 2001). However, at present, these terms have only been instituted for use among people with mental retardation—the only population that had been specifically identified by the former system. Most available measures for assessing level of developmental disability focus on levels of functioning in various key areas (e.g., personal hygiene, language skills, learning capacity, mobility, capability for self-sufficiency and self-direction). Levels of developmental disability have been globally defined as mild, moderate, severe, and profound.

While a limited number of study results suggest otherwise (Bromley & Blacher, 1989; Hodapp & Zigler, 1985), an overwhelming body of research has found that the severity of a child's developmental disabilities is positively correlated with time demands, pessimistic parental attitudes, negative parental perceptions of the child, family deterioration, and out-of-home placement (Blacher & Baker, 1994; Borthwick-Duffy et al., 1987; Dunst et al., 1987; Dyson, 1991; Eyman et al., 1972; Kobe et al., 1991; Martin & Colbert, 1997; Sherman, 1988; Westling, 1997). People with severe or profound

disabilities frequently have multiple disabilities. It is not unreasonable to posit that with each additional disability a child's special needs tend to increase accordingly; thus, children with severe and profound disabilities are the most likely to need special care and services due to the significant impairments to their growth and development.

Consequently, children with multiple disabilities are apt to have more special needs, be the source of more parentally-perceived stresses, and are similarly the most likely to be placed. In fact, the vast majority of children with developmental disabilities in out-of-home care are those who have been diagnosed as having severe or profound developmental disabilities (Blacher, 1994).

The extent to which parents of children with developmental disabilities experience the stressors described in this section (*Child-Related Stresses*) depends significantly on the level of the children's disabilities. For instance, consider raising a child whose legs are different lengths (mild); a child who has blindness (moderate); a child with extreme mental retardation (severe); and a child living with autism, cerebral palsy, epilepsy, and diabetes (profound). Accordingly, the more serious the impairment, the more intensely stresses are experienced by parents (Palfrey, Walker, Butler, & Singer, 1989).

Availability of, and access to, necessary services. Advocacy is crucial in the process of obtaining necessary services (Karp & Bradley, 1991). Securing appropriate services can prove to be a stressful responsibility for parents (Martin & Colbert, 1997). Acquiring the necessary services can be a very confusing and frustrating process with bureaucratic red tape, different services through different providers, conflicting professional recommendations, waiting lists, etc. (Bernheimer et al., 1983; Martin &

Colbert, 1997). Common services needed by parents include respite care, occupational therapy, physical therapy, speech therapy, and educational and recreational services (Martin & Colbert, 1997). Even after appropriate services are in place, high staff turnover rates and transitions from one program to the next often require parents to continually face complicated choices (Martin & Colbert, 1997).

Education. As with all children, the parental role in education is extremely important. Parents of children with developmental disabilities tend to be more involved with their child's education than parents of children without developmental disabilities (Westling, 1997). In fact, parents of children with disabilities have key responsibilities for enhancing their child's development by providing an integral part of their child's educational experience at home (Martin & Colbert, 1997). These responsibilities may require special training and instruction on the part of parents. Parents are required to collaborate with teachers and educational institutions to insure that their child's Individual Education Plan (IEP) is realistic and appropriate (Martin & Colbert, 1997). Parents can become easily discouraged when their child fails to meet educational expectations and IEP goals.

Financial stresses. Exorbitant health care costs, necessary services expenses, and reduced family income are common struggles faced by parents of children with special needs (Crnic, et al., 1983; Dunst et al., 1987; Martin & Colbert, 1997). Special diets, habilitative equipment, medical care, and special transportation are common expenses among children with developmental disabilities (Martin & Colbert, 1997). Medical advances have prolonged the lifespan of children with severe and profound disabilities

(Karp & Bradley, 1991; Martin & Colbert, 1997), resulting in extended child-related expenses.

Socioeconomic status (SES) is one of the predictors for placement of a child with developmental disabilities. People from higher SES levels (e.g., higher incomes, college education) are less likely to request placement than are people from lower SES levels (Erickson, 1990), presumably because the latter cannot afford the supplemental services necessary to adequately care for their child. The financial strains on parents are further magnified by the frequent finding that in two-parent households, only one parent is able to work, so that the other parent can remain at home to provide the necessary care, substantially reducing household income (Martin & Colbert, 1997). This scenario plays out even more harshly for single parents (Boyce, Miller, White, & Godfrey, 1995) (see Family characteristics in Family-Related Stresses).

Decisions about guardianship. Parents also find themselves worrying about their child's future welfare after they themselves (the parents) die, especially those whose children are unable to live independently (Martin & Colbert, 1997; Wikler, 1981). Asking someone else to take over the guardianship is an extremely difficult and emotional decision for parents who know firsthand how stressful some of the responsibilities may be (Martin & Colbert, 1997).

Family functioning and relationships. In addition to affecting family functioning, raising a child with developmental disabilities often has negative effects on both relationships within the family and interactions with extra-familial people (Cole, 1986; Dunst et al., 1987; Martin & Colbert, 1997). Within the family, marital discord and strained parent-child relationships are common. Familial associations with other

caregivers, caseworkers, neighbors, and extended family are a few examples of other relationships that may be adversely affected. The strain on these relationships may result in psychosocial problems including depression, withdrawal, elevated stress levels, and physical distress (Blacher, 1984; Crnic et al., 1983).

Family-Related Stresses

In addition to the stresses directly linked to raising a child with developmental disabilities, parents also have to deal with a variety of stressors unconnected to their child's special needs; these non-child related stressors can also be augmented by various family characteristics.

Non-child related stressors. Disruptions of family life have also been identified as a source of parental stress (Blacher & Baker, 1994; Eyman et al., 1972; Sherman, 1988; Sherman & Coccozza, 1984). Geographic relocation, health of caregivers, marital discord, mental health of family members, serious crises, social isolation, and unemployment are among other family stressors associated with adding additional stress to rearing a child with disabilities (Cole, 1986; Eyman et al., 1972; Kobe et al., 1991; Martin & Colbert, 1997).

Family characteristics. The household composition may generate family-related stresses. Family size has been established as being positively correlated with stress (Sherman, 1988; Sherman & Coccozza, 1984). It follows that because the amount of parental resources (e.g., time, money, and energy) is fixed, each additional child or relative puts additional demands on the parent's resources. Also, several studies (Boyce et al., 1995; Gottlieb 1997; Sherman, 1998; Sherman & Coccozza, 1984) indicate that single-parent households have fewer personal resources available to be allocated

specifically to the child with developmental disabilities. High child related demands and limited parent resources make single parents more likely to place than married parents.

The stresses discussed in this section have been studied and explored as predictive factors of placement; virtually no research has explored the stressors parents experience after placement.

Family Resources

The degree of stress experienced by parents is clearly influenced by the availability of family support services (Petr et al., 1995). Many of the relevant resources for parents of children with developmental disabilities are resources that reduce the experienced stressors. In other words, in most cases the necessary resources are going to be the ones that compensate for the areas of more acute stress. Family support services are aimed at reducing family stress in two ways: indirectly by minimizing the stressful effects that the child's characteristics may have on the family through services like respite care, behavior management, etc.; and directly by attempting to reduce the effects of family stressors through services such as therapy, quality health care, and family support groups. Therefore, although family stressors are the primary determinants of placement, family support services can be used to minimize family stress.

Karp and Bradley (1991) list the following three goals of family support services: (a) increasing the capacities of family caregivers, (b) circumventing preventable out-of-home placements, and (c) facilitating the return of family members in out-of-home care. Karp and Bradley continue by describing the ideal family support services as (a) flexible, (b) easily accessible (c) community-based, (d) family-centered, (e) displaying cultural and religious sensitivity, (f) providing interagency collaboration and coordination, (g)

striving to keep families together, (h) involving the family in all relevant processes, (i) putting families in control of decision-making, (j) changing according to family needs, (k) helping families access community resources, and (l) focusing on the entire family. Sadly, most parents report being highly dissatisfied with the support services available to them (Westling, 1997).

The intense demands of raising a child with severe or profound disabilities make it difficult for parents to maintain friendships, resulting in isolation (Martin & Colbert, 1997). Social isolation may also occur when neighbors avoid the family due to beliefs and misconceptions about developmental disabilities (Martin & Colbert, 1997). Research indicates that the larger the available social network to families with a child with developmental disabilities, especially extended family, the more effective it is at reducing stresses (Bromley & Blacher, 1989; Bruns, 2000; Crnic et al., 1983; Dunst et al., 1987; Martin & Colbert, 1997; Sherman, 1988; Sherman & Coccozza, 1984).

Access to resources (e.g., time, money, equipment) and community support services has been shown to reduce family stresses (Bruns, 2000; Cole, 1986; Sherman, 1988). Needed community services may include educational consultation and training, family social support, financial assistance, in-home professional assistance, information dissemination about available services, medical care and insurance, recreational programs, respite care, support groups, therapeutic services (e.g., occupational, physical, psychotherapy, and speech), and transportation (Cole, 1986; Crnic et al., 1983; Dunst et al., 1987; Eyman et al., 1972; Karp & Bradley, 1991; Kobe et al., 1991; Martin & Colbert, 1997; Ott & Langer, 1987; Petr, Murdock, & Chapin, 1995; Westling, 1997).

Parental Perceptions of Stressors

According to Cole (1986), parental perceptions include beliefs, attitudes, and awareness. Crnic et al. (1983) and Dunst et al. (1987) include parental self-concept as an important part of parental perceptions. The way in which people define their problems is primarily determined by their perceptions. Therefore, the way in which parents interpret their stresses has a significant effect on the degree to which the stresses are experienced. Parental interpretation of stresses is an integral part of the model resulting from the current study; each type of emotional stressor that parents experienced was influenced by the cognitions associated with it.

Furthermore, parental perceptions of stress are significantly influenced by the family's ecology (Crnic et al., 1983). For example, cultural contexts (e.g., beliefs and practices) like ideas about institutionalization and disability can influence parental attitudes toward placement and the stigma of being a parent of a child with developmental disabilities (Martin & Colbert, 1997).

Out-Of-Home Placement

Placement Decisions

Ironically, the decision that is often made to relieve stresses is perhaps one of the greatest stresses faced by parents: that of placing their child in some form of out-of-home care. The decision itself has been considered a stressful milestone encountered by parents of children with disabilities (Wikler, 1981). It is estimated that up to 40% of children with severe or profound mental retardation are placed by the end of adolescence (Meyers, Borthwick, & Eyman, 1985). The placement process is important to understand because of the lasting effects it can have on both the child and the family. According to Erickson

(1990), once children are placed in out-of-home care, they tend to remain in placement through the rest of childhood. Erickson also noted that a large number of children experience multiple placements. Although parents tend to express satisfaction with their child's placements (Westling, 1997), few parents make this decision without experiencing the pain of relinquishing an integral part of their lives (Blacher & Baker, 1994). Discussions about placement are anguishing to parents (Martin & Colbert, 1997). Parents have to consider the child's needs, their needs, and the needs of the entire family (Martin & Colbert, 1997). According to Blacher and Baker (1994), placements tend to follow a gradual accumulation of child-related stresses.

From Institutionalization to Permanency Planning

Throughout much of history, parents have responded to the challenges of raising children with developmental disabilities by turning to infanticide, orphanages, and institutions. The last quarter of the twentieth century saw a major push for *normalization*: providing people who have disabilities with elements and conditions as close as possible to those of mainstream society (Nirje, 1969). By encouraging deinstitutionalization through the development of community-based services, interventions, and treatments, the normalization principle increased the likelihood that persons with developmental disabilities would be able to remain at home (Blacher, 1994; Cole, 1986; Karp & Bradley, 1991; Martin & Colbert, 1997). Such community programs have included respite care, education programs, and home visits by trained professionals.

Recent relevant national policies have promoted *permanency planning*, a set of guiding principles aimed at protecting the rights and needs of people with disabilities, with an emphasis on preventing out-of-home placement by increasing the amount and

quality of available community-based resources, thereby making maintaining children in their natural home environments more feasible and practical (Blacher, 1994; Richardson, West, Day, & Stuart, 1989). The recent development of permanency planning has become the philosophical underpinning of many successful programs for children with disabilities. Research has concluded that children's needs are best met when the children live in a family environment (Webb, 1988), and permanency planning springs from that idea. The fundamental belief behind permanency planning is that "every child, including a child with developmental disabilities, has the right to a permanent home and a stable relationship with one or more adults" (Erickson, 1990, p. 2).

[Permanency planning] is designed to return every child who enters care to the stability of a family—his or her own biological family, an adoptive family, or, if need be, a permanent foster home—as quickly as possible" (Fein & Maluccio, 1984, as cited by Grayson, 1985, p. 4). The guiding principles of permanency planning have been set forth as "a stable, consistent family environment that provides nurturing, support, safety, and love with long-term attachments provides the greatest opportunity for a child to grow and learn during the time limited years of childhood. (Erickson, 1990, pp. 2-3)

A Statement in Support of Families and Children (Adapted from a Statement in Support of Families and Children from the Center on Human Policy, June 1986, as cited in Erickson, 1990) establishes the specific goals of permanency planning that include: (a) families shall receive the supports necessary to maintain their children at home; (b) family supports shall build on existing social networks and natural sources of support; (c) family supports shall maximize the family's control over the services and supports they

receive; (d) family supports shall be available for the entire family; (e) family support services shall encourage the integration of children with disabilities into the community; and (f) when children are without families, adoption shall be aggressively pursued.

Permanency planning also holds that the best family environment is typically that of the child's birth family, with situations of abuse, neglect, and parental irresponsibility being the exceptions (Grayson, 1985). Consequently, permanency planning advocates "provid[ing] services that will prevent the removal of the child from the family or that will permit the return of the child to the family from out-of-home care" (Ott & Langer, 1987, p. 15). In situations where out-of-home placement has already occurred, family reunification is attempted, and if not possible, high levels of family involvement are strongly encouraged (Blacher, 1994). It is important to note that permanency planning is the ideal; unfortunately, in many regions of the United States, it is far from a present reality, even though it proves to be less expensive than other forms of placement (Grayson, 1985; Karp & Bradley, 1991; Meyers & Marcenko, 1989). Consequently, out-of-home placement still occurs frequently.

Types of Placement

The responsibility of distributing services to people with disabilities has been allocated to the individual states; as a result, each state has developed its own unique system for deploying disability services (Richardson et al., 1989). Conversely, most providers of out-of-home care are private agencies (Webb, 1988). Because most families of children placed in out-of-home care receive government subsidies, once they become licensed by the state, providers must continue to satisfy state stipulations and operate within state guidelines. Even though many of the state agencies' functions, goals,

approaches, and policies are similar, the differences in types and delivery of services between states are such that literature reviews and resulting research must be rather extensive for findings to be generalizable across different states. Notwithstanding disparities among states, there are several general forms of placement for children with disabilities that are similar across states.

Adoption. Families participating in adoptive care are recruited volunteers who generally receive family support services. Adoptive care differs in its finality from the other types of placement because of its permanent nature. In fact, “adoption often becomes the plan of choice for children who cannot be cared for by their birth families because this alternative most closely simulates the parent-child relationship which exists in the birth family” (Michigan Permanency Planning Project, 1986, as cited in Ott & Langer, 1987, p. 24). Ott and Langer distinguish between varying forms of adoption: subsidized adoption, foster parent adoption, open adoption, permanent foster family, and co-parenting agreements (which are the least consistent with permanency planning because they do not ensure the child one permanent, stable family environment).

Foster care. Foster care is designed to allow birth parents to temporarily place their child in a family environment other than their own. *Specialized foster care* is the term used to refer to foster care for children with disabilities (Webb, 1988). Providers of foster care try to place each child with a family that will be able to provide the most beneficial environment for the child’s development (Webb, 1988). Consequently, normalization is a strength of foster care because the child is being raised in a family environment (Webb, 1988); however, the stability of that environment is limited as foster care is only a temporary placement and not a permanent solution. Foster families are

recruited on a volunteer basis. Most programs require foster parents to receive both pre-service and in-service trainings in areas such as child development and behavioral management (Webb, 1988). In many programs, the foster parents become *treatment parents*, as they are also trained to execute the therapies required by the child (Bryant & Snodgrass, 1991). As a general rule, foster families almost always receive multiple forms of family support services. There are several different kinds of specialized foster care: short-term, extended, treatment parent care, and kinship care (Ott & Langer, 1987). In shared parenting arrangements, also referred to as *professional parenting care*, parents are encouraged to remain actively involved with the treatment and growth of their child, in accordance with permanency planning (Richardson et al., 1989).

Residential care centers. Residential care is closest to what most people envision institutional care to be. Residential care centers employ a sizable staff to provide 24-hour care to multiple patrons with developmental disabilities. Recent trends and policies discourage institutional and residential placement because they fail to provide a stable family environment (Meyers & Marcenko, 1989).

Assisted living and group homes. The recent trend has been toward assisted living programs and group home settings. Group homes typically provide round-the-clock services to anywhere between 2 and 12 patrons, with a 1:2 to 1:4 staff-patron ratio. The group homes are generally in residential neighborhoods to facilitate integration with the community. Assisted living arrangements are similar to group homes, but smaller in scale: an assisted living apartment, as a rule, has only 1-4 residents with a staff-resident ratio of 1:1 or 1:2. The staff “assists” the residents in living as independently as possible by providing the necessary support.

In summary, an examination of the literature on placement indicated that parents of children with developmental disabilities are prone to facing considerable challenges, in terms of stresses relating to the nature of the child's disabilities and limited accessibility of frequently inadequate resources. The ways in which parents perceive the stresses determine, to a large extent, the degree to which they experience the stresses. When the stresses experienced by the parents become overwhelming, the parents may seek an out-of-home placement for their child in order to alleviate some of the stresses and pressures of caring for their child at home. The primary recent push has been away from institutionalization and toward permanency planning. Yet, how parents adapt to life after their child has been placed has been unequivocally neglected.

Research Questions

Researchers have explored stressors experienced by parents of children with disabilities, but have not addressed if, and how, stressors may continue after the child no longer resides with the parents. Although attention has been given to the factors that lead up to the decision to place a child with disabilities in out-of-home care, the aftermath of that decision has been largely ignored. All decisions have their ramifications, even if it is just adapting to change.

The data for the current study consist of interviews with parents of children in out-of-home care. The children were not interviewed regarding the decision, because research indicates that parents are the ones who make placement decisions, not the children (Minkes, Robinson, & Weston, 1994). The present study focused on parents of children with severe or profound disabilities. It was anticipated that because parents of children with severe or profound disabilities tend to experience more pronounced

stresses, interviewing parents of children with severe or profound disabilities would more easily facilitate the identification of patterns of family adaptation to life after placement. In addition, because parents of children with severe or profound disabilities are the parents most likely to make placement decisions, they stand to receive substantial benefits from the findings of the current study.

The research questions were developed from relevant research, the committee members for this study, and the guiding principles of grounded theory to tap the most basic elements of adaptation: advantages, stressors, and coping methods.

Questions

1. What are the prevalent advantages and stressors that parents experience *following* the voluntary placement of a child with severe or profound developmental disabilities in some form of out-of-home care?
2. What are the general parental coping methods for managing the stressors and adapting to the changes associated with life *after* placing a child with severe or profound developmental disabilities in some form of out-of-home care?

CHAPTER 2

METHOD

Background and Overview of the Study

The study design for this research was a data analysis of qualitative data from a one-shot, retrospective, self-report, exploratory study. The data were previously collected by the principal investigator. The original study was approved by institutional review boards at Brigham Young University and the Utah Department of Human Services in 2000; the study was subsequently reviewed and renewed annually through 2004 by both boards. The data were originally collected in conjunction with grants from the Office of Research and Creative Activities at Brigham Young University and from the Utah Governor's Council for People with Disabilities. Data collection began in March 2000 and concluded in February 2003. The data, which were transcribed and coded interviews conducted with parents who previously placed a child with severe or profound special needs in an out-of-home setting, cover a wide range of issues relating to the placement of such a child. Only the portions of the data set relevant to the purpose of the current study were used.

Theoretical Orientation and Design

This section will first explore and discuss the decision to adopt a qualitative approach for the proposed study. This dialectic is followed by a description of grounded theory and the qualitative research design selected for the structure and execution of the study.

Qualitative Research

Although considerably different in form and function, quantitative and qualitative research both make important and valid contributions to understanding human behavior. Yet, with the development of more sophisticated and intricate quantitative methods, the general research climate has focused on verifying theories, often at the neglect of generating new theories through qualitative inquiry (Guba & Lincoln, 1981). Whereas quantitative research is known for the ability to explain and illustrate phenomena through the use of numeric symbols and statistical analysis (Babbie, 1999), qualitative research has the distinction of exploring and interpreting observations and words holistically in an attempt to discover the underlying patterns and meanings of human phenomena (Babbie, 1999; Creswell, 1998). Qualitative forms of research inquiry focus on similarities and dissimilarities, behavioral norms, and universals (Babbie, 1999). In comparison to quantitative research, qualitative research tends to have more elusive and fluctuating conceptualizations and designs, a more rigorous data collection process, more lengthy and intricate data analysis procedures, and more lengthy results (Creswell, 1998). Both qualitative and quantitative forms of research have their strengths and limitations (Babbie, 1999), leading researchers to question which approach is most appropriate for the project at hand.

Guba and Lincoln (1981, 1998) cite the following reasons for deciding to employ qualitative research designs over quantitative ones. First, whereas quantitative designs necessarily limit the focus of study, qualitative designs promote an expansionist stance for holistically exploring the matter at hand. Similarly, where the language used in quantitative research is predetermined for the purpose of determining hypothesis validity,

qualitative research prides itself in the knowledge acquired through the connotations, emotions, and meanings communicated through language. Next, qualitative research provides contextual information that is often absent in quantitative work. Qualitative methodologies also reduce the ambiguities that may occur when statistically significant group findings are generalized and applied to individual cases (e.g., if 75% of people who exhibit 5 specific symptoms have clinical depression, this result provides inconclusive evidence that an individual with the 5 symptoms has clinical depression). In addition, qualitative research provides rich insight into human behavior. Further, qualitative inquiry allows investigators to generate theory inductively from data instead of deductively from *a priori* logic and assumptions. Guba and Lincoln assert that qualitative research yields inductively-generated, or grounded, theories by effectively addressing the issue of emics: Does current research really address the perceptions and experiences of the participants? In other words, is the research of the field (which is typically primarily quantitative) really measuring what is important to the experiences of the target population? Finally, qualitative research assists in the process of theory discovery that allows for future quantitative research to be more useful and valid.

The present investigator decided that a qualitative research design would be used for the original study for the following reasons: (a) to increase understanding of parents' experiences after placing a child with developmental disabilities in out-of-home care; (b) to inductively generate theory grounded in qualitative research by analyzing the experiences and perceptions of parents who decided to place; and (c) to provide results that will assist in generating designs for future qualitative and quantitative research.

Grounded Theory

The literature on qualitative research is vast, with noticeable divergence among writers' categorization and classification of their methods and approaches: what is called a theory by one author is called a philosophy, approach, framework, design and technique by others (Babbie, 1999). In an attempt to organize the conceptualizations of qualitative research, Creswell (1998) posits there are five primary paradigms of qualitative research design, or traditions of inquiry: biography, case study, ethnography, grounded theory, and phenomenology. Each of the five paradigms has philosophical origins and underpinnings, a theoretical framework, and is tailored to work most effectively with specific genres of qualitative inquiry. Every paradigm has delineated guidelines for conceptualizing (e.g., assumptions, purpose, questions) and designing (sampling, data collection, procedures, analysis, reporting findings) research.

The researcher determined that grounded theory was the best research design for the current study. John W. Creswell's work, *Qualitative Inquiry and Research Design: Choosing Among Five Traditions* (1998), written for the purpose of helping researchers decide which design is most appropriate to realize the purposes of a given project, was instrumental in facilitating the construction of this study. In addition, *the Handbook of Qualitative Research* (Denzin & Lincoln, 1994) was also helpful in determining grounded theory as the best fit for this study.

Developed by Barney Glaser and Anselm Strauss in 1967, grounded theory is an inductive approach to understanding human phenomena (Babbie, 1999; Creswell, 1998; Strauss & Corbin, 1994). Strauss and Corbin (1994) describe grounded theory as "a general methodology for developing theory that is grounded in data systematically

gathered and analyzed” (p. 273). The primary factor that distinguishes grounded theory from other qualitative approaches to inquiry is the emphasis on theory development (Strauss & Corbin, 1994). Another defining factor of grounded theory is the emphasis on continuous comparative analysis throughout the data collection process, which allows for verification of developing theory and hypotheses (Strauss & Corbin, 1994). The open methodology of grounded theory fosters the possibility that the researcher will discover the unforeseen (Babbie, 1999). Within this model of qualitative inquiry, the researcher has the responsibility to give voice to the experiences of the participants, and also to interpret their experiences (Strauss & Corbin, 1994).

Specific processes through which grounded theory develops the substantive theory seem an ideal fit for the scope of this study. These processes include identifying the central phenomenon, ascertaining and categorizing the strategies employed by participants to respond to the central phenomenon, and exploring the outcomes of employing the strategies (Creswell, 1998). Furthermore, grounded theory has been used in the past to understand stressors and related coping strategies associated with a given phenomenon (Morrow & Smith, 1995). Additional specifics of grounded theory relating to the study at hand, and adaptations from the methodology, will be discussed in the following sections of this chapter.

Sample

Theoretical sampling, a form of purposive sampling used in grounded theory qualitative research (Creswell, 1998; Dey, 1999; Strauss & Corbin, 1998), was used to identify potential participant parents. Within grounded theory, data are collected until categories become *saturated* (interviews no longer provide additional understanding of the

category) which typically requires a sample size of 20-30 individuals (Creswell, 1998). In grounded theory, it is essential that each participant have experienced the phenomena to be studied (Creswell, 1998). The firsthand experiences in common across participants allow for the development of themes and theory from the data (Babbie, 1999; Creswell, 1998). The theoretical sampling approach is used to select participants who will foster the sample homogeneity necessary to focus the data and generate results (Miles & Huberman, 1994). After the themes and an visual model have been developed, subsequent studies may be designed with a heterogeneous or more diverse sample for the purpose of confirming or disconfirming the results of the initial study (Creswell, 1998). Thus, in accordance with theoretical sampling, selection criteria were established to increase the likelihood that participants' experiences would be similar enough for saturation and convergence, yet unique enough to allow for depth and variability within themes. The levels of the sampling units for the sample are perhaps best described by the selection criteria.

Selection Criteria

All study participants met the following *inclusion criteria*:

1. The participant was a parent of at least one child with developmental disabilities.
2. The participant placed at least one child who has developmental disabilities in some form of out-of-home-care. For the purpose of participant selection, a *placement* was defined as a permanent, semi-permanent, or temporary out-of-home living arrangement for a child with developmental disabilities.
3. The disability level of the participant's child was determined as *severe* or *profound* at the time of initial placement. Level of disability was established as an

inclusion criterion to yield data representative of the group of parents most likely to make the decision to place (Blacher, 1994; Blacher & Baker, 1994; Borthwick-Duffy, Eyman, & White, 1987; Eyman et al., 1972; Kobe et al., 1991; Sherman, 1988; Westling, 1997) and for the purpose of creating homogeneity among the sample participants (Creswell, 1998; Miles & Huberman, 1994). *Severe or profound developmental disabilities* were operationalized in terms of the level of mental and/or physical disabilities of a person, as defined and measured by the Division of Services for People with Disabilities (DSPD) in the state of Utah. The Utah DSPD uses a six-point system to assess the level of disability and need (see Appendix A). A person receives one point for each category in which he or she manifests special needs. A person who obtains a score of one is considered to have mild disabilities, a score of two is considered moderate, a score of three or four severe, and scores of five or six are interpreted as profound. The Utah DSPS system for determining levels of disability has seven total categories within which level of disability is assessed: self-care, expressive and/or receptive language, learning ability (IQ), mobility, capacity for independent living, self-direction, and economic self-sufficiency. Categories 6 and 7 are mutually exclusive, according to the age of the child: ages 6-18 are scored on category 6 while children older than 18 are scored on category 7; for the selection criteria for this study, children placed under the age of 6 were only scored on the first 5 categories, with a total score of 3 still being required for inclusion. Half-points were used in rare situations where a child had displayed some special needs in a given category, but

not to the degree necessary to receive a full point for that category, as specified by the DSPD measure.

4. The placement(s) of the participant's child has (have) been in the state of Utah. The purpose of this inclusionary criterion was also to foster sample homogeneity. As previously indicated, notable variance exists among the structure, administration, and accessibility of state services for people with disability. Thus, parents receiving services in different states may have dissimilar placement experiences as a result of location rather than distinctive coping strategies.
5. The participant made the initial placement decision when the child was between 2 and 30 years of age. The age of the child at the time of initial placement was made an inclusion criterion to facilitate participant homogeneity along the lines of developmental stages of the children when the decision for their placement was made. It was hypothesized that parents who made the decision to place before their child was two years old may have had exceptional experiences, as the care for infants with disabilities is typically little different than care for a child without developmental disabilities. It was also theorized that parents who raised their children into their thirties at home before pursuing placement may have had different motives for seeking placement (e.g., concerns about who will care for their children when they are no longer able). The specified sample range was wide enough to allow for adequate variation between circumstances and motives.
6. The participant made the decision to place the child at least one year prior to the interview. This inclusion criterion served the purpose of increasing the likelihood

that at the time of data collection adequate time had passed since the placement decision was made for parental retrospection to be possible.

7. The participant was married at the time of the initial placement (the participant did not need to be married at the time of the interview). Again, this criterion was included to increase group homogeneity regarding the experiences surrounding placement. As previous research has indicated (Gottlieb 1997; Sherman, 1998; Sherman & Coccozza, 1984), single parents are more likely to place than married parents, most likely because the resources necessary to care for children with special needs tends to exceed those of single parents. Therefore, the motives for placement and surrounding experiences could disrupt sample homogeneity.

Exclusion from the study was contingent upon meeting any the following criteria:

1. The placement of the participant's child was obligatory (e.g., court ordered). This was determined as grounds for sample exclusion to maintain sample homogeneity. It was hypothesized that parents who have the placement decision made for them would have experiences very different from those parents who voluntarily made the decision to place.
2. The interviewer and the potential participant knew each other prior to the study. Preceding associations between the interviewer and potential participant was made an exclusion criterion to increase the probability that participants would feel free to be candid during the data collection processes.

In cases where two parents of the same child were available to be interviewed, an effort was made to interview both parents. However, if one spouse chose to participate and the other did not, the willing partner was not excluded from the sample. It was also

not necessary to be a biological parent of the child with special needs to qualify for participation in the study.

A pool of potential participants was identified from Davis, Salt Lake, and Utah Counties (known as the *Wasatch Front*) by state and private agencies in Utah. The state and private agencies had access to contact information for the parents of children receiving funding or services under their respective auspices. The sampling frame consisted of 75 families, of which 52 were successfully contacted. The researcher attempted to contact the remaining 23 families, but contact was never established due to non-responses (e.g., the individuals were not available) or inaccurate information (e.g., disconnected phone numbers, wrong phone numbers). From the 52 contacted families, 11 were not interested in participating after the study was explained; 20 did not meet the selection criteria (2 of which were never contacted because the researcher knew them); 2 met the selection criteria and expressed desire to participate, but could not because of various extenuating circumstances; which left 21 families who met the selection criteria and agreed to participate in the study. One of the 21 interviews was deemed unusable due to a large amount of missing data. Of the 20 usable interviews, 16 were conducted with couples; the remaining 4 were conducted with individuals. Of the four individual interviews, three were mother-only interviews (two of the mothers had divorced the fathers after placement, and the other mother's husband was deceased) and one was a father-only interview (the mother had passed away after placement). This yielded a total number of 36 participants. It is also important to note that all sample participants were volunteers who were given no remuneration.

Sample Characteristics

Of the 20 interviews, 16 were couples, 3 were individual mothers, and 1 was an individual father, bringing the total to 36 participating parents (i.e., 17 fathers and 19 mothers). Of the 36 participants, 3 were not biological parents (i.e., one couple had adopted their child with disabilities and the other non-biological parent was a step-father). One of the couples interviewed were both biological parents who were married to other people at the time of placement, and then married to each other prior to the interview. Out of the four participating parents interviewed individually, two of the parents had spouses who had died after the placement decision was made (one of those participating parents had remarried at the time of the interview), while the other two parents had divorced the other biological parent of their child since placement had occurred (both participating parents had also remarried by the time of the interview).

It was decided not to present the 20 interviews as cases with pseudonyms for two primary reasons: (a) compiling participant profiles may have compromised confidentiality, and (b) the sheer size of 20 cases seemed to be an unmanageable number for readers to be able to easily and readily distinguish.

Tables 1-3 were generated from demographic and other relevant information taken from the interviews and questionnaire and describe participant characteristics.

Table 1

Characteristics of Families

Characteristics	<i>n</i> =20	%
Time elapsed between initial placement and		
interview (in years)		
2-5	5	25
6-10	6	30
11-15	2	10
16-20	2	10
21-25	3	15
26-30	1	5
31-35	0	0
36-40	0	0
40-44	1	5

Table 1 continued

Characteristics of Families

Characteristics	<i>n</i> =20	%
Number of children in family at initial placement (including child with developmental disabilities)		
1	1	5
2	3	15
3	2	10
4	9	45
5	2	10
6	1	5
7	0	0
8	2	10
Length of marriage at initial placement		
2-5	2	10
6-10	4	20
11-15	5	25
16-20	2	10
21-25	5	25
26-30	1	5
NA	1	5

Table 1 continued

Characteristics of Families

Characteristics	<i>n</i> =20	%
^a Household income at initial placement		
Under \$10,000	0	0
\$10,000 - \$19,999	0	0
\$20,000 - \$29,999	3	15
\$30,000 - \$39,999	4	20
\$40,000 - \$49,999	4	20
\$50,000 - \$59,999	4	20
\$60,000 - \$69,999	1	5
\$70,000 - \$79,999	2	10
\$80,000 - \$89,999	0	0
\$90,000 - \$99,999	0	0
\$100,000+	2	10

^aThe household incomes were converted to the value of the dollar in 2003 using the purchasing power of money index.

Table 2

Characteristics of Participating Fathers and Mothers

Characteristics	Fathers		Mothers		Total	
	<i>n</i> =17	%	<i>n</i> =19	%	<i>N</i> =36	%
Age at placement (in years)						
16-20	0	0	1	5	1	3
21-25	1	6	1	5	2	5
26-30	0	0	1	5	1	3
31-35	4	23	5	27	9	25
36-40	4	23	4	21	8	23
41-45	7	42	6	32	13	36
46-50	1	6	1	5	2	5
Age at interview (in years)						
31-35	1	6	1	5	2	5
36-40	1	6	3	16	4	11
41-45	2	11	3	16	5	14
46-50	3	18	6	32	9	25
51-55	6	35	3	16	9	25
56-60	3	18	1	5	4	11
61-65	0	0	0	0	0	0
66-70	0	0	1	5	1	3
71-75	1	6	0	0	1	3
76-80	0	0	1	5	1	3

Table 2 continued

Characteristics of Participating Fathers and Mothers

Characteristics	Fathers		Mothers		Total	
	<i>n</i> =17	%	<i>n</i> =19	%	<i>N</i> =36	%
Education level at initial placement						
Less than high school	2	12	0	0	2	5
Completed high school	2	12	5	26	7	20
Some college	3	18	7	37	10	28
Undergraduate degree	6	35	4	21	10	28
Graduate degree	3	18	2	11	5	14
Doctorate degree	1	5	1	5	2	5
Employment status at initial placement						
Full-time	17	100	6	32	23	64
Part-time	0	0	3	16	3	8
Homemaker	0	0	10	52	10	28
Unemployed	0	0	0	0	0	0
Retired	0	0	0	0	0	0
Race						
Asian	1	6	0	0	1	3
Caucasian	16	94	19	100	35	97

Table 2 continued

Characteristics of Participating Fathers and Mothers

Characteristics	Fathers		Mothers		Total	
	<i>n</i> =17	%	<i>n</i> =19	%	<i>N</i> =36	%
Religious orientation						
Atheist	1	6	0	0	1	3
Catholic	0	0	1	5	1	3
Latter-day Saint (Mormon)	15	88	16	85	31	86
Unitarian	0	0	1	5	1	3
No religious orientation	1	6	1	5	2	5
Satisfaction with placement						
Extremely satisfied	6	35	10	53	16	44
Very satisfied	7	41	4	21	11	30
Moderately satisfied	2	12	3	16	5	14
Satisfied	0	0	1	5	1	3
Dissatisfied	0	0	1	5	1	3
Very dissatisfied	1	6	0	0	1	3
Extremely dissatisfied	1	6	0	0	1	3
Permanency of placement decision						
Permanent	15	88	17	89	32	89
Temporary	1	6	0	0	1	3
Undecided	1	6	2	11	3	8

Table 3

Characteristics of the Participating Parents' Children with Developmental Disabilities

Characteristics	<i>n</i> =20	%
Gender		
Female	9	45
Male	11	55
^aDisabilities		
Autism	11	55
Behavior disorder	13	65
Cerebral palsy	2	10
Communication disorder	16	80
Developmental delay	18	90
Down's syndrome	2	10
Epilepsy/seizure disorder	11	55
Hearing impairment	0	0
Mental retardation	20	100
Orthopedic impairment	5	25
Visual impairment	4	20
Other rare disabilities	3	15

Table 3 continued

Characteristics of the Participating Parents' Children with Developmental Disabilities

Characteristics	<i>n</i> =20	%
^b Level of Disability		
Severe	7	35
3	2	10
4	5	25
Profound	13	65
5	8	40
6	5	25
Initial form of placement		
Group home care	9	45
Professional parenting care	4	20
Residential care center	7	35

Table 3 continued

Characteristics of the Participating Parents' Children with Developmental Disabilities

Characteristics	n=20	%
Age at initial placement		
2-5	4	20
6-10	6	30
11-15	4	20
16-20	4	20
21-25	1	5
26-30	1	5

^aAll of the children of the participating parents had multiple disabilities, as indicated by the high frequencies for many of the disabilities.

^bThe Severe and Profound levels of disability each have two subcategories that indicate the children's scores (3-6) as measured by the Utah Division of Services for People with Disabilities (Appendix A); scores of 3 or 4 are considered severe and scores of 5 or 6 are considered profound.

Most of the participating parents had four or more children, an anomaly for parents living in the United States. This is most likely a function of the high frequency (86%) of Latter-day Saint (Mormon) participants, who tend to have larger families on average. Also noteworthy is the fact that all of the fathers (100%) reported full-time employment at the time of placement, whereas only one third of the mothers (32%) were also employed full-time; conversely, more than half of the mothers indicated that they were full-time homemakers at placement, which is likely a result of the high care demands of the children with developmental disabilities.

The vast majority of the parents reported satisfaction with their child's placement (91%) and that their decision was permanent (89%). As indicated in the footnote of Table 3, all of the children of the participating parents had multiple disabilities. For example, a typical child might have mental retardation, autism, epilepsy, and communication disorders. The high frequency of multiple disabilities of the children in the sample is corroborated by the fact that 65% of the children were determined to have profound disabilities through the Utah DSPD six-point system (Appendix A). Finally, approximately 75% of the children were placed before reaching the age of 18.

Measures

Interview Questions

In accordance with grounded theory, a semi-structured interview (see Appendix B) was developed to facilitate and organize the collection of the data. A semi-structured format was selected for the interview, as it was deemed explicit and specific enough to elicit the detailed information necessary for analysis across participants, yet flexible and open enough to allow participants to tell their story (Hill, Thompson, & Williams, 1997a). As a result, probing questions were used to insure that there was enough information on the topics covered by the semi-structured interview and to increase understanding of the participants' experiences (Hill et al., 1997a).

An initial review of literature was conducted for the purpose of generating interview questions already grounded in data (Hill et al., 1997a; Strauss & Corbin, 1998). This process allowed the investigator not only to identify existing findings to shape the interview questions, but also to explore areas that had not been addressed in the literature, as well as to guard against errors made in previous research (Hill et al., 1997a). The personal experiences of the principal investigator as a habilitation technician in an out-of-home care center also contributed to drafting potential interview questions (Creswell, 1998).

The interview questions were then reviewed, rewritten, and reevaluated over a series of revisions. Dr. Susanne Frost Olsen, associate professor in the School of Family Life at Brigham Young University; Dr. Tina Taylor Dyches, assistant professor of Special Education at Brigham Young University; Dr. George Kelner, Associate Director of the Utah Division of Services for People with Disabilities (Utah DSPD); and Catherine

E. Chambless, Executive Director of the Governor's Council for People with Disabilities were consulted in the formulation of the interview questions. These individuals were selected on the basis of their contributions to the study of children with special needs. The input of these individuals was instrumental in the development of open-ended, unbiased, and non-leading questions necessary to allow participants to respond freely (Hill et al., 1997a). It was this group of professionals who determined that the phrase *special needs* would be used instead of *developmental disabilities* because of its less-pejorative connotation.

This development process for the interview questions increased the potential for face and content validity, both of which are already inherently high in qualitative research. One indication of content validity for the questions was the following common phenomenon that occurred during the interviews: upon being asked to tell their experiences surrounding raising a child with special needs and making the decision to place, the participants provided responses to many of the interview questions without them ever being specifically asked by the interviewer.

The interview questions were grouped in sections by topic. These sections were subsequently arranged in an order that would ideally lend itself to natural conversation. The following general themes were included: (a) stressful factors associated with home life, (b) reasons why placement was considered, (c) the steps and processes employed in reaching the placement decision, (d) various forms of related supports, (e) information regarding the child's placement(s), (f) noticeable changes that have occurred within the family since the time of initial placement, (g) use of therapeutic services by participants and other family members, and (h) retrospective effectiveness of the decision-making

processes. Although many of the interview questions do not appear to address parental adaptation to post-placement life (e.g., post-placement advantages, stressors, and the associated coping methods), the interview was only semi-structured; participants were encouraged to share their stories. Consequently, the data collected by the interview extend far beyond the confines of the information targeted by the interview questions.

To ease the participant into the interview process, the interviewer began with a warm-up question regarding background information about the child with special needs (Hill et al., 1997a). This question was followed by several broad and open “grand tour questions” (Hill et al., 1997a) that allowed participants to include information that may not be elicited by the more specific interview questions (the concept of discovering the unforeseen) (Babbie, 1999). The Utah DSPD wanted the interview to end with a retrospective set of questions that reinforced the participants’ decision for placement, and their status as the experts on issues around making the decision to place a child with special needs.

Several ideas and techniques of a feminist approach to interviewing were applied to the interview process in the original study. This decision was made due to the apparent appropriate fit between the sensitive nature of the topics associated with placement and the humanizing emphasis of the feminist approach. Because a feminist approach holds that the interviewer forms a relationship with, and consequently may influence, the participants (Creswell, 1998; Winton, 1995), the interviewer has an opportunity to have a humanizing impact on the participants. In order to have such an impact, the researcher (a) highlights the uniqueness of each participant’s situation and experience; (b) avoids making verbal generalizations that might reinforce stereotypes and roles; (c) looks to the

participants as the experts on their experience; (d) accepts whatever the participants indicate as their experience; (e) seeks to empower the participants; (f) assists the participants in obtaining new insight; (g) provides empathy and acceptance; and (h) validates the participants and their experiences (Winton, 1995).

Questionnaire

A questionnaire was also designed to collect demographic characteristics for both the family and the child with disabilities, in addition to other descriptive information regarding factors associated with placement (see Appendix C). Two previously designed measures were incorporated into the questionnaire. The first was an adaptation of the *Mental Retardation: Definition, Classification, and Systems of Support* instrument, published by the *American Association on Mental Retardation* (Luckassen et al., 1992), which helps parents describe the special needs of their child (see Appendix C, Survey I).

The second measure was derived from the *Factors Preventing [Delaying] Placement Scale*, developed by Bromley and Blacher (1989). The redesigned scale used in this study assessed variables contributing to the delay of out-of-home placement (see Appendix C, Survey II). No psychometric properties or values were available to establish validity or reliability for either measure. However, Dr. Olsen, Dr. Dyches, Dr. Kelner, and Ms. Chambless were also consulted in the development of the questionnaire to increase face and content validity. None of the data collected from these measures were analyzed in the present study. Demographic information from the questionnaire was utilized in this study to generate descriptive statistics for the sample.

Procedures

Participants

Several steps were taken in the present study to maintain participant confidentiality and guard the reports provided by them: (a) previously assigned personal identifying numbers were used, and will continue to be used, for each participant and transcription; (b) the list of the participants' names and personal information, along with their corresponding personal identifying numbers, were kept in a secured location apart from the data (the transcriptions and questionnaires) to which access will be restricted to the investigators and researchers involved in this study; (c) the manner in which the results of this study is reported will assure confidentiality by preventing individual identification and assuring anonymity.

Data Collection

The following procedures were followed in the collection of the data. The support and assistance of these state and private agencies was provided in the hope that the results generated from this data set would be of assistance in evaluating the policies and administration of care for children with developmental disabilities in the state of Utah. The Utah DSPD contacted potential participants by mailing letters (see Appendix D) to parents who had children in some form of out-of-home placement at the time of the original sample collection. Additionally, other private service providers (Rise Inc., a professional parenting agency, and Topham's Tiny Tots, a residential care home) also assisted in the recruitment process by mailing letters (see Appendix E) to the parents of children receiving their services at the time of the original data collection.

The distributed letters outlined the original study and invited those parents who wished to receive additional information regarding the study to complete and return the bottom portion of the letter (Appendices D & E). The parents were informed that by responding they gave the agency permission to share their contact information with the principal investigator. Regrettably, it is not possible to calculate the response rate, as the agencies did not record the number of letters sent.

The principal investigator then contacted by phone families who indicated interest in the study, to further explain the study, answer questions, inform them that participation was completely voluntary and independent of services for their child, and then explore interest in taking part in the study (see Appendix F). Both the agencies and the principal investigator used a summary of the study (see Appendix G) when fielding questions, in order to keep the study description concise and consistent. Potential participants expressing a desire to contribute to the study were then assessed in terms of the selection criteria (see Appendix H). During the initial phone contact, the principal investigator set up a separate appointment time with each potential participant who met the selection criteria and expressed desire to participate in the study. The participant then determined whether the interviewer would meet with them in their home or at some alternative location.

At the beginning of the interview meeting, the principal investigator (who acted as the interviewer for all of the data collection) reviewed the purpose of the interview and the amount of time required for the interview, and then described the projected strategies for disseminating the results of the study. Next the interviewer explained and distributed the information and consent form (Appendix I). Then the interviewer responded to any

questions potential participants had about the study and their involvement. The potential participants elected to be part of the study by agreeing to the terms of and signing the consent form. Subsequently, the participants were asked to complete an additional form (see Appendix J), indicating their willingness to participate in future research and whether or not they wanted to receive a copy of the interview transcripts and/or the research results.

The parents were then interviewed using the semi-structured interview schedule (Appendix B). The interviews ranged from two to four and a half hours. The researcher informed the participants that they could choose not to respond to any given question for any reason. In the cases where both spouses were available for the interview and both chose to participate in the study, the parents were interviewed together. The interviews were recorded on audiocassette tapes for the purpose of verbatim transcription.

Because participants were encouraged to share their stories surrounding the placement of their children, they responded to many of the interview questions without the interviewer having to ask the questions. The interviewer kept track of the questions that the participants answered through the telling of their stories, and then asked the questions that had not been answered during germane discussions and at the conclusion of the interview. This trend resulted in interviews that did not proceed in any consistent order.

At the close of the interview, the parents were asked to complete the written questionnaires (Appendix C). This allowed those filling out the questionnaires to clarify with the investigator any questions they may have had, also increasing the response rate and accurate completion of the questionnaires. In the interviews where two parents were

present, the questionnaires were completed independently to help minimize some of the problems inherent with retrospective self-report. After the completed questionnaires were collected, the appointment was concluded.

The data collection process was continued until there appeared to be a general convergence of experiences and categories seemed saturated (i.e., once interviews begin providing minute new variation among experiences and little additional insights into understanding thematic categories, the interviewer discontinues collecting data) (Creswell, 1988; Hill et al., 1997b). In grounded theory, it is generally accepted that interviews with 20-30 individuals are necessary to achieve saturation and convergence. At this point, the elements of the participants' stories and experiences are primarily elements that the researcher has already heard in previous interviews. Thus, pursuing additional interviews would not provide substantial new information. (See the discussion of saturation in the data analysis section of the results chapter.) Accordingly, 20 usable interviews were collected with 36 individuals during the data collection process.

Transcription and Transcript Verification

After the completion of the interviews, the audiocassette tapes were distributed to trained transcribers for transcription. All transcribers who worked with the data for this study were trained by the researcher. It is crucial to note that before having access to the data, the transcribers signed a confidentiality agreement (Appendix K). A total of 18 individuals worked on transcribing the data. Ten of the transcribers received university credit hours as compensation by enrolling in research-related courses; the remaining eight transcribers were paid by the hour, as were two of the ten students who continued to transcribe after the completion of the course.

All of the transcribers were briefed on the purpose and scope of the original research project. Then the transcribers were trained using standardized instructions (see Appendix L). To insure confidentiality, all transcribers were instructed to wear headphones in situations where others could possibly hear the playback of the interviews. Furthermore, potential identifying information was removed from the body of the transcript and replaced by an assigned code (Hill et al., 1997a). A running alphabetical list of codes was generated in a legend at the end of the transcripts (see *Example Transcription* in Appendix L). After verification, all legends were stored separately from the transcripts. In accordance with grounded theory, the interviews were transcribed verbatim (Creswell, 1998). The following were the few exceptions to verbatim transcription: stutters (e.g., “I, I, I think we should, we should...”), filler words and phrases (e.g., “ok,” “you know”), and non-language utterances (e.g., “ah,” “er,” “um”), and proper nouns and other potentially identifying information, as previously mentioned (Hill et al., 1997a). Non-language verbal communications (laughing, crying, sighing, etc.) were reported in the transcripts parenthetically. All of the transcriptions were verified for accuracy by the principal investigator. The audiocassette tapes will be secured and stored for a period of five years following the completion of the transcription and verification processes, after which time the audiocassette tapes will be destroyed.

CHAPTER 3

RESULTS

Data Analysis

The transcripts from the interviews were analyzed using qualitative data analysis procedures set forth by grounded theory. The researcher coded approximately 2,000 pages of transcribed interviews through immersion in the data for approximately 1,500 hours to facilitate the repeated sorting, coding, and comparing requisite to grounded theory.

Coding

Grounded theory provides very specific procedures and recommendations for data analysis (Creswell, 1998; Strauss & Corbin, 1994, 1998). Coding was used to reduce data and categorize them into themes. Relationships among the themes were then analyzed, resulting in the development of a grounded theoretical model. The analysis of data in a grounded theory approach has three major processes of coding: open (creating and adjusting categories), axial (linking categories by perceived and causal connections), and selective (constructing a story) (Creswell, 1998). An actual example from the research, indicated by bullets, has been included for the purpose of clarification. Also, all themes, categories, properties, components, and elements of the model that was developed through the data analysis procedures are in italics for the purpose of clarification.

Computer software

The three-tiered coding process was facilitated through the use of computer-based qualitative software. Creswell (1998) recommends the use of computer software programs for the grounded theory analysis of data sets (a) of more than 500 pages and (b)

of 20-30 interviews. The current study involved analysis of approximately 2,000 pages from 20 interviews, meeting both premises to justify the use of qualitative software. NUD*IST Vivo (Non-numerical Unstructured Data Indexing, Searching, and Theorizing), or NVivo (a play on the grounded theory term *in vivo code*, which refers to category code labels derived from a descriptive word or phrase used by a participant), was designed by *QSR International* specifically for grounded theory research analysis (Creswell, 1998). NVivo 1.3 was the version utilized in the data analysis processes. For each aspect of the coding system described below, a bulleted example is provided.

Open coding

The first of these phases, open coding, seeks to answer the question: “What are the general categories to emerge in a first review of the data?” (Creswell, 1998, p. 103). Although it is unlikely that any researcher can fully break free from prior conceptions when looking at raw data, the researcher rigorously attempted to set aside information obtained from related research during the coding process to “allow the data to ‘speak’ for themselves” (Hill et al., 1997a, p. 535).

- This was accomplished, in part, by waiting several months between completing the writing of the literature review and beginning the analysis, which helped foster a *Tabular Rasa*, or blank slate (i.e., beyond the guidance of the research questions, the researcher tried to remain open to the themes presented in the data and unencumbered by established ideas, models, and theories).

Additionally, one danger associated with qualitative research is that during the coding process, the researcher may only notice things that support the researcher’s

hypotheses (Babbie, 1999). Grounded theory attempts to resolve this problem by utilizing research questions over hypotheses.

- Instead of hypothesizing: “Parents will experience feelings of guilt after placement,” the researcher asked: “What are the prevalent advantages and stressors that parents experience following the voluntary placement of a child with severe or profound developmental disabilities in some form of out-of-home care?” Consequently, the research question did not create “blindness” where the researcher was only looking for feelings of guilt, but kept the analysis open to exploring all types of advantages and stressors.

Open coding was implemented in order to tag and label the data according to prevalent and relevant themes and concepts (Newman, 2000). Through in-depth reading and rereading of the transcripts, the researcher used the research questions as a guide for relevant information.

- One of the first codes generated from the data was the parents’ sense of guilt after they had placed their child.

The participants’ language was used to guide the creation of the labeled tags, and in many instances, *in vivo* terms were used for the labels (e.g., *Emotions, Depression, We couldn’t do it any longer, We couldn’t handle him anymore, It freed us just to love him, It was the best decision, It was inevitable*) which were accordingly reflected in the results.

- The guilt that parents reported was tagged with the *in vivo* term *I felt guilty* from one of the transcripts.

The labeled tags were, in turn, expanded or collapsed to form thematic categories through the processes of category comparison. Prior to additional code collapsing in the two subsequent processes of coding, 153 open codes were created.

- *I felt guilty* was collapsed into the thematic category of *Stressors* with other related categories that seemed to be stressors, such as *Sadness*, *Uncertainty*, and *Problematic Placed Child Adaptive Responses*.

Subcategories, referred to as *properties*, containing the variations of specific perspectives were subsequently dimensionalized along a continuum determine the extreme possibilities for each property (Creswell, 1998).

- The properties *Failure*, *We were shirking our responsibilities*, *Guilty relief* (i.e., feeling guilty for feeling relieved), and *Critical Greek Chorus Voices* (i.e., feeling guilty when other people disagreed with the placement) – all forms of guilt that parents discussed experiencing during the interviews – were each individually dimensionalized by placing the coded passages along a continuum. This process allowed the researcher to better understand each property and establish the respective boundaries used for defining each of the properties.

This process was facilitated in part by creating analytic and self-reflective memos in the text as the transcripts were read and coded (Straus & Corbin, 1998).

- While performing open coding on the data, the researcher began to wonder if *Failure* and *We were shirking our responsibilities* were too similar to be distinct subcategories. Because *I felt guilty* represents an emotion, the researcher also asked himself if all of the *Stressors* were primarily a function of

uncomfortable emotions. These questions were noted in a memo that was created and stored via the software with the *I felt guilty* code.

Open coding for a category was discontinued once saturation occurred (Creswell, 1998). Saturation is a term for describing a category “when no new information seems to emerge during coding” (Straus & Corbin, 1998, p. 136). In other words, the data provide no additional categorical properties or relationships among categories, indicating that “a category has become theoretically saturated in grounded theory” (Dey, 1999, p.116). It is important to clarify that saturation does not suggest that all category properties and variations have been methodically exhausted; saturation only implies that a category has been developed sufficiently enough to adequately include new data without major adaptations or modifications (Dey, 1999). Although there is always the possibility for new properties or dimensions to emerge (Dey, 1999), once category saturation was reached, to continue open coding would be “counterproductive; the ‘new’ that is uncovered does not add that much more” (Straus & Corbin, 1998, p. 136) to that which has already been discovered.

- Saturation occurred by the completion of open coding for 11 of the 20 interviews. This did not mean that the researcher discontinued coding data regarding categories such as *I felt guilty* when parents reported feelings of guilt in the remaining 9 interviews; instead, it meant that each time a guilty emotion was discussed by a parent in the final 9 transcripts, what the parent said did not provide new insight into the category, or in other words, it was nothing the researcher had not heard before.

Axial coding

In a simultaneous process in tandem with open coding, axial coding procedures were used to (a) refine categories, (b) generalize themes and ideas, (c) identify the key concept for analysis, also known as the central phenomenon of interest, and (d) investigate interrelationships and causal conditions between categories and the central phenomenon of interest (Creswell, 1998; Newman, 2000).

The memos that were created to record insights about categories from open coding were utilized to facilitate the axial coding procedures (Straus & Corbin, 1998).

- When reviewing the previously-described memo under the *I felt guilty* code, the researcher was able to refine the subcategories *Failure* and *We were shirking our responsibilities* by reading all of the data coded for each property. Upon examination, *Failure* and *We were shirking our responsibilities* were determined to be distinct enough to remain separate subcategories; however, a new subcategory, *We were abandoning our child*, was extrapolated from the *We were shirking our responsibilities*. The memo also helped to generalize themes and ideas by suggesting that the *Stressors* had distinct cognitive themes (*Appraisals*) that could be categorized by the associated emotional responses. Comparative analysis among all of the *Stressors* confirmed the existence of five core emotions: *Guilt*, *Sadness*, *Fear and Worry*, *Anger and Frustration*, and *Uncertainty*. Consequently, the *Stressors* were organized into one of the five emotional categories, *I felt guilty* was renamed *Guilt*, and the *Stressors* were renamed *Emotional Stresses*.

A large portion of the axial coding phase of analysis was accomplished by finding answers (bulleted) to the following questions set forth by Creswell (1998):

1. What was the emerging central phenomenon of interest?
 - *Emotional Stresses (associated with cognitive appraisal themes)*
2. What caused the central phenomenon of interest to occur?
 - *Placement*
3. What intervening (broad) and contextual (specific) conditions influenced the central phenomenon of interest?
 - *Problematic Filial Adaptive Responses (the adaptation processes of the child with developmental disabilities and the adaptation of the parents' other children that create additional *Emotional Stresses* with associated appraisals for the parents)*
4. What consequences or strategies did the participants employ in response to the central phenomenon of interest?
 - *Reappraisals, Involvement, Therapy, and Time*
5. What were the outcomes of these strategies?
 - Increased parental adaptation to life after placement

The information yielded by the answers to these questions is then depicted in a coding paradigm diagram, the forerunner of the conditional matrix, and eventually the grounded theoretical model.

Selective coding

The last stage of analysis, selective coding, was implemented to compare and contrast themes, and validate categorical relationships to the central phenomenon of

interest by identifying direct quotations that best represent the themes (Creswell, 1998; Newman, 2000).

- For example, for the subcategory *We felt guilty for shirking our responsibility* in the category *Guilt*, the following quotes were selected as representative of this property: “It’s our responsibility, and he’s our child, and we shouldn’t push him off on everybody else.” “This is my job! It’s my kid, and it’s my job!” “And I certainly felt like I was giving him, or entrusting him, to someone else to take care of. And it was really painful - really painful.”

The coding paradigm diagram was developed into a conditional matrix (or a rough draft of the model) – a visual analytic tool that diagrams the level and relationship of factors and consequences to the central phenomenon, which in turn was refined to provide the grounded theoretical model (Creswell, 1998; Strauss & Corbin, 1994).

Demonstrative quotes were then compiled to illustrate the story contained in the model. Lastly, a set of theoretical propositions was derived from the theoretical model (Creswell, 1998; Strauss & Corbin, 1998).

In developing the model, the frequency of the properties across the 20 interviews was consistently considered; however, property frequency as a full criterion for model inclusion was compromised due to the semi-structured form of the interview that yielded a hit or miss trend: many of the properties were identified solely because a number of parents happened to mention similar phenomena that were not addressed by the interview questions. For instance, the property *Should something happen to us, we know our child will be taken care of* was not a topic ever brought up by the interviewer; yet it was an advantage to placement perceived by approximately half of the parents – enough to merit

its inclusion in the model. While the other half of the parents did not spontaneously mention this advantage, that does not preclude the possibility that *Should something happen to us, we know our child will be taken care of* may be an advantage recognized by those parents, because none of the interview questions elicited a response on that particular topic. Thus, just because a participant did not indicate a particular property does not necessarily mean that it was not part of his or her experience.

Nevertheless, with the exception of *Therapy* and the *Problematic Filial Adaptive Responses*, all of the 20 cases appeared to have experienced the remaining primary themes: *Appraisals*, *Emotional Stresses*, *Emotional Advantage (Relief)*, *Desirable Filial Adaptive Responses*, *Greek Chorus*, *Reappraisals*, *Involvement*, and *Time*. It is important to point out that all of the categories and subcategories represent an additive conglomeration of common experiences, not a cookie-cutter model where every parent experiences every category, property, and component. For instance, some parents reported that they had not come across any problems with the bureaucracy. For those parents, the absence of *Bureaucratic Stresses* was an *Invisible Advantage*: a benefit that was only perceived when it was not present (i.e., parents who experienced *Bureaucratic Stresses* recognize them as an emotional stress; parents who did not experience *Bureaucratic Stresses* may not consciously view the absence of the stress as a relief or an advantage because the non-presence made it invisible to them).

Furthermore, it is paramount to note that all of the aspects of the model, even those relating to the child with developmental disabilities and her or his siblings, were generated by parental self-report, and, consequently, were based on the parents' perceptions of their children's experiences, rather than direct self-reporting by the

children. Therefore, all of the characteristics derived in this study were based on the parents' perceptions, even the stresses and advantages of the placement that were believed to be experienced by the placed child and her or his siblings.

Although a sizeable amount of quantitative data was collected through the questionnaires that were administered after the interview, no quantitative analyses beyond descriptive sample characteristics were performed. Even though the sample included 36 participants, the fact that there were only 20 cases yielded a sample size that was not quite large enough to warrant statistical analyses (e.g., effect size). Furthermore, even if there had been a large enough sample to conduct statistical analyses, it would not have been directly within the scope of this thesis, which was to generate a model grounded in data that describes how parents adapt to life after placement.

Results

The remainder of this chapter sets forth the grounded theory model and its accompanying theoretical propositions. The theoretical model entitled *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* is presented.

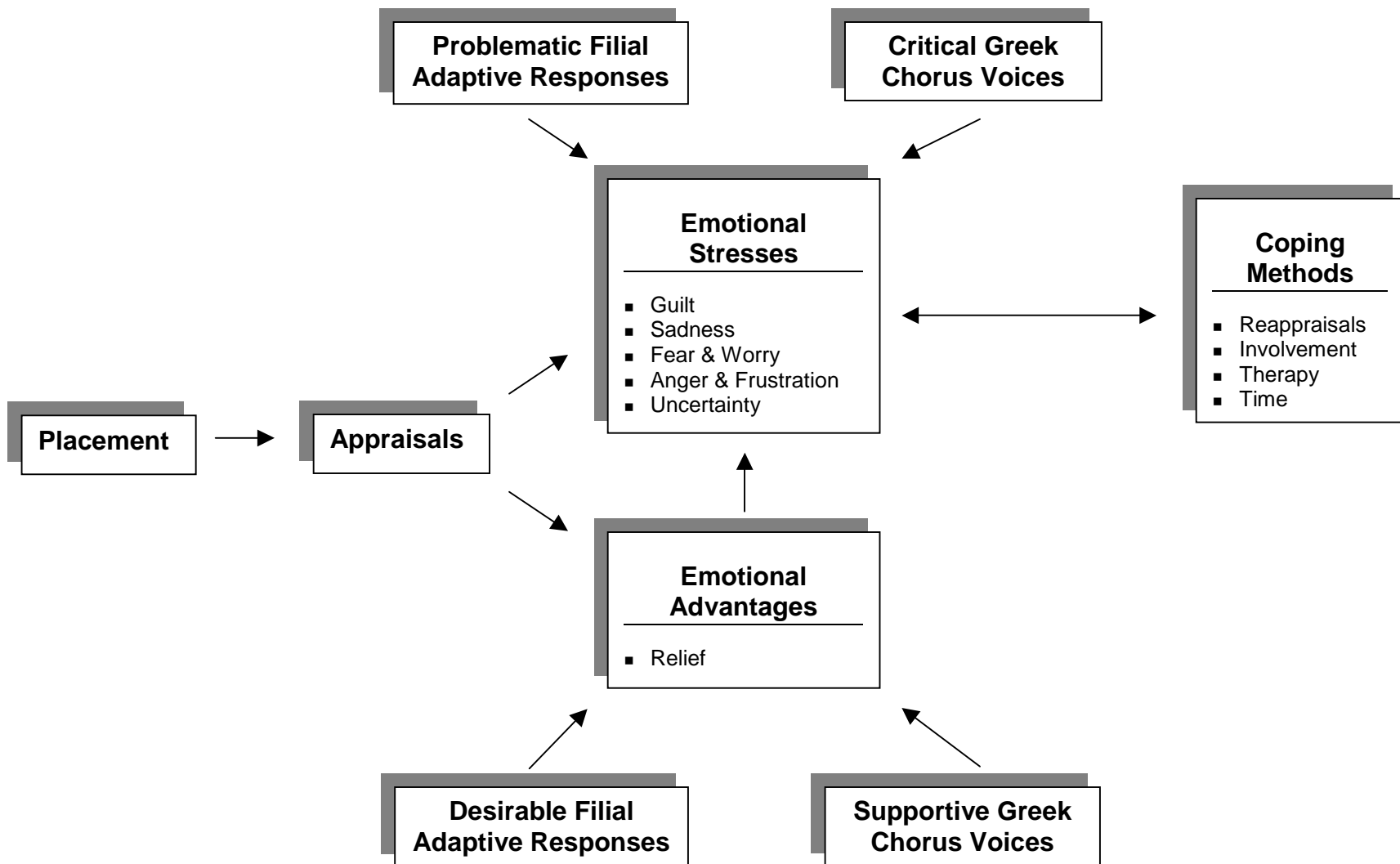


Figure 1. Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities

Figure 2: Outline Presentation of the Model of Parental Adaptation to Life After Placement of a Child with Developmental Disabilities

Legend	
➤	<u>Themes</u>
➤	Categories
■	Subcategories/properties
◆	Components
○	Elements

➤ **Emotional Stresses**

- **Guilt**
 - We were abandoning our child
 - We were shirking our responsibility
 - We were failures
 - We feel guilty for feeling relieved
 - We feel guilty about not visiting enough

- **Sadness**
 - The Initial Drop-off
 - Subsequent Visits and Drop-offs
 - Emptiness
 - Depression

- **Fear & Worry**
 - Poor Child Care
 - ◆ Maltreatment
 - ◆ Nobody loves, knows, or can care for my child like me
 - Less Control
 - ◆ I'm not there to make sure...
 - ◆ Legal adulthood allows my child to make poor choices for himself
 - ◆ The staff's values are different than ours
 - Our child will have to return home from his placement
 - ◆ For our sake
 - ◆ For our child's sake
 - The Fear Dilemma

- **Anger & Frustration**
 - Marital Relationship
 - ◆ We disagreed about placement
 - ◆ We had different coping methods
 - Financial Stresses
 - Bureaucratic Stresses

- **Uncertainty**

➤ Problematic Filial Adaptive Responses

- Problematic Placed Child Adaptive Responses
 - I don't know that he really understands it
 - She doesn't like her placement
 - ◆ She doesn't want to go back after a visit home
 - His placement is his home
 - She may have forgotten who we are
 - Losses are hard
 - ◆ Staff
 - ◆ Fellow patrons

- Problematic Sibling Adaptive Responses
 - Anger: What kind of a parent would do that?!?
 - Sadness & Happiness: It was a mixed bag
 - Guilt: It's my fault my sibling was placed
 - Worry: Will I have to go live somewhere else, too?
 - Fear: You have to fix it!
 - Uncertainty: Where do I fit in the scheme of things?
 - Focus on Self: It's almost like he's not my brother anymore
 - ◆ I have my own life
 - ◆ I'm resentful

➤ Greek Chorus

- Critical Voices

➤ Emotional Advantages: Relief

- Reducing or Eliminating Disadvantages
 - Providing care for our child was stressful and challenging
 - ◆ Our child required SO much from us
 - ◆ We couldn't do it any longer
 - ◆ We couldn't handle him anymore
 - ◆ We couldn't provide what she needed
 - ◆ We were worried about his safety
 - We weren't able to provide adequate care for everyone else
 - ◆ We were neglecting our other children
 - ◆ It was hard on our marriage
 - ◆ We were concerned about everyone else's safety
 - Siblings
 - Parents
 - Neighbors

- We felt isolated
- We were afraid of becoming bitter toward our child
- Amplifying or Generating Advantages
 - Parent Advantages
 - ◆ It freed us to just love her
 - ◆ Now we're happy to see him – now it's quality time together
 - ◆ Our life is better
 - Our marriage is better
 - We have more personal time and we're freer to focus on us
 - Family Advantages
 - ◆ Our family life has improved
 - We've been able to do more things than ever before
 - Caretaker Advantages
 - ◆ Their lives are enriched by our child.

➤ **Desirable Filial Adaptive Responses**

- Desirable Placed Child Adaptive Responses
 - Our child receives good/better care
 - ◆ Our child has had increased potential, growth, and development
 - ◆ We're lucky to have such good care providers
 - ◆ Our child is safe/safer
 - ◆ Our child is more independent
 - ◆ Should something happen to us, we know our child will be taken care of
 - Our child is happy/happier
 - ◆ Our child enjoys being with other people like him
- Desirable Sibling Adaptive Responses
 - Our other children receive better care and attention from us
 - Our other children are happier
 - ◆ Less responsibility
 - ◆ Better sibling relationships

➤ **Greek Chorus**

- Supportive Voices
 - Family
 - Friends
 - Professionals
 - Support Groups
 - Community & Neighbors
 - Religious Leaders

➤ Coping Methods

- Reappraisals
 - It was the best decision
 - It was inevitable
 - It was needed
 - It was a blessing
 - It would have been bad if we hadn't placed
 - Visits with our child confirms our decision
 - Our faith and trust confirms our decision
 - Leaving home is a developmental norm
 - ◆ Placing before adulthood
 - ◆ Placing after adulthood
 - We had to sacrifice our child for the good of the family
 - We're still our child's family
 - We did the best we could
 - We're not the only ones who have a hard time caring for our child
 - Life was just too stressful
 - We were lucky to get a placement
 - We could have kept our child home IF...
 - ◆ If we had received better training...
 - ◆ If there had been better programs...
 - ◆ If we were rich...
 - ◆ Yes; on second thought, No
 - Nobody knows
 - ◆ It's our decision, no one else's
 - We shouldn't be so hard on ourselves
 - There's no place that's perfect
 - ◆ It could be worse
 - ◆ You can't protect your child from everything
 - Our decision is fairly permanent
 - ◆ Miracles: serious improvements that would make us reconsider
 - ◆ Unforgivable Sins: serious problems that would make us reconsider
 - If our child seemed distressed or unhappy
 - If we felt our child was not safe
 - If we felt that our child was getting the care she needs
 - If we felt our child was regressing
 - If things didn't get better after we had tried the correct channels
 - If we found out our child was dying

- Involvement
 - We felt more in control
 - Our child gets better care when they know we're watching
 - ◆ The staff are the key
 - ◆ Surprise! We just thought we would stop by for a little visit
 - ◆ We decided to take matters literally into our own hands
 - Visitation
 - Custody & Guardianship
 - Child's Individual Plan and Other Meetings
 - Financial Involvement
 - Active at the Placement and in the Community

- Therapy
 - Therapy for Parents
 - ◆ We got therapy, and we're glad we did
 - ◆ We got therapy, and we wish we hadn't
 - ◆ We didn't get therapy and we're glad we didn't
 - ◆ We didn't get therapy, and we wish we had
 - Therapy for Siblings

- Time
 - As time goes by
 - ◆ The more time goes by, the more we know it was the right decision
 - ◆ Does time really heal all wounds?

*Model of Parental Adaptation to
Life After Placing a Child with Developmental Disabilities*

In response to her husband saying, “I don’t think it was a hard decision, to be honest with you,” one woman commented very emotionally, “Making it wasn’t hard, it was living with it - that was so hard.” Without doubt, the semi-permanent absence of a family member constitutes a significant change in a family. In reference to the stresses resulting from placement, one mother described: “I think we were all traumatized.” As one of the fathers articulated, the process of adapting to life after placement is substantial:

Also, when our child with special needs was placed, for 14 years she had been with our family, and everybody had to kind of shuffle, rearrange where the family was sitting at. And there was a lot of give and take and pushing and pulling, and everything else until everybody kind of understood where they sit in the new family situation.... It just took a while to finally remold the family a little bit....

You’re going to have to realize that you’re going to have to go through a period of adjustment, and your kids are going to go through a period of adjustment.

It is theorized that learning to manage the emotional stresses associated with placement is the adaptation process through which the parents go.

The *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* presents an understanding of what parents experience after voluntarily placing a child with developmental needs in out of home care and how they adapted to those experiences. The model involves two foundational components: The central phenomenon of interest *Emotional Stresses*, and *Coping Methods*, the strategies employed by the parents in response to the central phenomenon of interest. Thus, the

Coping Methods (Reappraisals, Involvement, Therapy, and Time) were the means utilized by parents to better manage the *Emotional Stresses* they experienced after placement; the *process* of learning to manage the *Emotional Stresses* was the adaptation.

The parents appeared to implement cognitive (*Appraisals* and *Reappraisals*), emotional (*Relief*) and behavioral (*Involvement*) *Coping Methods*. The emotions that parents experienced were markers and manifestations elicited by the parents' particular ways of interpreting (*Appraisal* and *Reappraisal* cognitions) a major stressor event (placement) in their lives. While negative social support (*Critical Greek Chorus Voices*) and the perceived maladaptation of children to placement (*Problematic Filial Adaptive Responses*) increase parental *Emotional Stresses*, positive social support (*Supportive Greek Chorus Voices*) and the perceived bonadaptation of children to placement (*Desirable Filial Adaptive Responses*) increase *Relief* (an *Emotional Advantage*) and decrease parental *Emotional Stresses*. Therefore, the *Problematic and Desirable Filial Adaptive Responses* and the *Greek Chorus* were determined to be contextual factors affecting the *Emotional Stresses* and *Advantages* of the parents.

The model developed and discussed in this chapter explores the stressors generated by placement, and the methods adopted by parents to cope with those stressors. The following section presents and explores these themes and their categories and subcategories.

When germane, the development and interrelationships of the themes and categories are discussed and supported by quotes from the participants. The researcher rarely provided commentary *after* the included quotations; this was done intentionally out of deference because the participating parents' descriptions and experiences explain the

aspects of the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* with such power and clarity that, by and large, it seemed unequivocally redundant and anticlimactic to follow them with annotations. The term “child with special needs” is used for the children with developmental disabilities to maintain confidentiality.

Emotional Stresses: “You go through a roller coaster of emotions”

The central organizing phenomenon of interest identified from the analysis in understanding parents’ adaptation to life after placing a child with developmental disabilities was determined to be the Emotional Stresses experienced by the parents that the parents attribute to placement. The parents’ Emotional Stresses are undoubtedly the central phenomenon of interest because all of the remaining categories are contingent upon the existence of the stressors; if there were no Emotional Stresses, there would be no need for Coping Methods. Although placement is the impetus for the stressors, the model developed in this study focuses on life after the placement decision.

It became evident throughout the interviews that the stress-eliciting cognitive *Appraisals* that parents reported experiencing post-placement could be categorized in terms of the emotions associated with them. The five categories of *Emotional Stresses* pinpointed from the data are (a) *Guilt*, (b) *Sadness*, (c) *Fear and Worry*, (d) *Anger and Frustration*, and (e) *Uncertainty*. Interestingly, although many of the parents’ experiences could be definitively classified as one of the five *Emotional Stresses*; a degree of overlap existed among experiences. The subsequent statements made by parents are representative of the types of cognitions and *Emotional Stresses* that they experienced (the overlying *Emotional Stresses* follow in parentheses):

“You feel just an enormous amount of guilt wondering if you’re doing the right thing” (*Guilt and Uncertainty*); “You go through the blues of having your child put in, and wondering if [you]’ve made the wrong decisions” (*Sadness and Uncertainty*); “Just feeling really bad and sad that this little kid has to leave” (*Guilt and Sadness*); “I love the fact that we are able to be in this situation, so I definitely don’t want to rock the boat there, but I don’t feel like they check with us on a lot of things” (*Fear and Worry and Anger and Frustration*).

Guilt: “Sometimes I still struggle, feeling like it’s my fault”

One of the most prevalent emotions experienced by parents was *Guilt*. One father described the way placement had affected him in the following way: “The only disadvantage [of placement] is your emotional feelings about losing him - his presence - and your guilt of placing him.” One mother expressed the feelings of guilt she experienced when she said, “I felt so guilty. The guilt....I thought, ‘Maybe I’m a bad mom - maybe I didn’t do everything I should have done.’ ” Although there were often only subtle differences between them, several different subcategories of guilt were developed from the data.

We felt like we were abandoning our child: “And honestly, I felt like I was (begins to cry) abandoning him.” Most of the parents interviewed put across the painful feelings they experienced after they placed their child. Several parents drew a connection between a sense of abandonment and having caused the death of their child:

I felt like a rat. (Becomes emotional) I guess I did, I felt I had abandoned him and sacrificed him for the good of the family. And, in some ways, it was kind of like having a funeral every week, to go down there and be with him.

In the following quote, the overlap of guilt and sadness is palpable:

Father: Because in some ways when you put a child in a placement, it's like dealing with a death. The child is suddenly not there anymore, even though you can see them on the weekend, you know, the child is not there 24 hours a day, 7 days a week. And there's that void that you have like when you get somebody that dies.

Mother: And there's the guilt, you feel like, "Well, you're the one that placed them." And you caused [the death]. And it's hard to go through.

We felt guilty for shirking our responsibility: "Are we backing out or shirking our responsibilities?" One of the most common aspects of guilt shared by parents was that of feeling guilty for having passed their responsibility to care for their child on to someone else. The following statements are representative of what most parents reported experiencing. "It's our responsibility, and he's our child, and we shouldn't push him off on everybody else." "This is my job! It's my kid, and it's my job!" "And I certainly felt like I was giving him, or entrusting him, to someone else to take care of. And it was really painful - really painful."

The ensuing statement is by a mother who pointed out the lose-lose aspect of the guilt associated with feeling like she was not meeting her expectations of responsibility: "I hate to shirk my responsibility. But we're shirking our responsibility to our other kids if we don't [place], so here we are."

Failure: "There was a lot of guilt; a lot of feeling like a failure." Parents also shared how they felt guilty because they had failed as a parent for their child with

developmental disabilities. The father quoted below shares the source of his feelings of *Failure*:

When [you]’ve got a child that’s handicapped, you want to feel like you can take care of anything - you can handle your child. And when it gets to the point that you can’t handle the child anymore, you feel like you must be failing as a parent.

This mother discusses her feelings of failure in terms of her relationship with her child, her struggles to meet her child’s special needs, and then ties in the guilt associated with *We felt guilty for shirking our responsibility*:

I felt like a failure: “Why couldn’t my husband and I take care of our child?”

When I first put him in, I felt like I was a failure because you feel like somehow you have neglected something in your relationship with your child, or you haven’t been able to meet his needs well enough; therefore, as a parent, you’re a failure because you have to have society to come and help you with that particular responsibility.

This father provides the insight that *Failure* also entails feeling like you have admitted to yourself that your child will not progress:

We felt like by putting him in a group home, we’d given up, and we didn’t want to have that feeling like, “We’ve failed.”.... And by putting him in a group home, we were quitting on him, like “Oh, he’s never going to change.”

We feel guilty for feeling relieved: “*We felt torn between guilt and the relief.*” In addition to the feelings of *Guilt* created from a sense of abandonment, not fulfilling parental responsibilities, and failing their child with developmental disabilities, parents also conveyed a sense of being plagued by *Guilt*: they feel guilty for not feeling guilty – what

the researcher has termed *Guilty Relief*. One parent referred to this phenomenon as “a catch 22:” “You almost felt guilty because you felt relieved that you didn’t have to keep watching your child with special needs every second.”

One couple shared their experience with guilty relief in the context of visits with their child:

Father: We can’t wait go pick him up, and we can’t wait to take him back once we do. Try dealing with that-

Mother: Yeah, there’s a lot of guilt there.

Father: Yeah, I feel guilty for not being with him right now; and then when I’m with him, I want to take him back, and I feel guilty for wanting to take him back.

We feel guilty about not visiting enough. Some parents also mentioned feeling guilt when they do not visit their child frequently. One father confessed, “We make it out - (sighs) and this is an issue of guilt for us - at best we make it out once a month now - at worst, we've gone as long as two months.”

Sadness: “You miss them so much”

While the source for feelings of *Guilt* seemed to be connected to the fact that the child might be missing or losing, the origins for feelings of sadness seem to be what the parents might be missing or losing; in other words, *Guilt* is more about the child and Sadness is more about the parent. Thus, the category of Sadness seemed to be generated from the *absence* of the child with developmental disabilities from the home. Parents talked about death, loss, and grief to explain their feelings, as is demonstrated by one father’s explanation:

One [of the feelings you experience] is separation - I mean the loss - probably a grieving process or reaction you'd just expect because of the loss of that child out of your home; I mean, he's gone. And again, it's almost like losing a child out somewhere, even though you know you're going to get him back, there's still that loss.

Virtually every parent disclosed difficult feelings that stemmed from missing his/her child. Although mothers more frequently discussed their sadness throughout the interviews, almost every father also shared the presence of sadness surrounding the placement of his child. Parents tended to discuss their sadness in four different contexts: (a) *The Initial Drop-off*, (b) *Subsequent Visits and Drop-offs*, (c) *Emptiness*, and (d) *Depression*.

The Initial Drop-off: "That was hard - the hardest day in my life." Almost every parent had something to say about the day he/she took his/her child to the placement for the first time, many citing it as the hardest day of his/her life: "It was the hardest thing I have ever had to do - ever." Other reoccurring comments included: "I cried.... I think I cried all day long." "It was like, 'Oh, gosh, I'm losing my child....' It was rough. It was very hard. That was an emotional day." "It's just a painful process. And when they're actually placed, and you walk out the door for the first time, (becomes emotional) I, I don't know how you make that easy; I just don't how you could."

Subsequent Visits and Drop-offs: "It still is hard." In addition to the high emotional toll of the actual initial placement, parents also expressed duress and sadness in regard to visits: "And then Sunday nights when we would take him back, we would just crash - we would just crash - we had the Sunday night major blues every Sunday night."

In some aspects, visitation seemed to be a constant reminder that stirs up emotional turmoil and sadness for parents, as demonstrated by this couple:

Father: But the hardest thing is, is that you know what, every week it stares you in the face because when you have to take your daughter back and drop her off at these homes, you just say, “Why does it have to be this way? Why does it have to be this way?”

Mother: Well, the pain never goes away-

Father: The pain doesn't go away-

Mother: It's just an open sore every Sunday night.... She's been there for a year and a half, and the pain is no different today than it was the day we dropped her off. It is just really excruciating to have to drop her off and say, “We'll be back,” because she'll say, “No [I don't want to go].”

Emptiness: “*I felt a little bit empty.*” This subcategory captures the sense of loss and grief that the participating parents reported experiencing. The most frequent comments about *Sadness* painted a picture of a void – a sense of incompleteness – made visible through the following collage of observations: “There was a part of me that really grieved because I didn't have my little guy there with me all the time.” “We physically, we emotionally, we spiritually, we mentally yearn to be with him.” “I miss him; he's a big gap in our family.” “Well, anytime a child leaves home, it's an empty spot in the home, until you kind of get used to it.” “Yeah, kind of like the empty nest syndrome - it was kind of like a big void in our lives.”

But it's empty; (becomes emotional) it's an absolute empty feeling to go back in her bedroom and know that she's not there. Your family's not complete- it's just

never complete because there's an empty bedroom and there's an empty spot at the table.... We still have a missing link - you still have to remember that there's a part of us that's still missing, and we're ever, ever aware of that- it never goes away - there's always something missing.

Depression: "I was probably just depressed." Perhaps not surprisingly, a handful of parents' sadness developed into depression. Those parents who reported depression typically saw placement as one of several contributing factors; however, some parents did cite placement as the primary factor behind their depression. The prevalence of depression was strongly gender-specific: all of the parents who reported depression were mothers. According to the DSM-IV-TR (2000), women are twice as likely as men to experience major depression during their lifetime. Thus, it would seem logical that at least one or two of the 17 fathers in the study sample experienced depression; yet none was verbally reported during the interview. As such, some questions remain about the fathers and depression as not enough data were obtained in this area to draw specific conclusions.

The mothers who did report depression shared: "And how did we handle it? We went to the doctor and got on Prozac- (laughs)," and "I think we just spent so much time crying," and "I just felt really depressed. (Becomes very emotional) And I was deeply depressed for a number of years.... It wasn't really until I came out the other end that I really had some awareness of how depressed I'd been."

Fear and Worry: "I was scared to death"

The next primary form of *Emotional Stresses* experienced by parents after placement is fears and worries about their child's care. One mother expressed that just

because her child was placed did not mean that she no longer worried or felt responsible: “You still have all the worry and you still have the responsibility - it just looks different to you.” The data relating to parental fears and worries were grouped into four subcategories: (a) *Poor Child Care*, (b) *Less Control*, (c) *Our child will have to return home from his placement*, and (d) the *Fear Dilemma*.

Poor Child Care: “When he’s away, you’re guessing; you’re hoping that someone else is taking care of him.” First and foremost on parents’ minds were fears about maltreatment and poor care at their child’s placement. It appeared that parents had three kinds of fears and worries about the care their child was receiving: (a) a fear of the possible (e.g., I worry that my child could be mistreated), (b) a fear of the actual (e.g., I’m worried about my child because I know she is being mistreated), and (c) a fear that the actual would happen again (e.g., I know that my child was mistreated, and I’m afraid that it will happen again). These fears and worries are compounded by the fact that the majority of the children of the parents interviewed have limited communication that would prevent them from letting their parents, or anyone else, know about any problems:

“She can’t stick up for herself; she can’t tell us if something’s not right, or if someone’s mean or does something bad.” “And none of these kids talk, so [the staff] could get away with it.” “Now that he’s away, we don’t have that secure feeling of: ‘We know where he is and what he’s doing, whether he’s sleeping at night’ - we have to take somebody else’s say-so.” “And my daughter not being able to describe and tell me what her life was really like left me in the world of assumptions and “who knows?” It was hard.”

Maltreatment. Unfortunately, coding for this category was substantially abundant; most of the parents' had experiences where some of their worries about what could happen to their child became reality. The following is a list summarizing parents fears and experiences: (a) poor physical care, (b) unsafe conditions, (c) injuries from other patrons, (d) neglect, (e) physical abuse, (f) sexual abuse, (g) overmedicating, (h) unhealthy diets, (i) higher susceptibility to illnesses, (j) poor delivery of services (e.g., physical therapy, occupational therapy, speech therapy), (k) regression (e.g., behaviors, abilities), (l) untrustworthy staff, (m) poorly-trained staff, (n) insufficient staff, (o) overworked and underpaid paid staff, and (p) misappropriation of funds. While it is not possible to provide data for all of these areas of concern, the following is the epitome of the possible becoming the actual:

We went to check on her one day unannounced, she was laying on the floor, and kids were all over her, and she was soaking wet, and she was having a seizure. And they were so understaffed to take care of her.... And they were like, "Well, we're getting to her." And I thought, "No. She can't just be a number.... She cannot just be 'She's number 342, and we will change her diaper when we get to 342.' "

Tragically, some parents even experienced fears that their child's life was in danger: "I felt that her life was at risk down there," "Right now we are realizing that we really may have slipped up with this last placement, to the point where maybe it could have been our child with special needs who passed away, and not [her roommate]." The emotional stress for these parents was obviously intense.

Nobody loves, knows, or can care for my child like me. Up until this point, all of the parental fears discussed have been worries of maltreatment, or bad care (the presence of a negative). In addition to worries of maltreatment, parents were also afraid that that the care their child received would be “poor,” or substandard, in comparison to what they themselves could provide (the absence of a positive). A significant finding was that all of the concerns in this area were voiced by the mothers, and not by the fathers. Although most parents acknowledged during the interview that the staff may have more energy and may have received better training to take care of their child (see discussion of *Our child receives better care under Emotional Advantages, Relief, Amplifying or Generating Advantages*), the mothers seemed to focus on two reasons why they were afraid the care their child would receive in placement would not be as good as what they themselves could provide: (a) nobody loves my child like I do, and (b) nobody knows my child like I do.

Here is how several of the mothers put across these points: “Because I’m her mother, and nobody’s going to love her like we love her! Nobody is ever going to love this child like we love her!” “I was sick. I never felt so sick and worried in my entire life because no one knew my daughter like I knew her.” “Parents know them more than anyone.” “And then I was also afraid that they might not take care of her as good as I could, you know.” “I feel as if nobody does it like I would do it.” “I felt she needed me. No one else could take care of her as good as me, and she needed me.... And it was very hard to come to grips with that.”

Less Control: “Most [placements] do not mind telling you exactly what you can do.” Directly related to the fears is the property where parents feel somewhat powerless

over the care that their child receives. Feeling less in control only further compounds the fears of poor care. Most parents expressed that they “still wanted full control of every decision that was made in her behalf.” Yet, most parents communicated that they did not feel completely in control. The data from the interviews yielded three components of this subcategory: (a) *I’m not there to make sure...*, (b) *Human Rights allow my child to make poor choices for himself*, and (c) *The staff’s values are different than ours*.

I’m not there to make sure... Although some parents had experiences where they felt they had little control over visitation, medical care, and selection of staff, schools, and subsequent placements, the primary concerns centered around feeling like they did not have enough command over the care their child receives at the placement. One mother summed up her concerns by saying, “Their needs may come up, and you may not be aware if they are outside the home.”

Legal adulthood allows my child to make poor choices for himself. Many of the fears relating to parents feeling like they have less control are exacerbated when the child becomes a legal adult at age 18; even if the parents obtain guardianship (i.e., legal stewardship) for their child, regardless of mental ability, the child has a right to make decisions for him- or herself, be they safe or unsafe. According to one of the participating fathers, “Their rule for our child with special needs: ‘She’s legally an adult.’ But can she make the right decisions? No.” These concerns were echoed by this couple:

Father: These kids are handicapped - you have to use good judgment. You don’t just let them do WHATEVER they want to do just because they decide to do that. I mean, it’s like letting a two year old decide whenever he wants to walk

out in the street; I mean, there has to be supervision. And so, this is where the law is: “You can’t make them do this. You can’t make them do that.”

Mother: Human rights and all that stuff.

Father: They says (sic), “If he wants to smoke, he can smoke.” I says (sic), “Wait a minute. That’s a health hazard. I’m sorry.... I don’t agree with that. I will not tolerate that.”-

Mother: “Besides that, I’m his legal guardian, and I say he can’t smoke, so you don’t get any cigarettes.”

Father: And then he’s got a seizure disorder. And I’m saying, “He does not need another health risk. He’s on multiple medications....”

Mother: But human rights said, “We can’t tell him that he can’t smoke.”

The staff’s values are different than ours. A common concern and thread between I’m not there to make sure...and Human Rights allow my child to make poor choices for himself was that the staff would endorse, and subsequently transmit, values that conflicted with those espoused by the parents:

Well, one of the other things is you worry: you don’t know if he is going to be taught your same moral standards. We had certain beliefs: standards the way things should be done. “Is he going to be taught? Are they [the staff] going to be supportive of those ideas and beliefs that are important to us? Are those going to be carried on? Are they going to be thrown out the window and other things that we don’t agree with thrown in at him?” and stuff like that and there were those concerns, too. And sometimes it was very hard for me when things we didn’t

particularly approve of were taking place, and you know, feeling like, “Oh man! What did I do here?”

The following conversation pulls together the components of *Less Control*:

Father: And the state says once an individual turns 21, they make their own decisions. And I say that’s-

Mother: That’s bull.

Father: My personal thing is that’s horse pucky.... If you’re considering that a 21-year body that’s got the intellect of a 4-year old, that’s ludicrous-

Mother: “But that’s still their right.”

Father: A lot of the time, the staff takes advantage of that because they want to go to [Nevada] and go gambling, or the staff wants to go see some pornographic movie somewhere, “Well the kid said he wanted to go see it, so I took him.” That’s the excuse; that’s horse pucky.

From these examples, it logically follows that parental concerns over poor care are multiplied when parents have no control over the selection of the staff: “There can be some real strange staff...we don’t have any say so on who they’re hiring....”

In addition to the heretofore mentioned parental worries, one parent mentioned a fear that trying to do something about poor care might actually make things worse for her child: “Plus the whole concern of parents: you really don’t want to be on everybody’s ‘not good list’ because you just don’t know how that’s going to trickle down to your child.”

Our child will have to return home from his placement: “I think that’s always a fear: that something might happen, and we might have to have him again.” This

subcategory differs from *Poor Child Care* and *Less Control* in that it is a fear of the lack of placement, not worries about problems created and/or perpetuated by the placement. Parents were worried about the possibility of their child returning home for two principal reasons: (a) for the parents' and the other children's sakes, and (b) for the child's sake. Parents repeatedly expressed concern while entertaining the possibility of their child returning home, presumably because that would entail a loss of the *Advantages* obtained through placement and a reacquisition of the *Disadvantages* eliminated or reduced through placement (see *Relief* under *Emotional Advantages*).

For our sake. Parents were afraid of how their child's return into their home would affect them. The following statements provide a representative idea of how anxious parents were about their child returning home: "We wouldn't be able to take her back." "He may end up in a different setting all the way along the way, but I don't know that he'll ever come back." "Other than something happening with all the possible placements, I don't see bringing our child with special needs home as a feasible thing."

For our child's sake. Although parents primarily discussed their fears of having their child return home in terms of how it would affect them, this following interview excerpt conveys how returning home is difficult on the child:

Mother: They gave us 24 hours notice and said, "Your child with special needs has to be out. Do what you have to do."

Father: So we brought her home, which was devastating to our child with special needs.... But there was no explanation - I mean, we tried to explain to her-

Mother: That her home was broken up.

Father: ... it really was insecure for her.

Mother: ...[It] was throwing her off to have us butt back into her life.

The Fear Dilemma: “We didn’t know what was worse.” Parents recurrently experienced the following impasse created by these worries and fears. When parents are concerned about *Poor Child Care* (particularly of actual poor care and the risk that it may continue or happen again) coupled by fears of *Less Control* over the situation, parents may begin to contemplate moving their child into a different placement, or removing their child from placement altogether. However, such decisions are often complicated ones because parents typically are also afraid that *Our child will have to return home from his placement*. Thus, fears are pitted against fears, generating *Uncertainty* about what to do.

A mother voiced her experience of feeling uncertain what to do in this predicament when she admitted, “But when we went to pull her out, they said, “Well, there’s no place to put her right now, so you’ll have to bring her home or leave her here.” And we didn’t know what was worse.”

Another mother explained her particular *Fear Dilemma*

If I felt like someone was being cruel with her, yes, that would certainly affect me. But I don’t think I’d take her out of the group home.... I don’t think there are too many group homes that would take my child with special needs with her disability.

This mother’s observation of the quandary further clarifies how complicated this scenario can become:

I’ve seen parents fear [changing their child’s placement when problems don’t get better] because...they are so afraid of having to have their child come back that

they would leave their child in a bad situation. I've seen that until the point that it's not healthy for the child. And it's that part of dealing with the system.

The specific coping methods parents used to manage the *Fear Dilemma* and their other *Fears and Worries* are presented later in this chapter.

Anger and Frustration: "You feel just an enormous amount of...anger towards why this happened to you."

Another apparent major category within the theme of *Emotional Stresses* to come out of the data was *Anger and Frustration*. As parents sought to adapt to life after placement, they encountered aspects and obstacles related to placement that characteristically resulted in feelings of anger and frustration. The three key areas contributing to the emotional stress of parents in this category are: (a) the *Marital Relationship*, (b) *Financial Stresses*, and (c) *Bureaucratic Stresses*.

Marital Relationship: "It comes between you." Perhaps one of the most discernable properties of parental *Anger and Frustration* was when the spouse was the genesis of those potent, influential, and challenging emotions. In all fairness, parents said that while it was hard to know exactly how much placing a child with developmental disabilities had affected their marital relationship – "Who knows how much the experience with our child with special needs contributed to [our marital difficulties]" – the majority of the participating parents acknowledged that placement had an appreciable impact on their marriage. Two distinct groupings evolved within the subcategory of *Marital Relationships*, namely: (a) disagreement about placement, and (b) different coping methods.

We disagreed about placement. Of the 16 interviews completed with both parents, all but one of the couples experienced the phenomenon where one parent struggled more with the *Emotional Stresses* of placement than the other parent. At least half of the parents reported a situation where one parent desired and had pushed for placement more than the other. It does not require much of an imagination to see how such circumstances set the stage for anger, frustration, and marital discord. The following excerpts illustrate different aspects of the emotional stresses brought about when parents disagree about placement.

This first interview extract represents the most frequent scenario where the mother, who has been primarily responsible for caring for the child, has felt like they must place their child because she cannot handle caring for the child anymore; the father, who is somewhat further removed from the stresses of caring for the child, is taken aback by, and struggles with, his wife's desire to place:

Father: In fact the only time I think things were hard [in our marital relationship] was when we talked about giving him up [i.e., placing our child]. For the first little while, as far as our relationship, we had some struggles a bit for a while.

Mother: Yeah. It was really hard for [my husband] to place our child with special needs.

Father: It took me a while-

Mother: But it was because - my husband's problem with that was because, you know, I couldn't do it any longer. (Sighs) So I had made the decision that it [placement] was going to be, and I kind of made it more from my

perspective and from my needs than as a unified decision between us. And so I was longer coming to it than he was because I was dealing with it all the time and he wasn't quite as much....

The next quote from a mother provides an additional foray into the thoughts and feelings behind why the parent who is the primary caregiver has decided to place:

Now [my husband] at first fought me on that. He says (sic), "He's too little. You can't put him in a home." I said "You're not here to deal with him, so don't tell me what you think." (Laughs) I was so mad at him - like, "You have a job. You can go and deal with normal adult people all day. And you come home and tell me he's too young, and you need to hang on and all this stuff. Don't tell me this." because I was there. I was the one. I was there and I didn't have help. I didn't have a job that I could run off to, you know, and be with people who talked to me normally everyday.... I was just worn out. And my [husband] didn't want to do it right then; he did not want to put him in there. And I had to convince him of this. I said, "I am frazzled. I'm worn out. And you're not here to see...how tired I am, but I am tired. I can't do this anymore." And so that was pretty much our decision.

Although the gender situation in each of the three previous quotations was the more prevalent scenario, there were situations where the genders were reversed: the father is the one who wanted to keep their child in a placement, and the mother wanted to bring their child home. Such is the case in the following selection:

Father: And my wife would threaten to jerk him out of the program, and I knew that once he got out, we'd have our child with special needs home. I liked the idea [of placement] because-

Mother: [My husband] would have his life back.

Father: Yeah, but [my wife] wanted to get our child with special needs back again, and it was a tug-of-war. She talked to the director of the program on the phone and said, "I want him back." And I'd have to call and say, "Let's keep him in," and it was really hard.

Mother: Yep.... If I'd had a gun, I would have shot him. (Laughs)

Father: Who, me?

Mother: Yeah (Laughs).... It was difficult. I didn't know if I was doing the right thing, or if my husband was being selfish: "I don't want our child with special needs around anymore." And he was wondering what was wrong with me...it probably made me more angry because my husband would be for it so much, and I would be against it, and it would just tug in this way [back and forth].

There were also cases like the following in which the father was worried enough about how stressful the mother's life was caring for their child, that the father decided on placement for the mother's sake, even though the mother initially did not want to place their child:

And overtime, it became a real issue with my wife, I worried a lot for her, just because she was 24 hours a day and seven days a week, and never could get away from him.... I came home and my wife wasn't doing very well, [and] that was the day that it became clear, "This is nuts, we're not going to make it this way."

In this next passage, the couple's experience with *Anger and Frustration* is painfully evident. The mother in this example was frustrated that her husband did not see how at the end of her rope she was, so she placed their child without discussing it with him, which caused the father to feel angry and betrayed:

Father: (very emotional) Well, the biggest thing here is that I am still hurt with this situation: my wife and her family went behind my back and placed my daughter in a home that I did not know....

Mother: I think maybe I was going to tell him I was going to do it, but I didn't really come out and tell him - I just did it behind his back.... If you can talk about it, that's the way to go; but it's not always the case.

In this final excerpt, this couple's experience of differing opinions about placement almost resulted in divorce:

Father: Yeah. A lot of the problem that we had was that I knew that we was (sic) going to have to place her, and it was hard for me to convince my wife that we had to place her. That put a lot of stress on both of us.

Mother: Yeah. I didn't want to. I thought that I'd be a terrible parent if I ended up having to do that. Then I felt like I'd have to choose between either our marriage or my daughter, and I was afraid at one point it would be my daughter. And I felt terrible about that, but I felt she needed me: no one else could take care of her as good as me, and she needed me. And I would be abandoning her if I did that. And it was very hard to come to grips with that.

We had different coping methods. In addition to the *Anger and Frustration* produced when parents did not see eye to eye on whether or not their child should have been

placed, parents also reported similar emotional responses when their spouse went about coping with the stresses of placing a child differently than he or she did.

This first instance considers differences in emotional display (e.g., sadness, stoicism) and emotional reactions (e.g., engage/disengage, pursue/distance):

I was just so upset. [My husband] was with me, and he didn't show any emotion at all. I'll never forget that because usually parents are more emotional - he was just so stoic...I guess you'd call it. And I was crying, and I was wanting comfort from him, and I didn't get any. It was just awful. (Cries)

This next example considers how therapy became a divisive issue, emphasized how the parents physically distanced themselves from each other, and indicates the adaptation process of coming to a mutual understanding:

Mother: And then when we put our child with special needs at the...group home, there was a counselor there affiliated with the group home, and I went to see her. And I tried to enroll my husband in going, and he kept avoiding going - he would be busy or he would forget. And I got really angry then. And that really could just have been more of the process to do with having placed our child with special needs.... If you look at the whole grieving process, there's a number of steps...that could have been the anger part; but I can't be mad at our child with special needs so I was mad at my husband. And the reason I could be mad at him was because he wasn't participating in this counseling....

Father: I think that the bad time was after he was placed...and I went through what you might call a mid-life crises: I didn't play around, I didn't go to bars, I went back to school, and I played golf on Saturday mornings, and then I'd

play golf during the week if I could, and then I'd go to school, and I'd either study or I'd be at work, or I'd be at golf-

Mother: Well, then I did my own whole process of leaving, too, with all the seminars, and personal development stuff, and I took off for a while. I think both of us were just trying to, I don't know, figure things out.

Father: Yes.

This final illustration explores the frustration created when one parent copes intellectually, while the other parent deals with placement emotionally:

Father: When you don't know what programs are out there for you and what your options are, then you start that whole, "What do I do now? What are my options? What can I do?" "How can I solve this problem?" And I think that's the way I looked at almost everything, "Okay I have a problem. What do I do to solve this problem?"

Mother: His solutions would sometimes be annoying, and that would be where our conflict would be... He was logical; I was hitting with the heart.

Financial Stresses: "We still pay a large amount of money to keep our daughter outside our home." This category was notably a greater source of frustration among fathers. One such father explained, "We had to pay a certain amount of money for the time she was out. And then it wasn't until she was 18 and got fully on the programs themselves, that the state picked up the whole tab."

In the following quote, the couple explains how expensive it was to place their child, who was younger than 18-years old, in terms of net cost:

Father: As a matter of fact, it costs us to place him-

Mother: Yeah, it does actually-

Father: He was never a financial strain when he was with us [at home] - we got SSI, so the government was sending us money. Now that we've placed him, not only do we not get SSI, but I have to pay a portion of his nursing.... If you look at lost income and then spent income, it costs us about \$600 a month to place him in lost revenue. So, him being with us has never cost us.

This last passage segues into the next source of *Anger and Frustration: Bureaucratic Stresses*:

They don't explain to you your obligation to pay for any of this either, and so as a parent we were very shocked after we got him into the system, thinking, okay, because what we were told is that we would get social security, he'll have all these benefits, he'll come pretty much self sustaining, you're in good shape. But they don't tell you that until he turns 18 there's a good share of this that you're going to have to pay. So one Christmas we got that \$30,000 surprise bill that we owed for back-care for our child with special needs that was our share. Well, nobody ever told us that any of this was coming.... None of that was ever explained to us in any shape or form, and that really bothered me.

Bureaucratic Stresses: "It is a bureaucratic thing; it is not John Q. Public friendly." This category is different from the *Less Control* category of *Fear and Worry* in that *Less Control* is derived from a parental sense of feeling powerless to help one's child that may or may not stem from interactions with the bureaucracy; whereas *Bureaucratic Stresses* is the *Anger and Frustration* component that parents sometimes experience when dealing with the bureaucracy. Hence, the difference is the kind of *Emotional Stress* created by the

situation. Once again, the experiences of the subcategories were not universal across participants; for many parents, *Bureaucratic Stresses* were an *invisible advantage*.

A bureaucracy is generally considered to be an entity with tiered administration and organization, characterized by complex processes, interaction, and proverbial red tape. The composition of the bureaucracy for services for people with disabilities in the state of Utah has two primary organizations: the state (e.g., state administrators; caseworkers, support coordinators, and case managers which are all synonyms for the same position); and the service providers (administrators, managers, supervisors, and staff, in hierarchal order); therefore, the system with which parents must deal is an intricately-complex two-headed bureaucracy: the state and the private providers. Parental frustrations from trying to deal with both the state the provider are voiced by this couple:

Father: I think one of the major disadvantages was [the state's] lack of communication with us.

Mother: And even the communication with the care providers and their staff.

Father: Right.

Mother: Sometimes we'd find out two or three weeks later that she had been sick and that someone had taken her to the doctor.

Other aspects of *Anger and Frustration* from dealing with *Bureaucratic Stresses* mentioned by participating parents include (a) breakdowns in communication, (b) unresponsiveness, (c) unnavigability, (d) unequivocal power, (e) broken promises, (f) caretaker turnover, and (g) underpaid, understaffed, and overworked staff. To sum up the

Emotional Stresses of dealing with the bureaucracy, one mother complained, “And that was always really the answer: I was always the problem.”

Uncertainty: “*It was difficult; I didn’t know if I was doing the right thing*”

Wondering if placement was the right decision was an *Emotional Stress* virtually universally experienced by parents. One father’s comment sheds light on why so many parents had questions and doubts about their decision to place” “After you make a major life decision, you can’t ever tell what the other road would have led to - you just don’t know.” It is this “not-knowing” that is so difficult for parents to live with, particularly because the placement decisions of all of the participants were made voluntarily.

The following is a compilation of representative quotes from parents about the emotional duress created by feelings of *Uncertainty*: “I was relieved because it felt like it was such a gut-wrenching decision to make, and finally when we made it...then I started getting worried about whether we made the right decision or not.” “It was so hard knowing what to do and what not to do.” “It’s always a concern for a parent - if you’ve done the right thing - if you’ve made the right decision for her.” “So there’s been some good feelings about it, but still, in the back of your mind, you are constantly evaluating: ‘Was it right? Did I do the right thing?’ ” “There are no serious decisions that are 100% correct.”

The final citation for *Uncertainty* comes from a mother who foreshadows the most common method employed by parents to cope with *Uncertainty: Time*

I was scared to death, I didn’t know whether it was the right decision or not. Even with those safety things in mind, I just didn’t know, I kept hoping, and I knew time would tell that we had made the right decision, but I was really scared.

Problematic Filial Adaptive Responses:

“He was falling apart. And that caused us to fall apart”

Problematic Filial Adaptive Responses was categorized as a contextual stressor because of the way in which the parents discussed it. Throughout the interview, it was plainly visible that the many aspects of the placed child’s and the siblings’ adaptation to the placement decision cause the parents additional *Emotional Stress* (as indicated by the arrows in Figure 1). Therefore, one person’s level of adaptation becomes another person’s stressor. The categories of the contextual stressors *Problematic Filial Adaptive Responses* that were generated are (a) *Problematic Placed Child Adaptive Responses* and (b) *Problematic Sibling Adaptive Responses*.

Although terms along the lines of *Children’s Negative Adaptive Responses to Placement that Were Emotional Stresses for Parents* or *Negative Aspects of Child and Sibling Adaptation that are Emotional Stresses for Parents* were considered, not all of the subcategories (e.g., *His placement is his home*) are necessarily negative adaptive responses. The adjective *problematic* was selected to convey that the adaptive responses of the children are problematic for the parents because of the additional *Emotional Stresses* they create for the parents.

Although the possibility exists that what the child with developmental needs and the other children really experienced could differ substantially from what the parents perceived that they experienced, the fact that the categories *Problematic Placed Child Adaptive Responses* and *Problematic Sibling Adaptive Responses* are all based on parental perceptions is irrelevant. This is the case because as long as the parents perceive something negative about the way in which their child with special needs or other

children adapt to placement, regardless of whether the children actually experience the same phenomenon, it has an emotional stressing effect on the parents. In other words, the parents' perceptions of how their children and family were adapting to placement were sources of additional parental *Emotional Stress*. This again illustrates the importance of cognitive *Appraisals* in creating the *Emotional Stresses* experienced by parents.

With the exception of *Therapy*, *Problematic Filial Adaptive Responses* was the only category where saturation did not occur. While several interview questions addressed this area, the information obtained in the interviews was only enough to confirm that one person's way of adapting becoming another person's stressor was a prevalent phenomenon that seemed to be experienced by all parents after placement had occurred. Even though the properties for the categories are somewhat underdeveloped, there were enough data to merit inclusion and presentation.

It is important to clarify that because of a lack of saturation, the subcategories are not exhaustive or comprehensive. Moreover, the subcategories are only an organized collection of adaptations, and, as such, are a partial laundry list of things parents *could* expect, not *should* expect. Furthermore, only subcategories (the children's behaviors and reactions involved in adapting to the placement) that caused *Emotional Stresses* for the parents were designated *Problematic Filial Adaptive Responses*; just as the children's adaptive responses that parents view as difficult are stressors for the parents, the children's adaptive responses that parents view as positive are *Emotional Advantages*, associated with cognitions that parents use to help counter the *Emotional Stresses* generated by the contextual stressors. Finally, *Timás* a reasonably obvious function of adaptation; it is explored more fully later in this chapter.

Problematic Placed Child Adaptive Responses: “That was one transition for our child with special needs that was really hard.”

Several parents commented that the nature of their child’s developmental disabilities make it difficult for them to communicate what is going on for them. Thus, the parents, in many situations, were left to speculate not only on how their child adapted to placement, but also on many other aspects of their child’s life. One father noted:

Well, I think the hardest thing is, because he’s not very communicative, you don’t know what he is feeling. You don’t know if this is traumatic for him or if he is just throwing a tantrum.... So, you’ve got your conscious playing on you: you’ve got the welfare of your child playing on you.

In fact, this relates to the first subcategory: *I don’t know that he really understands it.*

This subcategory explores the difficulty that children may have in adapting to their placement when they lack the cognitive abilities to understand why they are being placed, and the effect this situation has on the parents. In essence, the parent believes that the child’s confusion about why he or she is living apart from the family may cause the child pain, which the parent cannot alleviate, so the parent feels *Emotional Stresses* like *Guilt*, *Sadness*, and *Uncertainty*. One mother expressed, “Actually, it was harder to let our child with special needs know. And I don’t know that he really understood it.... And he still, to this day, has a hard time understanding why.... It is very difficult.”

These parents convey their heartache over the fact that their daughter does not understand why she was placed:

Father: But deep down in my heart, it’s hard to get over the trial - and that’s basically what it is-

Mother: Because you can't explain that to her, either - she wouldn't understand that - it's not like you can say, "This is better for all of us."

It is evident from these examples how this specific property created emotional stress for the parents.

She doesn't like her placement seemed to be a fairly common experience.

Consider what one of the mothers said about her child's adaptation to placement and the emotional effects (e.g., *Guilt, Sadness*) it had on her:

After that first month we could take him home on a weekend, for a day, and that poor kid would bawl - And to get him in the car was a chore. To get him out of the car - he refused to get out of the car. "I don't want to go! I don't want to go!"

And then he would just cry. He was falling apart. And that caused us to fall apart.

The effects on the parents of the child disliking the home are easily observed in the following quote:

Father: I don't think he's happier in a group home - he'd rather be with us.

And sometimes we feel real guilty and sad having to drop him off because he's always staring at us as we're driving away-

Mother: "Please come back."

The idea of *His placement is his home* indicates that the child enjoys the placement, has developed a routine, and adapted to it, so that the placement has become "a comfort zone" or a home away from home. Even an element of adaptation that might seem positive, such as this, can generate emotional stress for the parents. This father and mother articulate the two-sided nature of *His placement is his home*, and once again, the

emotional impact of the *Problematic Placed Child Adaptive Responses* on the parents is overtly clear:

Father: I was very pleased to see how much he enjoys being there.

Mother: Yes, I was pleased and disturbed, actually, because there was a period there where he actually wanted to go to the home more than he wanted to be with us because he enjoyed it so much - there were so many other kids, and constant attention, he gets lots of feedback-

Father: He gets to play with his peers all day long, he gets constant feedback - and it really did kind of hurt our feelings-

Mother: It did.

Father: When we would take him back, he'd get real excited walking up to the home and meeting the people, and then we would be out of sight out of mind. So, on one hand, that's really nice because he's really happy there; on the other hand, it hurt us because it's kind of like, "Well, does he think we don't love him?"

Between *She doesn't like her placement* and *His placement is his home*, there appeared to be a lot of middle ground: sometimes the child likes the placement, and sometimes he does not; sometimes the child likes coming home, and sometimes she does not. This mixture of child reactions is stressful for the parents produces feelings of *Uncertainty* due to the unpredictability of when the child will be okay with the placement and when he or she will react negatively. The following couple describes this gray area as follows:

Father: Yes, there are still times when our child with special needs doesn't want to go back to the group home-

Mother: But he's got a comfort zone here [in our home]; he doesn't have to do anything - he's not required to do things here.

Father: But there's also times when our child with special needs can't wait to go back to his group home because there's other things going on there.

Mother: That's true, and there's too much going on here. (Laughs).

Father: It gives him choices and he has places he can go to get away from it all, to have that quiet time, or to do things that he wants to do, when maybe we've got other things planned.

She may have forgotten who we are raises some of the *Fears and Worries*, along with generating *Sadness*, for parents that their child may have forgotten whom her or his parents are. As one father put it, "We were not interested in giving up our parental status in his life." Consider the following statement from one of the mothers:

And for a while, at that first placement, we really wondered if he really did know who we were. We would go down and get him, and go to [a restaurant] and get a milk shake, and he would just about climb inside the cup to try to get the milkshake down. I started to think that that was who he saw us as: the milkshake people. I wondered if he had an idea of "Mom" and "Dad."

Other parents expressed concern that their parental status would not only be forgotten, but lost to their child's care provider(s):

[Our child's care provider] is definitely not us; she's not "mommy" by any means, and she never implies, "I'm mommy...." I think my biggest fear was that when I would talk to [our daughter with special needs], she'd just say, "Yeah, so what?" But it's not; it's: "Mommy this. Mommy. Mommy. Mommy. Daddy?"

The last subcategory of *Problematic Placed Child Adaptive Responses* is *Losses are hard*. This property expresses the adaptation that occurs for a child each time he or she loses someone, be it staff or a fellow patron. This phenomenon may be marked by a regression in the child's behaviors and abilities, which changes are also stressful for parents. One father observed:

And some of those people have been there for a long time too and so my child with disabilities gets used to those. When someone leaves though, that's so tough again because she now has to re-establish her relationship. And there have been at least a couple of residents that have passed away there. One that she had been very close to that passed away and she of course would not understand that. And a couple have moved away.

Problematic Sibling Adaptive Responses: "Your kids are going to go through a period of adjustment"

Interestingly, the subcategories of how parents perceived that their children were adapting manifested core emotions similar to what the parents report experiencing. One parent referred to *Problematic Sibling Adaptive Responses* as "a process."

Anger: What kind of a parent would do that? Several parents indicated that their children were very upset that their sibling with developmental disabilities had been placed. One family recalled:

Father: According to my one son, the fact that we took her to live in a group home was the worst we ever did. He just hated us for it.

Mother: He's still not over it.... He used all sorts of bad words to tell us how terrible we were giving away his sister-

Father: We had driven this girl from our family.

Mother: “You just gave her away! You’re irresponsible parents!”

For the most part, parents reported that their children’s anger subsided with time as they adapted to the change. In fact, when speaking of his son who was initially very worried about his brother being placed, one father hypothesized, “I think that if we told him his brother with special needs had to come back, he would be concerned”

This brings us to the next subcategory of stressors associated with problematic responses to a sibling’s placement, *Sadness and Happiness: It was a mixed bag*. Parents expressed that their children experienced several, often contrasting, emotions after their sibling with special needs was placed, and the mixture of positive and negative responses was experienced by the parents as stressful. This subcategory is optimized by what this mother had to say:

Well, if a child would come to us and talk to us, and say, “Well, I don’t want my sibling with special needs to go,” or say, “I’m so glad he’s going!” (Laughs)....

And they each did the mixed bag thing where they would be excited about, “Yeah. It’s going to be good for this reason,” but “Oh. It’s going to be so sad for this reason - I don’t want him to leave,” you know, kind of that heartstrings thing.

Another mother’s perceptions concur with that view:

I just remember them feeling kind of like us: good and not good - good and bad - just really complex. Like, “How can you do this?” and, “Oh, you have to do it!” You go through this emotion. Well, [one of our children] said, “Get rid of him,” and then, “Don’t get rid of him.”

Another subcategory of problematic sibling responses to placement that emerged was *Guilt: It's my fault my sibling was placed*. Just from the title, it appears that this property may be similar to children's responses to divorce: the semi-physical loss, the strained connections, adapting to a new family constellation, and the taking responsibility for parents' decisions. For example, one father and mother said:

Mother: And the siblings go through just as much guilt probably as the parent.... Because they think it's their fault, too.... They think it's their fault that we're putting them in because they couldn't watch the kids good enough-

Father: Or they feel like that we're putting them in so we can spend more attention with you instead of giving attention to our child with special needs, or whatever. And so they kind of blame themselves, too.... The kids felt like, "Well, Mom and Dad are putting the child with special needs in because they are supposed to be spending more time with me, and it's my fault." And that wasn't the reason why, but I think that they were expressing some guilt.

A different common theme involved in *Problematic Sibling Adaptive Responses* to placement is *Worry: Will I have to go live somewhere else, too?* This was unique to younger children who worried that they might also be placed. "[One of our children], of course, was really too little to understand too much what was going on. I think she did have questions about whether she would have to go live somewhere else." The parents who had children with these concerns attempted to allay these fears.

Fear: You have to fix it! is an interesting parallel with the *Fear and Worry* subcategory *Poor Child Care*. This is the sibling version, in which siblings want their

parents to take care of situations where the child with developmental disabilities may be receiving poor care:

They would say, “Mom, you just have to do something about that placement. You just can’t leave him there.” (Becomes emotional) And you know, it was a very passionate plea, “You have to fix this. What’s wrong? You have to fix it!”

Uncertainty: Where do I fit in the scheme of things? This subcategory considers the reshuffling and changes associated with adapting to placement. Each of the following paragraphs is an example from a different interview. In the first passage, the parent uses the analogy of missing building blocks to explain the siblings’ struggle; in the second excerpt, the parent describes how one of the children felt ambiguous about the loss of his brother.

[Our other children] did not know where they fit in the scheme of things. So they wanted to keep blocks the family was taking out, they were kind of readjusting to see where they fit in the scheme of things.

Our [other son] told me at one time that the girls had each other, and he was supposed to have a brother, and he didn’t.... He was right - he lost his brother and his sisters still had each other.

The other subcategory of *Problematic Sibling Adaptive Responses* that surfaced from the data was *Focus on Self: It’s almost like he’s not my brother anymore*. Parents frequently mentioned their distress when their other children grew apart and/or distant from their child with developmental disabilities. Therefore, this property was a major source of *Sadness* for parents. One set of participating parents explained:

Mother: And the fact that these two youngest will not know their brother-

Father: Yeah, the two youngest will never know him, and that hurts us because he is a special part of this family, and they'll never know that - they'll just know him as this big man who they visit once in a while, who is kind of scary. And that's extremely unfortunate - that hurts.

Parents seemed to attribute their children's distance from their sibling with developmental disabilities to one or both of these two reasons: *I have my own life* and *I'm resentful*. Parents lamented that since their child had been placed, most children played less of a role in the life of their sibling with developmental disabilities. These comments appeared to center around visits: "They don't like him coming home at all.... And they really don't like to go visit him." "The kids were more remote, more distant, there's just a, 'Where is our child with special needs? I'll be somewhere else.' "

The following quote is a mother explaining the resentment that one of her children feels toward his sibling with special needs:

And [my other son] dearly loved my child with special needs back then. He hates him now. But back then he loved him. And my child with special needs kind of was always hitting [my other son] and being mean to him. And he missed his brother.... I think now [my other son] really has a problem with his brother, and I think it's because he might be looking back at that, and realizing "Hey. My mom spent more time with him." And so he's very jealous now. If my child with special needs comes over now he says "You're spending time with him and not me." So I have to include both of them now. I think he remembers that, and I'm sorry that that happened, but what else could I do?

Perhaps a combination of siblings having their own lives and feeling some resentment results in the less compassionate, less responsible, and less cooperative behavior described by this mother:

[Before our child with special needs was placed], the kids were less selfish - thinking of themselves. They knew that he was the top priority, and he took it, and that they had to pitch in and help a lot more - and now they just kind of take whatever they want.... [The amount of cooperation at home] has definitely gone down because when our child with special needs was gone, it was like, "Oh, Mom, you got all that time, so you do everything. We're not going to pitch in and help because you don't have our brother with special needs anymore to worry about.

While this next property was not included formally in the model due to its singular occurrence, it is, at a minimum, descriptive of one parent's feelings of remiss (an *Emotional Stress*) in not knowing how to help her other children adapt to life after placement:

I think they just dealt with it. I don't think we ever were very adequate about helping them, and that would be a regret: I think we could have done a better job helping them, and having done more than just explaining the situation to them and expecting them to go on as though everything was normal. I would wish that we had had more resources and more understanding about what they would go through.

Critical Greek Chorus Voices:

“They made us feel guilty for placing our child with special needs.”

In the theatrical dramas of Ancient Greece, Greek playwrights implemented the use of a chorus of voices to provide the audience with moral and ethical commentary on the actions of the principal characters. Accordingly, the concept of the *Greek Chorus* as a contextual theme in the *Model of Parental Adaptation to Life After Placement of a Child with Developmental Disabilities* is that the voices of other people either confirm or invalidate the other parental *Appraisals* and *Reappraisals*.

The *Critical Greek Chorus Voices* are the antithesis of a *Coping Method* for the *Emotional Stresses* experienced by parents; in fact, as a rule, the *Critical Greek Chorus Voices* actually exacerbate the *Emotional Stresses*. The following paragraph is a collage of some of the *Critical Greek Chorus Voices*' messages that the parents reported hearing:

“They’re the ones that have their child placed.” “Why couldn’t the parents care for their child with special needs?” “You’re not strong enough to take care of your child.” “You must not love your child your child very much. You threw your child away. He was a defective car, so you traded him in.” “How could you do that?” “Well, you know, my sister has a handicapped child and she kept him home and raised him, and sacrificed her life for her child.” “Well, why should your child with special needs be put in if these other families can take care of these other kids?” “Yeah, we just don’t think your child with special needs is that bad.” “You don’t place your kids.”

The subsequent paragraph is conglomeration of some of the parents’ reactions to the messages of the *Critical Greek Chorus Voices*. Specific attention should be paid to

the feelings of *Guilt, Sadness, and Uncertainty* elicited by the *Critical Greek Chorus Voices*.

“I was just portrayed as Cruella DeVile - that I had just given up my child and just shoved her out into the world. It was agonizing.” “I felt pretty ostracized because they definitely saw it as abandonment.” “That made me feel guilty.” “I thought, ‘Maybe I am a bad mom. Maybe he’s not that bad, and I put him in there, and I shouldn’t have.’ ” “And then it made us wonder, ‘Well, are we doing the right decision then, are we doing the right thing?’ ”

Emotional Advantages: “There’s a happier way to look at life”

The way in which parents cognitively viewed their decision to place after placement, and both their lives and the lives of their children after placement, was one of the preeminent methods used to cope with the stressful impact of adaptation of their children. These *Appraisals* focus primarily on how life is better because of placement. The parents overwhelmingly spent the majority of the interview focusing on the how placement had (a) decreased or eradicated many stressors experienced before placement, and (b) augmented or created advantages not only for the child with developmental disabilities, but also for the entire family. This process of cognitive restructuring resulted in the parents experiencing a sense of *Relief*. Therefore, just as negative *Appraisals* elicited *Emotional Stresses*, positive *Appraisals* brought about *Emotional Advantages*. As was the case with the negative *Appraisals*, the positive *Appraisals* were organized with the associated emotion, which was determined to be *Relief*.

Reducing or Eliminating Disadvantages: “You could damage your family by NOT placing your child.”

A large portion of the *Appraisals* incorporated by parents centers around how life is better post-placement because previously-existing stresses have been reduced or, in some cases, eliminated. Most parents spent a good portion of the interviews conveying how stressful life had been before placement (the disadvantages) and how much better things have been after placement (the advantages).

In describing life before placement, one mother explained, “It was never easy - none of it was easy;” while one of the fathers proclaimed, “There was something wrong with almost everything.” In explaining why she and her husband had decided to place, this mother said, “The purpose of our child with special needs being in a group home was to take the stress off us.” When another father indicated, “This is better than it used to be,” he seemed to be communicating how placement had helped reduce or eliminate some of the pre-existing negatives.

In an attempt to depict how much better life is now after the reduction and elimination of the stresses of life before placement, which is investigated within this category, two different mothers recapitulated: “By comparison, there was nothing we could do that was as hard to deal with as what we had been going through the last few months that he was [at home].” “Before it was 200%; and now it’s like 1% - it’s like a hundred times less.”

The *Reducing or Eliminating Disadvantages* category has two *Appraisal* subcategories: (a) *Providing care for our child was stressful and challenging*, which

focuses on issues relating to childcare; and (b) *We weren't able to provide adequate care for everyone else*, which explores the stressors of having the child at home on family life.

Providing care for our child was stressful and challenging: "The stress level when he was here was incredible." This subcategory explores the stresses surrounding caring for their child at home that parents felt had either decreased or disappeared with placement. It is significant to point out that each of the 20 cases discussed how difficult caring for their child with developmental disabilities at home had been. In discussing how challenging life had been before his child was placed, a different father stated, "And as parents you kind of ride in that emotional roller coaster that he'd put you in or on, as you go through these events."

This subcategory yielded five components: (a) *Our child required SO much from us*, (b) *We couldn't do it any longer*, (c) *We couldn't handle him anymore*, (d) *We couldn't provide what she needed*, and (e) *We were worried about his safety*.

Our child required SO much from us was the most frequently-used code throughout the interviews. Parents expressed frustration over the demands that having their child with special needs at home placed on their lives. Several stressful reoccurring elements were the need for constant care, a lack of flexibility in life (e.g., hard to find appropriate babysitters, not easy to go somewhere spur of the moment), difficulty in doing things together as a family (e.g., vacations, eating out, grocery shopping), challenges with their child's idiosyncratic behaviors (e.g., child running away from home, breaking things, fixing things, getting into things, etc.) poor attendance at work because of problems with their child, and implausibility of having a nice house because things would get destroyed or ruined.

The following two paragraphs are assemblages of representative quotes from almost all of the cases that depict some of the disadvantages parents experience in caring for their child at home:

“It just was constant - it just was constant.” “You had to keep an eye on her constantly.” “I constantly had to watch to make sure that he wasn’t in trouble because his reputation was if he was out of site, he was in trouble. And that was ever a challenge.” “We couldn’t turn away from him for 5 minutes. He needed CONSTANT care - CONSTANT watching.” “You had to consider his schedule in every facet of your life.” “I seldom was in the other room that he wasn’t in: if he was downstairs, I was downstairs; if he came upstairs, I came upstairs...I dared not leave him alone for just a second.”

“I always wanted six children, but our child with special needs is like having 25 kids!” “It’s like having triplets or quintuplets. It’s just really hard.” “You try half a dozen two-year olds for several years in a row, and then you’ll know how it feels.”

We couldn’t do it any longer is the phenomenon of reaching the breaking-point where the parents did not feel that they could continue to care for their child. This experience was reported in three quarters of the cases. As in the previous component, *Our child required SO much from us*, the vast majority of the coded responses were those of the mothers, who tended to be the primary care providers. The subsequent sets of quotes vividly describe various *Appraisal* aspects of *We couldn’t do it any longer*:

“I just said, (begins to cry) ‘That’s it. I’ve had enough.’ (chuckles) I’m not going to do this anymore.... And I’m admitting I can’t do it.’ ” “It had to be, or we’d be dead.... Or we would have left our child with special needs at a truck stop somewhere.” “I would not want to re-live those years.” “It was just the ongoing care.” “You can’t do it

forever.” “We were just totally burned out.” “We were way past our breaking point - way past our breaking point.” “We just were at jumping off the edge.” “We were already over the edge - mentally, spiritually, emotionally - we were already over the edge.”

“There certainly came a point where we had to start doing better, or things weren’t going to work out. So that was when we decided to place our child with special needs.” “I want[ed] him in the system because I was getting frustrated and didn’t know what else to do.”

We couldn’t handle him anymore is an *Appraisal* which describes how the parents were no longer able to successfully manage their child’s behavior. Placement would have reduced this disadvantage, as parents still could encounter problems during visitation. The subsequent quotes demonstrate several of the *Appraisals* associated with the *We couldn’t handle him anymore* component.

“It was me not being able to handle her anymore.” “I think just realizing that we couldn’t handle him anymore.” “We began to recognize that we weren’t going to be able to handle him at home.” “We knew that we couldn’t handle him, so we needed to have him somewhere.” “Our child with special needs is bigger than the both of us.” “And he was getting bigger, too, which made him harder to handle, and...we thought, ‘If he gets 16 or 18, then we’re not going to be able to handle him anymore’ ”

We couldn’t provide what she needed is the stress that parents experienced about feeling unable to provide the kind of care their child deserved. The equivalent advantages are *Our child receives good/better care* and *Our child has had increased potential, growth, and development*.

“I wanted my child with special needs to have the best life that he could, and I knew I couldn’t give him everything that he needed or desired.” “My search was for something that could give him more than what we were already doing for him.” “I was getting to the point where I recognized that I really wondered what more I could do for her.” “We realized that our child with special needs needed a little more than we had available here.” “I didn’t know what more to do for him, and I knew that somebody else could help him more than I could because I didn’t have all those skills and all that staff to help me.”

We were worried about his safety is an *Appraisal* surrounding the parents’ struggles with controlling their child’s aggressive, dangerous, and destructive behaviors. “Safety has always been my biggest thing with him because I’m always paranoid about him getting hurt or something - I know he doesn’t have a concept of danger.” “That was my biggest fear - was he was going to get hurt.” “Those kind of things were a concern to us - the safety issues that jeopardized his safety.” “I think the primary thing, though, was that your whole life is just centered around keeping one human being safe - not helping them grow, not helping them develop - it’s just keeping him safe.”

We weren’t able to provide adequate care for everyone else: “Your entire existence is focused around one human being, and any other human being in your life suffers.” Whereas *Providing care for our child was stressful and challenging* focuses on parents’ *Appraisals* relating to how placement alleviated many of the problems associated directly with providing full-time care for a child with severe or profound developmental disabilities, this subcategory looks at parental *Appraisals* regarding how post-placement life is less difficult in terms of how negatively having their child at home affected them,

their children, and their neighbors.

This subcategory begs the question, “What is the difference between the component of *It was hard on our marriage* in this category and *Our marriage is better* in the *Amplifying or Generating Advantages* category?” Saying, “Having our child with special needs at home was hard on our marriage” is different from saying, “After our child with special needs was placed, our marriage improved,” in that the former expresses the presence of a disadvantage (i.e., things were bad) while the latter confirms the incidence of an advantage (i.e., things have gotten better). The same is true for the *Appraisals* behind the *Disadvantage: We were neglecting our other children*, and the *Desirable Sibling Adaptive Response: Our children receive better care and attention from us*. The distinguishing idea between these congruent *Appraisals* is similar to a coin: while both sides of a coin indicate the same amount of currency, both sides are distinguishable by their conspicuously different images; similarly, although both components represent the marriage or parent-child relationship, both aspects (i.e., the reduction of a disadvantage and the presence of the equivalent advantage) represent different forms of *Appraisals* for coping with the *Emotional Stresses* associated with placement.

Parents generally agreed that most everything else in life had to take a back seat to providing care for their child. As one mother explained, “There was just absolutely no way of pulling our family together; [caring for our child with special needs] was such an enormous wedge.... I could just see our family falling to pieces before my eyes - I literally could.” This subcategory has three components: (a) *We were neglecting our*

other children, (b) It was hard on our marriage, and (c) We were concerned about everyone else's safety.

We were neglecting our other children is an *Appraisal* for why placement was so necessary. "Having a special child with special needs meant that we didn't have a lot of time to spend with our other children" "It's so much stress you know you're going to kill yourself off, and you won't have anything to give to your other kids." "And we're very, very fortunate [that our other children are not] juvenile delinquents because, for three or four years, we were just completely engrossed in caring for one soul."

It was hard on our marriage is another parental *Appraisal* that explains why placement was required. "It put us in a mind set that we're parents first and married secondly." "For me, there was not any focus on how things were with my husband - I think there was more in the survival then" "I think it was 15 years before we went and did something with just my husband and me by ourselves." "You get to the point where if there's a lot of bad and there's a lot of stress, that starts breaking up marriages." "We would have killed each other, because it was just that frustrating." "It was awful. And it's hard on a good marriage, but on a bad marriage [laugh] it's a death sentence."

We were concerned about everyone else's safety addresses the parents' cognitive *Appraisal* that placement has made (a) the parents, (b) the other children, and (c) the neighbors safer from the child with developmental disabilities' aggressive and dangerous behaviors. "Certainly we wanted to keep our child with special needs in our home as long as we could, but when it came to a certain point, it was obvious that that was not feasible, not safe, not wise." Concerning safety issues reported by parents included playing with knives, fire-starting, sexual misconduct, suicidal and homicidal threats, cruelty to

animals, destruction of property, physically abusing siblings, parents, and neighbors, and other violent behaviors.

The following selection expresses a father's concern regarding all three elements of *We were concerned about everyone else's safety*: the parents, the other children, and the neighbors:

There was concern for the other kids in the family. How our child with special needs was going to affect our family, and risks and concerns there. And even in the neighborhood there were some concerns: some of the neighbors were worried about some of our child with special needs' behaviors and things.... He even was doing things to my wife.

We felt isolated looks at how pre-placement life created a sense of separateness and loneliness. "You couldn't go places with the family that other families [could] - it sort of isolated our family - we felt isolated from other people and we were different. It was like our whole family was handicapped or retarded."

But I think at that time, you are just so alone - there is not a lonelier feeling than walking through a mall, walking through somewhere, with a disabled child and having people gasp. I don't know how you tell someone how to cope with that.

You have to have skin of steel because you get your feelings hurt everyday - I still get mine hurt sometimes, but I think I'm growing and so I don't let it alarm me as much.

We were afraid of becoming bitter toward our child is a parental *Appraisal* that establishes placement as the vehicle reducing or eliminating either the fear of developing

bitterness, or actual resentment, or both, toward the child with developmental disabilities. Parents chiefly discussed this component when talking about their other children.

Mother: [And we thought,] “And if we put him in now, I think we are far less likely to be bitter towards our child with special needs and toward what we had to give up to take care of him.”

Father: Yeah, we met some pretty bitter people who dedicated their lives to taking care of their child...but emotionally they were bitter-

Mother: Yeah, emotionally they were very angry at having...to give up that much of themselves; and then there was also the damage to the other children.

Father: Oh, the other children were...just terribly resentful of their sister for having taking their childhood away.

“I felt somewhat resentful about our child with special needs because of not being able to spend more time with my wife. So there was (sic) a lot of emotions that was (sic) involved.”

Amplifying or Generating Advantages: “Hey, if it helps them, and it helps you, it’s all worth it.”

Whereas *Reducing or Eliminating Disadvantages* contains *Appraisals* in which placement minimizes or completely remediates stresses and challenges, resulting in the *Emotional Advantage of Relief*, the *Appraisals* in this category also facilitate *Relief* by endorsing placement as the reason for increases in previously existing advantages or the creative force behind new advantages. As demonstrated by the number of coded passages for each category, parents tended to focus more on *Appraisals* about the *Amplifying or*

Generating Advantages (586 coded passages) than the *Reducing or Eliminating Disadvantages* (448 coded passages). Witness the role that *Amplifying or Generating Advantages* plays in this mother's coping with the *Emotional Stresses* of placement as she passes what worked for her onto other parents:

There's certainly no way to escape from the pain of [placing a child] because, effectively, (becomes very emotional) you're handing your precious, precious child over to someone else to take care of. But I know the only thing that got me through that was the knowledge that he was in a good place - because I spent so much time making sure that he was - and that I was doing the best thing for my child with special needs. You know, the best thing for *me* would have been to keep him with me, but that wasn't what was best for *him*. And I think if [other parents who have decided to place] can focus on that, and know that what they're doing is giving this child opportunities that they may not be able to give him otherwise, and really stay focused on that, then I think that it will help.

In addition to statements along the lines of "Things were better, and...the common good was being achieved," most of the parents also commented on advantages that were pleasant unexpected surprises – benefits that they did not foresee at the time they made the decision to place their child: "We didn't imagine it would be as good as it has been." "It's a great outcome. Better than we ever could have hoped for."

The emergent subcategories of *Amplifying or Generating Advantages* consist of cognitions surrounding the advantages received by: (a) the parents, (b) the family in general, and (c) the child's caretakers.

Parent Advantages: "It gives you a life." While the benefits that parents believe their children receive from placement (*Desirable Filial Adaptive Responses*) were more abundantly discussed, parents also exhibited *Appraisals* regarding the advantages they get from placement: "But for the most part, it has been very positive and very helpful for us. I mean, it gives you a life, basically. That's what it does for you." "[Placement] gives [parents] a chance to have a life of their own."

Freedom is a major *Appraisal* undergirding much of the three components of the *Advantages* that the parents see for themselves: (a) *It freed us to just love her*, (b) *Now we're happy to see him – now it's quality time together*, and (c) *Our life is better*.

It freed us to just love her captures the idea that placement makes it possible for parents to love their child without all of the stresses described in the *Reducing or Eliminating Disadvantages* category.

I just remember...still having this very overwhelming feeling that it was the right thing to do, and that it freed us to just love him - and that was all he needed from us because everything else support-wise was in place for him, and it was easy to love our child with special needs...it was so easy for us to be there for him and love him.

Now we're happy to see him – now it's quality time together summarizes the genre of *Appraisals* parents used to describe how their relationship with their child has improved because of placement. Parents usually discussed *Now we're happy to see him– now it's quality time together* in the context of visitation.

When that stress is gone, you can still have a relationship with [your child with special needs]...if you still want to have that relationship; you can have a good

maximally improved relationship with them over time because some of the threats and some of the difficulties are removed....

Our life is better is an *Appraisal* about how placement has made life easier and better for the parents. The interviews yielded three elements of *Our life is better*: (a) *We're relieved*, (b) *Our marriage is better*, and (c) *We have more personal time and we're freer to focus on us*.

We're relieved is the *Appraisal* that parents use to describe how placement has made their life more comfortable and manageable (the other side of the coin of the *Reducing or Eliminating Disadvantages Appraisals of Providing care for our child was stressful and challenging*).

“Well the advantages was (sic) relief and time.” “I feel a little bit of relief.” “And the stress level has really come down.” “I think it’s far less stressful.” “It was a relief to get him into the system.” “It was almost too good to be true for me.” “I was just happy - I thought, ‘Oh man, what a relief.’ “I thought, ‘Boy, aren’t we lucky! It’s like hitting the lottery or something!’” “Oh dang, it was so nice to have a whole night without a temper tantrum!” “It is more peaceful when she’s not here.” “Well, I want him there because I think easier for us personally.”

Our marriage is better is an *Our life is better Appraisal* that asserts that the parents’ marital relationship is better because of placement. Once again, just because *Our marriage is better* is listed as an advantage does not mean that every participant attributed improvements in marital satisfaction to placement; other scenarios some participating parents reported consist of the relationship remaining the same and even the parents

drifting apart. However, the vast majority of the participating parents reported marked marital progress resulting from placement.

“I think things are more better (sic) than when our child with special needs was here.” “Well, it’s better because there’s not the stress. I think stress is bad on a couple.” “Just less stress on our relationship, I think.” “It’s helped our relationship to grow closer, too.” “We’ve been able to pay more attention to the needs of this relationship than we have at any other time.” “We’ve been able to focus energy on our relationship.” “Rather than just on our child with special needs.” “It’s been fun rediscovering ourselves.” “I feel in love again; only this time it’s deeper.” “It’s just become better and better and better.”

That’s not to say that ever since we placed our child with special needs our relationship has been happy happy joy joy, flowers spread all over the place,

“let’s look at the moon” - it’s just that we’ve been able to work on it now.

We have more personal time and we’re freer to focus on us, the third and last element of *Our life is better*, was formed from data where parents mentioned being able to relax more and do things they wanted to do. Specifically, many parents talked about how placement had allowed them to advance their personal development in areas such as schooling, physical fitness, hobbies, and work. One father explained why the *We have more personal time and we’re freer to focus on us Appraisal* is so important: “The fact of the matter is that if you don’t pay attention to your own needs, you will suffer, your family will suffer, and those around you will suffer.” One of the mothers provided a concurring statement when she declared: “I know that I’m freer to focus on me, which I think is probably very important for the soundness of my family.”

Family Advantages: “So we got to the point where it seemed like placement was a rational thing to do for the family.” This subcategory generated only one component: *Our family life has improved*, which contains cognitions that explain how positive familial changes merit placement:

“I think it’s good for a whole family” “I never dreamed we’d be where we are now; it just didn’t seem like life would ever return to normal. So, that’s been really good.” “The whole family has [grown from the placement]; we’re all calm again.” “Of course, the family’s been able to pretty much carry on their life in a normal manner, which they would not have been able to do as freely as we are now.”

We’ve been able to do more things than ever before is a cognitive component of *Our family life has improved* that reflects on the activities in which the family can participate because of placement. Parents routinely mentioned an increase in the following activities: vacations, going to movies, concerts, eating out, going to church, and recreational activities.

“We felt somewhat free that we could go somewhere and be a normal family.” “The amount of activity and the nature of what we do [has changed].” “Well, we were able to go do something without worrying about what is going to happen here.” “Now we can go and enjoy ourselves.” “We don’t have to worry.” “We can spend more time with the kids and doing other things, different activities, and things like that.” “We can go do things as a family.”

Caretaker Advantages: “We shouldn’t be selfish and just keep our child with special needs to ourselves because of her sweet personality.” As with the property *Our family life has improved*, the *Caretaker Advantages* property also yielded only one

component: *Their lives are enriched by our child.* Some parents viewed placement as a way to let their child enrich the lives of their caretakers.

Mother: And it was also reassuring to me when that friend of mine says, “Well, don’t be selfish. Your child with special needs is a wonderful person, let somebody else enjoy her personality.”-

Father: “Let somebody else enjoy the pleasure of being with your child with special needs.”

Mother: We have had a lot of workers tell us, “Your child with special needs is so sweet.” And that just makes you feel good, “Oh, she’s one of our favorites!”

Desirable Filial Adaptive Responses: “Has it been better for our other children? Yes.

Has it been better for our child with special needs? Yes.”

Just as the *Problematic Filial Adaptive Responses* increased the parents’ *Emotional Stresses*, the *Desirable Filial Adaptive Responses* seemed to increase the parent’s perceived *Emotional Advantages* (i.e., *Relief*), and subsequently reduce the weight of the *Emotional Stresses*. The categories developed within the *Desirable Filial Adaptive Responses* are also similar to those within the *Problematic Filial Adaptive Responses*: (a) *Desirable Placed Child Adaptive Responses* and (b) *Desirable Sibling Adaptive Responses*.

Desirable Placed Child Adaptive Responses: “I think it’s been the best thing for our child with special needs.”

This category contains the types of *Appraisals* demonstrated by parents that focused on how placement is better for their child. Of the 586 coded passages for

Amplifying or Generating Advantages, 319 were *Appraisals* about the *Desirable Placed Child Adaptive Responses* of placement, making *Desirable Placed Child Adaptive Responses* the most prevalent subcategory of the *Appraisals* leading to the *Emotional Advantage of Relief*. Concentrating on the benefits that their child received from placement appeared to be one of the most effective *Coping Methods* parents had for allaying the *Emotional Stresses* of placement.

“It was the best thing for our child with special needs.... So that intervention probably is the most important intervention of her life.” “I know that he’s better off.” “I think it’s worked out better for my child with special needs.” “And it gives our child with special needs a life and helps him feel more independent.” “I think I would advise other parents to realize that placement is helping the child, not just them.” “Maybe being in a placement is really the best thing for your child. And even with the hard times for our child with special needs, I still think it was better for him in his experiences than being at home.” “I think the hardest thing for me is getting past my own emotions, and needs, and feelings, and thoughts about what I expect or what I want, and to focus more on what is necessary for the child.” “That’s the only way you can decrease your guilt - it’s the only way to not be wallowing in guilt.”

Two subcategories of *Desirable Placed Child Adaptive Responses* emerged from the data: (a) *Our child receives good/better care*, and (b) *Our child is happy/happier* .

Our child receives good/better care is the *Appraisal* about how the care the child receives is either good (i.e., not bad, but not better than what he or she could receive by living at home) or better (i.e., better than what the parents could provide for their child in their own home).

“What’s improved [our child with special needs’ life] is the quality of the staff that’s there to give him the care day after day after day.” “We had other children that we had to worry about; [our child’s care provider] just had our child with special needs, and so she was able to focus on [him].” “It needed to be something that was going to give him the supervision - he needed 24 hour one-on-one” “She’s getting better taken care of than we could at home, because she’s got more professional people working with her.” “She gets way more services when she’s placed outside the home.” “She had those opportunities that we could not give to her.”

A very persistent thread of *Appraisals* among parents about the care their child was receiving consisted of the fact that the care providers and staff were able to provide better care because they only had to do it for eight hours a day:

You know that’s the thing about the group home, they work shifts. (Laughs) It’s not like you’re 24 hours a day 7 days a week dealing with this kid. They get to leave. When their shift is done, they go home. And then the next person, all fresh and happy, comes in. (Laughs) And I thought “That’s probably a good thing because it wears you out.”

Five components exist within the *Appraisal Our child receives good/better care*: (a) *Our child has had increased potential, growth, and development*, (b) *We’re lucky to have such good care providers*, (c) *Our child is safe/safer*, (d) *Our child is more independent*, and (e) *Should something happen to us, we know our child will be taken care of*. A brief outline of each follows.

Our child has had increased growth, development, and potential was the most prevalent form of the *Our child receives good/better care Appraisals*. Almost every

parent dwelt on how placement had helped their child learn new skills and acquire new abilities. Parents referred to things like better opportunities (e.g., recreational activities, camps, trips, work training and experience), better child-centered programs (e.g., behavior modification, life skills, structure provided by the staff), and better access to services (e.g., medical care, medication, physical therapists, occupational therapists, speech therapists, dietitians). Another reason often cited by parents was that their child's placement provided better care because the staff had received better training than they had.

“They had some kind of activities going on to try to help her reach as high a maximum potential that our child with special needs could reach.” “I don't know if I could have taught him all that because as a parent...you don't know the teaching techniques that they use. And so it's been really helpful.” “And so there's some real growth there that wouldn't have come if he was in the home. I'm sure it just wouldn't have come.” “We watched him and his growth....We feel rewarded that he has progressed.” Now I don't have any guilt at all because I see how much progress he's made.”

An exception to *Our child receives good/better care* was one family whose child with developmental disabilities did not grow and improve; these parents, instead, focused on how their child did not regress: the mother explained, “She stayed the same in a lot [of areas], but I have not seen her regress,” to which the husband added. “She hasn't gone backward.” Thus, the parents had adopted an “it could be worse” perspective in this scenario.

We're lucky to have such good care providers is an *Appraisal* that emphasizes the advantages of *Our child receives good/better care* because of the qualities of the care providers and staff.

“I was very impressed with the staff.” “They’ve taken good care of him.” “We really were impressed with the facility - they really care for the kids.” “I think there were good people down there.” “They have people who really try to help them to progress in certain areas. They have been very good.” “Most of the folks at his group home that’s their second or third job. And something they do not for the bucks, but for the difference.” “Someone’s loving her.” “And everybody that works there is in love with him. So it’s kind of like instead of having two parents or four grandparents, he just has a multitude of people that care for and love him.”

Our child is safe/safer is the other side of the coin for the *Reducing or Eliminating Disadvantages Appraisal* of *We were worried about his safety*. The *Our child is safe/safer* component confirms *Our child receives good/better care* because the parents perceive that the child at least safe, if not safer than he or she would have been at home.

“Well, my first number one concern was that he would have safety... And they said, ‘It’s one-on-one care.’ So I thought, ‘Okay. I can handle this.’ That was my number one.” “I was relieved, I could work in peace knowing he’s taken care of, he’s not going to be hurt - somebody’s going to be with him all the time.” “It comforted me to know that she was in a secure place.”

Our child is more independent was a prized advantage professed by the parents. The following selection depict parents using this form of *Appraisal*:

Special needs children...might actually be better off with placement because it transitions them into society, and it makes it less dependent in the long term, which is the ultimate goal for your children is that you want them as independent as possible.

Should something happen to us, we know our child will be taken care of is a parental *Appraisal* that says: “We wanted to make sure, if something happened to my husband and I, she’d have a good place.” “I know that when I die...I know that she will be well cared for.”

I still struggle with the idea of what his future will be, but one thing that I feel at peace with is that, even though he doesn’t like the system, I feel that now that he is in the system, if something happened to us, our child with special needs would still have good quality care, and he would be watched over.... I also feel that he has a direction, he will be cared for, he is not going to be institutionalized with people that don’t care for him.

At some point during their interview, most of the parents mentioned that their child with developmental disabilities does not handle change well. In fact, several parents stated that it is an advantage for their child to be placed before they die because (a) they are around to help their child with that transition and (b) make sure that the placement is a good fit for their child. The other common thread within the *Should something happen to us, we know our child will be taken care of* component of *Our child receives good/better care* was a general concern that the parents’ other children should not have to have the responsibility of caring for their sibling; consequently, parents also perceived advantages

for their other children within the *Should something happen to us, we know our child will be taken care of Appraisal*.

“Unfortunately, we do suspect that he will outlive us; quite honestly, we would prefer he didn't so that he is not his brothers' burden, do you know what I mean?” “Our child with special needs...can't be here; not when we're our age. And what you do in 20 years? I refuse to turn him to my children, and say, 'Here's an opportunity.' It's not fair to them.”

Our child is happy/happier is the other subcategory of *Desirable Placed Child Adaptive Responses*. *Our child is happy/happier* is an *Appraisal* parents espoused regarding how their child is happy at the placement (i.e., not sad, but not necessarily happier than what he or she would be living at home) or happier (i.e., more happy at the placement than at home).

“She's a whole lot happier.” “And afterwards, we could see that he seemed to be in some ways happier.” “He's really happy where he is.” “She likes it there; that's her house.” “He loves being a single dude in an apartment.” “We were almost relieved to find out she had a better time without us.” “When a Sunday night comes and she says, 'It's time to go home now. Please somebody drive me to my apartment.' - and you realize it's what she wants - then you know you did something right.”

Our child is happy/happier has one component that became visible from the data: *Our child enjoys being with other people like him*. Many of the parents seemed to lock into the *Appraisal Our child enjoys being with other people like him*:

“He enjoyed it so much; there were so many other kids.” “The interaction that I think he needs to have with members of his peer group - I think that social interaction is

so incredibly important.” “I think it’s much better for a child to leave home and be in a situation where she’s with her peers.” “He certainly needs to have the social experiences - that he is kind of interacting with members of his peer group, and the opportunities he’s having to go on dates with his girlfriend.” “[One of the other patrons] had very similar characteristics to our child with special needs: with...a lot of the same interests behaviors; they were fast friends.”

Desirable sibling Adaptive Responses: “I know that the other children are better off.”

In addition to using *Appraisals* that placement was advantageous for their child with developmental disabilities as a *Coping Method* for the *Emotional Stresses* that they experienced, parents also saw many advantages for their other children: “Has it been better for our other children? Yes. Do we have an obligation to our other children? Yes.” “I think it has also been the best decision we made for our other children.” “They’re much better all the way around.” The *Model of Parental Adaptation to Life After Placement of a Child with Developmental Disabilities* presents two subcategories for the *Desirable sibling Adaptive Responses* category: (a) *Our other children receive better care and attention from us* and (b) *Our other children are happier*.

Our other children receive better care and attention from us was the most frequently cited positive *Appraisal* that parents perceived their other children received as a result of placement. The subsequent selection for *Our other children receive better care and attention from us* provides clear evidence of the effectiveness of this *Appraisal* in managing the *Emotional Stresses* parents face after placement:

I had that horrible guilt when I put my child with special needs in the home, but then after I calmed the tears down and I had to start thinking positive, I realized

“Hey, I can spend time with [my other child] now.” because I almost feel like I’ve just kind of left him on his own to deal with things. [My other child] and I have improved our relationship...we’ve gotten a much closer relationship now. He talks to me; he tells me everything. And that’s good.

Our other children are happier is the other subcategory of *Desirable sibling Adaptive Responses*; it has two components: (a) *Less responsibility* and (b) *Better sibling relationships*. Parents also attributed some of their other children’s happiness to being relieved that their sibling with special needs had been placed:

“The kids were happier.” “I think they’re all grateful that she’s where she is, I really do.” “Oh I think they’re all just pleased and relieved, like I am.” “They were all, I think, relieved...to have him out at that time.” “And they were happier.” “The thing I would know, or assume, was it had taken some obviously some pressure off of them, some stress out of the home.”

Less responsibility is the component that explains part of *Our other children are happier* by zeroing in on how their children are less stressed because they do not have as many responsibilities as they did when their sibling with special needs was living at home.

“During their growing up years and the time our child with special needs became mobile, which was delayed, thank goodness, they had to be ultra responsible because they were responsible for their well being and for his.” “I mean, it was a big responsibility placed on little kids. So to that degree, in terms of they grew up being very responsible.” “We knew it would be better for them because they wouldn’t have the responsibility of

our child with special needs.” “I think he felt relieved because he felt a lot of responsibility for his brother with special needs’ care.”

The other component of *Our other children are happier* is a parental *Appraisal* regarding *Better sibling relationships*. The aspects of this component include improved relationships between the siblings of the child with special needs, as well as the siblings’ relationships with the child with special needs.

“I would suspect that it maybe helped them spend more time together.” “They seem like they enjoy seeing him.” “The difference was like night and day. When she came home for visits everybody was happy to see her. They made her feel like a guest.” “They were happy to see their sister, you know; they wanted to spend time and do stuff with her.” “They really, really, really, really love him. They are kind to him, they love him and care for him.”

Supportive Greek Chorus Voices: “We were lucky to the support of people around us.”

The voices of other people reduced the *Emotional Stresses* by augmenting the *Emotional Advantages* in terms of providing additional weight to parents’ *Relief Appraisals*. The more people agree with the parents’ placement decision, the better parents tend to feel about their decision.

“I think it’s an emotional support. I think everyone has been really marvelous.” “Well, most people thought that we should place him, especially with how much we’d already gone through.” “I think when we got advice...that helped us an awful lot.”

The voices of significant people in the parents’ lives appeared to carry more weight with the parents: “The ones that knew our child with special needs were very understanding; the ones that did not know her were the least understanding until they

found out.” The *Supportive Greek Chorus Voices* were determined to include six primary components: (a) *Family*, (b) *Friends*, (c) *Professionals*, (d) *Support Groups*, (e) *Community and Neighbors*, and (f) *Religious Leaders*. The following selections represent the messages from the *Greek Chorus* that matter the most.

“I thought we had very good support.” “They knew how hard it was on us.” “I had family members that were so incredibly supportive that sometimes I wonder if I could have done it without them. I’ve just been so blessed to so many wonderful people in my life.” “I had quite a support group of friends...that’s what kept me going.” “[My friend] knew I was hurting and wondering, and she was just reassuring.” “Well, we could hear other parents going through it that had already done it. That helped so much.” “Well, I went to my priest, and...that helped me so much.” “The neighbor that lives two houses down that has a retarded daughter, they are very supportive.” “[The social worker] told us that he would do well. It was because of her that I was able to place him.”

Coping Methods: “You just need to learn to cope.”

Within grounded theory, a major part of model development is cultivating an understanding of the strategies utilized by the parents in response to the central phenomenon of interest. Through the data, it became clear that after parents voluntarily place a child with developmental disabilities, they experience *Emotional Stresses*; the processes parents used to manage the *Emotional Stresses*, or *Coping Methods*, also evolved and took shape from the interviews. In reference to dealing with the *Emotional Stresses*, parents responded: “Somewhere you have to make a decision about how you’re going to deal with it.” One father emphasized that coping is a choice when he said:

Somewhere you have to make a decision about how you're going to deal with it. And you can choose to be angry and frustrated and mad...or you can just choose to pick the pieces up as best you can. And I think that's a big deal, and I think that's a choice you have to make.

As previously indicated, it is theorized that parental adaptation to life after placement is the process of developing *Coping Methods* to manage the emotional stresses associated with placement. The approaches and patterns for parental adaptation consist of the following *Coping Method* themes that surfaced from the data: (a) *Reappraisals*, (b) *Involvement*, (c) *Therapy*, and (d) *Time*

Reappraisals: "It just really solidified in our own hearts that what we did for her was the right thing."

The *Reappraisals* are different from the *Appraisals* in that they are not necessarily cognitions asserting the absence of a disadvantage or cognitions emphasizing the presence of an advantage; they are principally cognitions that reevaluate and reconfirm the correctness of the parents' decision to place. Being able to latch on to reasons why placement was necessary is a cornerstone *Coping Method* for handling their *Emotional Stresses*. The *Reappraisals* also help parents challenge their own negative thinking by identifying more positive views: "You have got to focus on the reason that led you there." "I realized that that confirmed again to me that it was a good thing to have placed our child with special needs." As parents were very apt at clarifying, the fact that life is better does not mean that problems, whether child-related or not, do not exist, but that life after placement is comparatively better than it was before.

The first clear inter-thematic relationship to emerge from the interviews was that between the *Emotional Stresses* and the *Reappraisals*. The subsequent selections are a few of the excerpts that helped define the *Reappraisals* as a primary *Coping Method* for *Emotional Stresses*. The excerpts are almost exclusively quotes from fathers; although mothers were less likely to voice or view how *Reappraisals* helps manage *Emotional Stresses* in terms as unequivocal as the fathers, the mothers were more likely than the fathers to report implementing *Coping Methods*. Consequently, it is assumed that the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* still explains the adaptation process of both genders of parents, despite the more frequent reporting of the *Reappraisals* theme by fathers.

One father expounded:

Well, there's emotions and there's logic. And the logic is pretty clear. I mean the logic is there - it was clear to me: "This is what's got to be done." I don't like it feeling-wise; emotionally, I don't like it; but I could see that this has got to be done...logically, actually, I could see the need, and the reason for it, and why it had to be done. But, still the emotions were there - the hard part is the emotional part.... But really, it's been a more positive than negative [decision].

In another interview, the following was shared:

Father: Yeah, we know intellectually that it was the right thing to do in every respect-

Mother: It was the best-

Father: But, the intellect does not rule over the emotional. We still have emotional issues to deal with. But intellectually, there is not a single argument

that can be made that would demonstrate that we've harmed somebody; everyone is coming out ahead in this, including our child with special needs. Emotionally, we struggle every day... we still deal with it.... So, there are all kinds of pros; the pros, in numbers, far outweigh the cons - but the cons are pretty heavy-

Mother: Emotionally-

Father: Emotionally, yeah. So you just have to be strong enough to deal with it. You have to be strong enough to say, "I'm doing the right thing for me, for my children, and for my child with special needs" - that should be enough.

Quotes like these were used to understand that the parents viewed the stressors as essentially emotional in nature, and that parents were better able to manage the *Emotional Stresses* by focusing on *Reappraisals* of placement in terms of ways that it had been beneficial. The *Reappraisal* process of restructuring the cognitions associated with the *Emotional Stresses* through cost-benefit analysis helped decrease parents' *Emotional Stresses*.

The *Reappraisal* subcategories developed from the data are: (a) *It was the best decision*, (b) *It was inevitable*, (c) *It was needed*, (d) *It was a blessing*, (e) *It would have been bad if we hadn't placed*, (f) *Visits with our child confirms our decision*, (g) *We had to have a lot of trust and faith*, (h) *Leaving home is a developmental norm*, (i) *We're still our child's family*, (j) *We did the best we could*, (k) *We're not the only ones who have a hard time caring for our child*, (l) *Life was just too stressful*, (m) *We were told "Take it, or leave it,"* and (n) *We could have kept our child home IF....*

It was the best decision: "Looking back, it was the right thing to do." This first property optimizes the concepts of the *Reappraisal* cognitions as it confirms the need for

placement. *It was the best decision* was universal among all parents interviewed. It seems reasonable that the presence of the *It was the best decision Reappraisal* would be so widespread and overarching among parents who have placed; if it were not, one would be led to wonder why parents still had their child placed in out-of-home care. The following selections provide an overview of *It was the best decision*:

“I think it was the best decision at the time.” “I feel really good. I know that I did the right thing for my child with special needs.” “I think it’s been the best thing for our child with special needs.... And I think it has also been the best decision we made for our other children.” “I wanted to help him and help me. And I figured that’s the best decision - for both of us.” “But for us, it was not a hard decision because you could see where we were going; it just wasn’t going to work out.” “Oh, I felt it was absolutely the right thing to do.” “And the positive aspects of [placement], I think, far out way the negative aspects of what you’ll have to live with that type of problem in your home.” “So, even though it’s very difficult and still is painful, I think it was the best decision that I could have ever made.”

It was inevitable: “*And if it wasn’t today, it would be in a short time anyway, so it was inevitable.*” A substantial number of parents also appeared to use *Reappraisals* about how placement was unavoidable.

“I think it was an eventual course.” “We knew that it would happen sometime; it would happen eventually.” “At some point I would have had to come to that decision, and I would have had to work through that mentally that, ‘Yes - this is what we had to do.’ ” “We knew right from the beginning when our child with special needs was born.” “We could see, for probably at least the last year before we put him in there, that this is

where we are going to be end up heading at some point.” “Our child with special needs is only going to get bigger, and older, and stronger, and more affective, and more difficult; if we don’t put him in now, we’re going to put him in later.”

It was needed: “*It was what we needed to do.*” The idea that placement was needed was a common one among parents: “It was appropriate; it was needed.” “That’s what I want. That’s what we need. That’s going to be the best for her and the best for us.” “This is what we really need to do.” “I think that intellectually we understood that was going to be necessary.” “Deep down inside, we saw the transition happening, and we knew.” “I think that at a point, it became quite clear that that was the decision that we had to make.” “It was pretty clear.” “The only way I got through it was to keep thinking back, ‘Well, I don’t know of any alternatives.’ ”

It was a blessing: “*It was a blessing, even though it was stinky.*” The *It was a blessing* property conveys the gratitude that parents expressed that they were able to secure a placement for their child.

“I think Someone higher and mightier - and this is only because of my religion - took care of that for us because we were at a crisis - we could not even think.” “I remember a major feeling of gratitude that we found something, and it was something that was a major solution that was going to take care of some major frustration problems and depression problems.” “And I was like, “Yes! Thank You.” And that was a good thing for me at that time.” “A major light in the tunnel.”

It would have been bad if we hadn’t placed: “*If he lived here, it would be another story.*” The *It would have been bad if we hadn’t placed Reappraisal* was derived from the widely-observed phenomenon of parents contemplating what their lives might be like

now if they hadn't placed. The *It would have been bad if we hadn't placed Reappraisal* is a *Reappraisal* vehicle that parents used to verify their placement decision. The tendency among parents seemed to be focusing on potential worst-case scenarios that might exist if their child were still at home.

"If we had our child with special needs these last four years, who knows? Who freaking knows what would have happened?" "Well, we can only suppose it would have been pretty darn bad if we had kept our child with special needs - you could spin off to drugs and alcohol, and all kinds of negative things." "He could've have stayed in the home and the home wouldn't have stayed together, it would have broken down one way or another, however homes break down."

Visits with our child confirm our decision: "When the child is with you on a visit...you realize you made the right decision." *Visits with our child confirm our decision* was the most frequently mentioned *Reappraisal*; all of the 20 interviews made mention of this cognition. The parents reported that when their child came home for a visit, it validated the parent's placement decision.

"I can't have her anymore at night - she's way too heavy and she can't walk by herself - I just can't handle her, and that makes me feel very badly." "I think just realizing that we couldn't handle him anymore. I think it's when he'd come home from overnights or whatever, and it was just SO difficult." "It's like, 'Man the battle stations!' " "It's just so tough." "So our activities have to do with things that she enjoys - not us!" "She runs the show - she definitely runs the show." "We tried to bring him home on Christmas and New Years, but the price was that we didn't have Christmas through New Years, or Thanksgiving or whatever it was." "So the Holidays are really difficult."

“I like to pick him up. I enjoy him when he is home, and it feels like a relief when I take him back.” “It’s intense when she’s home; I’m relieved when [she] goes back.”

Our faith and trust confirms our decision: “You’ve got to have faith that that was the right decision.” This *Reappraisal* subcategory derives its strength from a belief in a Higher Power. Several parents described placement as an act of faith that God would take care of their child; others testified of receiving Heavenly confirmation that placement was the best thing and sanctioned by God.

“Well, I had to have a lot of faith that she’d be taken care of over there. If I hadn’t had that faith, I probably wouldn’t have let her go. We had to have a lot of trust.” “We had to have a lot of trust and it was hard for us to do trust at that time, but when the situation kind of demanded it, we just put trust (sic).” “We had faith that it would be good, and [that] it would work fine, and that it would work for all of us.”

“I had to actually pray about it and think about it.... And I had to go on that faith because I could not...see it.” “Personally, I had to pray about it, and fast about it, and [received an] overwhelming feeling that this was the right thing to do - the best thing to do.” “We stood there, and we prayed, and we had a feeling: ‘This is the right idea.’”

Leaving home is a developmental norm: “An analogy [we used was] that this was our child with special needs’ moving on time; and for a lot of it, that was really how we justified it.” Another regularly-occurring thread of *Reappraisals* was that it is a normal developmental process for a child to leave home and become more independent. Parents whose child was placed after reaching adulthood seemed more likely to use the *Leaving home is a developmental norm Reappraisal* than parents who placed when their child was an adolescent or child. In fact, placing a child with developmental disabilities in out-of-

home care before adulthood, which would be considered an off-time normative transition (the result of an event that happens before it is expected to happen), appeared to be a source of *Emotional Stresses* for parents, similar perhaps to the death of a family member in her or his thirties.

In order to more clearly understand how the *Leaving home is a developmental norm Reappraisal* works, the experiences of *Placing before adulthood* and *Placing after adulthood* are explored.

Placing before adulthood seemed to be an aspect of placement that made for additional *Emotional Stresses*. A father describes his angst at placing his young child in the subsequent paragraphs:

And here we're thrusting a kid who's at the time, 15 1/2, 16 years old, into that system. So you're feeling guilty because here's a young boy who ought to be enjoying life and finishing high school, having friends, going through all those experiences.

You're just not prepared to give a child up, at least I wasn't, at that age.

They're not ready to leave home yet. My magic age was out of high school. Then you can do whatever you want. Basically you're out on your own, making all your own decisions. But until then, you're there to kind of guide him and help him.

Parents who had placed non-adult children often discussed the *Emotional Stresses* of *Placing before adulthood* in tandem with the *Reappraisals*. For instance, the mother in the following selection focuses on a timing aspect of *It was the best decision*:

I wanted to wait until she was 18 because I would have felt more like, “Well, she just was a kid who grew up, and all of the other kids leave when they’re 18.” But I don’t think that could have happened, we knew that the time was right.

The father in the subsequent excerpt juxtaposes *It was inevitable* with the additional *Emotional Stresses* of placing his six-year-old child:

Really, all the signs were there, but we had to be forced to do it because we just didn’t want to place him. It was hard for us to feel like we could place him. It just wasn’t an option in our minds, even though we knew that it would happen sometime: “It would happen eventually, yes, but not right now - not when he’s six years old.”

In this third and final example, a mother and father actually employ *Leaving home is a developmental norm Reappraisal* by looking at the pre-adulthood placement of their child as normative through a comparison to sending a child to boarding school, like parents would do in England:

Mother: For me, it was more just plain giving up my child - having him live elsewhere, not in my home under my care 24 hours a day, is like giving up my child. And I had to become very much accustomed to that idea. It helped to think of him as going to boarding school or-

Father: Yeah, that’s how we’d look at it. A lot of kids are sent to boarding school.

Mother: In England at six, or even earlier, they’re gone - they’re at boarding school. So that helped.

Father: And the way we looked at it is that he's going to a superior boarding school where he's getting-

Mother: He can get far more help - far more consistent help - so that hopefully, eventually, he'll be able to do those basic skills and maybe to be able to live in a group home eventually.

Placing after adulthood seemed to more naturally facilitate the use of the *Leaving home is a developmental norm Reappraisal*. The following quotes demonstrate parents sharing *Leaving home is a developmental norm Reappraisals*:

“And our child with special needs is getting older, too, where I felt like I wasn't deserting a little kid [because] he was a little older.” “It's not normal to have a child home all the time.” “I believe that people with disabilities shouldn't always stay at home.” “For me, it was: ‘She has to move on, she can't stay here for ever.’ ” “As you get older, you want your kids to leave home, whether they are disabled or not. You want them to leave home.” “And it's no different for a retarded person, I don't think. When all of a sudden they're alone with two old people [their parents], that's just not what they had in mind.” “After the other kids have gone and they realize that's the thing to do.” “It's a natural transition, so you get used to it about anything.”

We had to sacrifice our child for the good of the family: We didn't do it to break up a family; we did it to save a family.” This subcategory is a *Reappraisal* that takes many of the *Appraisals* associated with *Emotional Relief*(i.e., *Reducing or Eliminating Disadvantages* and *Amplifying or Generating Advantages*) into consideration, particularly the subcategory of *We weren't able to provide adequate care for everyone else*. By evaluating the detrimental effects that caring for their child with developmental

disabilities at home was having on all of the rest of the family members, parents recounted being faced with the question: “Do we sacrifice one to save the family?” In retrospect, parents look back logically on *We had to sacrifice our child for the good of the family* as a decision that ultimately reduced or eliminated the most pre-placement disadvantages for the most people. This dilemma was reported in approximately three quarters of the cases, making it a fairly prominent experience shared among parents.

“We were just completely engrossed in caring for one soul. (Becomes emotional) And I said to my husband, ‘Do you sacrifice one to save three, or do you sacrifice three to save one? What do you do?’ ” “Make the decision that is going to be the best for the most people. And that’s a pretty cold way to look at it, but it’s the right way, in my view.” “I think that we just made a hard decision that had to be made; we couldn’t sacrifice the other three.” “We felt an obligation to other children; that was our other family obligation.” “Has it been better for our family? Yes.” “I didn’t believe it was going to be better for him, but I knew it was going to be better for the rest of the family.” “I felt I had abandoned him and sacrificed him for the good of the family.”

“[You can’t] get too tied into this issue about ‘guilt’ and ‘my responsibility’ and ‘I’m going to sacrifice myself and everybody else for the sake of keeping my child home’” “Someway you have to live life, even though there’s a piece of you that hurts. You just have to do that.” “We did it because we had to survive. We didn’t do it to break up a family; we did it to save a family.”

[We decided] that if we took all the energy that we were putting into our child with special needs, and put it in to the other kids, they could have a real life; and

we could continue putting in that much energy into our child with special needs, and not have any idea if there would be any kind of a return.

This final quotation takes a different spin on *We had to sacrifice our child for the good of the family*; this mother didn't experience placing her child as sacrificing her child, she viewed it as an opportunity for her child to have something better. The sacrifice was the mother's willingness to place her child and, as a result, live through the *Emotional Stresses* and *Problematic Filial Adaptive Responses* that accompany life after placement. This perspective of how placement allowed her child to receive better care focuses on the augmentation of the care that the mother was able to provide:

I think that sometimes you need to accept the idea of: "It's possible that there are other people that can do better than I can do, if I don't have the skills" - and there are people that can do a better job than you can do. So you're not sacrificing your child, it's more you are sacrificing a part of yourself. Maybe being in a placement is really the best thing for your child.

We're still our child's family: "He's still a part of this family." This *Reappraisal* proclaims that just because the parents have placed doesn't mean that their child is no longer their child or that they are no longer their child's parents. *We're still our child's family* may also be one of the driving cognitions behind *Involvement*.

"We were not interested in giving up our parental status in his life, we were interested in finding him full-time qualified help." "We are his parents - we were not giving up our child - we were trying to find something that would allow him to grow and have professional help, and allow us to grow and have a family." "But he's still part of

our family and we want to keep him a part of our family and integrate him as much as we can.”

We're still our child's family may also be a *Coping Method* for the *Emotional Stresses* associated with *She may have forgotten who we are* and *Less Control*:

“Because we’re still her [family]. I think my biggest fear was that when I would talk to her she’d just say, “Yeah, so what?” But it’s not; it’s: ‘Mommy this. Mommy. Mommy. Mommy. Daddy.’” “You still want to be their parent, because he’s my child and I want to have a say in what goes in his life.” “You can do anything. You’re in control.”

We did the best we could: “*We did what we did with what we had.*” The *We did the best we could* property operates on the logic that you don’t feel as bad about something (*Emotional Stresses*) when you know that you gave it your all:

I don’t have guilty feelings.... I look at it saying, “We did the best we could. We could have done better if we would have known from some of the teachings that we have had from hindsight, but everything we did, we did to the best of our ability in all areas.” And so I don’t have guilty feelings.

We're not the only ones who have a hard time caring for our child: “*I came to the realization [that] I don't think anybody could have done it.*” The *We're not the only ones who have a hard time caring for our child Reappraisal* subcategory demonstrates a kind of reassuring cognition that the problems they experienced with their child and the fact that placement became necessary are functions of the nature of their child’s disabilities, and not their inabilities as parents. Furthermore, this *Reappraisal* hints at the idea that placement is okay, because no one else in the parents’ situation could have kept their

child at home because they would have also had a difficult time, and would have also needed to place the child. Most of the *We're not the only ones who have a hard time caring for our child Reappraisal* occurred in the context of trained caretakers having a difficult time managing their child. This *Reappraisal* seemed to afford parents a sense of relief from *Guilt* and a comfort that they are not failures.

“He was just a hard little kid to deal with.” “We really felt that he would wear out any other family, and to some degree that’s already been born out. He wore out...his first placement within a year.” “The respite care people would take our child with special needs for an hour and not want to take him again.”

Life was just too stressful: “It was it was just too much.” This category is for the cognitions that parents used regarding how difficult it was to care for their child in the home within the context of all of life’s other stresses. Life was just too stressful generally conveyed the idea that the parents had too many other things on their plate in addition to caring for a child with severe or profound developmental disabilities.

Several of the more common contextual stresses discussed by parents included: (a) the parents pursuing an education; (b) the parents having heavy work-related demands (specifically situations in which both parents had to work); (c) the parents having problems with their physical and mental health (e.g., reduced physical capacity, fatigue, depression, psychological disorders); (d) the parents experiencing anxieties over their other children (e.g., behavior and school); (e) the parents having to handle crises with extended family (e.g., providing additional care for relatives); and (f) the parents trying to manage financial difficulties (e.g., tight budgets, financial strain).

“During the timeframe leading up to our child with special needs’ placement, we experienced an extreme amount of stress.” “That was too much. That was too much.” “But everything combined was very stressful.” “That was the most trying time. Yeah, that was tough.” “There was just absolutely no way of pulling our family together...I could just see our family falling to pieces before my eyes - I literally could.”

We were lucky to get a placement: “You better take it, or you may never get it again.” Many of the parents reported having experiences in which they were told that not taking a placement when it became available was a risk because they might not be able to secure a placement for their child in the future. *We were lucky to get a placement* evolves from these experiences as a *Reappraisal* that the parents are only partly responsible for placement because their hand was forced; focusing on the fact that a person had limited choices seems to be a *Coping Method* for the *Emotional Stresses* that result from a decision (e.g., if we had had more and better choices, then we would have...). (See the next subcategory, *We could have kept our child at home IF...*)

“My advice to parents would be to find a place that will take your child as soon as you think they’re ready to go because those places aren’t always available.” “Actually, we kind of lucked out there; there was a spot open...so they just barely got us in.” “But once it came up, we knew that we probably shouldn’t let it go - he may not be eligible later.” “You take this opening now, or you go back on the waiting list - and we don’t know how long it will be.” They basically said, “You can take this one now, or you can take your chances with one the next one that comes.’ ” “Then the decision had to be made almost overnight.”

We could have kept our child at home IF...: “Maybe we would have been able to keep her longer if...” The *We could have kept our child at home IF... Reappraisal* addresses the “would have, should have, and could have” aspects of placement. This *Reappraisal* has similarities with other *Reappraisals* like *It was inevitable* and *We were told, “Take it, or leave it.”* – the distinguishing characteristic of the *We could have kept our child at home IF... Reappraisal* are cognitions that suggests that if various factors had been or were part of the picture, the parents’ child would not be in a placement.

Thus, this subcategory seeks to reduce the *Emotional Stresses* of post placement by endorsing ideas such as the following: (a) if there had been better choices, we would have chosen something better, and (b) we only did it because we had to. After her husband speculated, “I don’t know about prevent forever, but I think that we could have kept him at home several years longer,” a wife pointed out, “Yeah, I think if we had had options other than what we had...there were no options.”

The *We could have kept our child at home IF...* property was found to have four components: (a) *If we had received better training...*, (b) *If there had been better programs...*, (c) *If we were rich...*, and (d) *Yes; on second thought, No.*

If we had received better training... hypothesizes that the parents might not have had to place if they had received better instruction on how to better care for and manage their child.

I always had wished that there had been more [training] for parents to handle a child like ours. I always thought maybe that if we could have had the [training], then we wouldn’t have had to end up where we were at with having to have our child with special needs leave our home.

If there had been better programs... conjectures that if parents had had access to more support services, they would not have placed, or at least delayed placement (and delaying placement could be monumental, especially for parents of non-adult children, as indicated in *Leaving home is a developmental norm.*).

“I wish there had been better programs for him.” “I think if there had been anything available - any kind of support - I think I would have tried to keep him longer at home - but there was zip.” “If I’d had more breaks maybe, and my husband would have been around more, it might have been a different story.” “Wow, if we could get the same support services that are available to the [professional parenting] families that our child with special needs is with right now, he could still be at home.”

If we were rich... imagines that if parents had enough money, they wouldn’t have placed their child; they would have kept their child at home and paid for the instruction and services described in *If we had received better training...* and *If there had been better programs...*

Father: You want to know one of my fantasies?

Mother: This is something that we like to think about.

Father: Here's my fantasy. I dream it; I really do think about this. My fantasy is to one day earn enough money that I can build a little separate home onto our home that is designed 100% for our child with special needs: no outlets, soft carpeting, nothing around to break-

Mother: Nothing to hurt him-

Father: It’s really protective glass and everything, and have this as his home.

Mother: And then hire 24-hour care-

Father: And then pay a 24-hour nursing service to come-

Mother: And, of course, at that point we would be wealthy enough to afford all kinds of physical, speech, whatever-

Father: Afford the therapies and so forth. And to have him live at home. If I could earn enough money to do that, I would do it - I would do that in a heartbeat. I think that's a pipe dream that I'm going to get that from social services; but if I can earn enough money to do that, I will do that. I will bring him home, build a little home for him, and have a nursing service come in to help us. You bet. You bet.

Yes; on second thought, No. was a frequent cognition associated with the *We could have kept our child at home IF... Reappraisal*. As parents were sharing *We could have kept our child at home IF... Reappraisal* (i.e., Yes), they would often add a qualifying statement by citing benefits that their child would not receive if he or she were placed in out-of-home care (i.e., No). The manifestations of *Yes; on second thought, No Reappraisals*. are similar to the *It was the best decision Reappraisals*.

If my child with special needs could have had the opportunity in the home for everything that he has now, the only thing that would maybe push me toward his placement...is the interaction that I think he needs to have with members of his peer group - I think that social interaction is so incredibly important. So all things being equal, if I could have somebody come in and care for my child with special needs the way that he's receiving care...I still think that his life has been greatly

enriched by this experience that he's had - more so than we could have done if he would have been at home.

Reappraising *Critical Greek Chorus Voices* also appeared to be a common theme among parents. As one parent put it, "You have just got to try to drown those voices out and not pay attention to them." Likewise, in order to cope with the augmented *Emotional Stresses* reinforced by the *Critical Greek Chorus Voices*, the parents utilized two *Reappraisals*:

(a) *Nobody knows* and (b) *We shouldn't be so hard on ourselves*.

Nobody knows is the concept that until the people with the *Critical Greek Chorus Voices* have walked a mile in the parents' shoes, they just have no idea. Almost all of the 20 interviews contained evidences of *Nobody knows*. *Nobody knows Reappraisals* assist parents in "try[ing] not to worry about what other people think."

"Ignore what other parents may say about your decision because they just don't know." "They didn't understand all of the circumstances behind why we put our child with special needs in." "They weren't with her 24 hours a day." "It's one of those things where you have to constantly remind yourself that they may not know all the details." "I would like you to take our child with special needs for a month, and then see if you have that same perspective." "They just have no idea how agonizing the situation was." "Well, you don't know - you never know until you're put into the situation."

It's our decision, no one else's is a *Reappraisal* that is somewhat of an offshoot or outgrowth from *Nobody knows* which emphasizes that because *Nobody knows*, the parents are the only ones in a position to make a decision as important as out-of-home placement. "But when it comes right down to it, it's our decision. Nobody knows because they haven't got that child, so they really do not have the right." "You just can't listen to

what other people say; you have to be the ones making the choice.” “We just had to come to the conclusion at that point that [placing our child with special needs] was just what was right for us.”

We shouldn't be so hard on ourselves is a *Reappraisal* that also appears to be uniquely suited for coping with the negative emotional effects of *Critical Greek Chorus Voices*. In the following selections, all of the parents seem to be passing on aspects of *We shouldn't be so hard on ourselves Reappraisals* that they found helpful in dealing with the *Critical Greek Chorus Voices* and the *Emotional Stresses* of post placement life:

“Well, try not to be too hard on yourself.” “Don't let it bother you.” “Don't beat yourself up if you don't do everything right. Just keep trying. It will all work out in the end. It may not be exactly the way you planned it, but it will work out.”

Just as parents seemed to implement specific *Reappraisals* for the *Critical Greek Chorus Voices*, parents also appeared to employ particular *Reappraisals* for the *Fear Dilemma*. Early on in the analysis, it became evident that there was a unique set of parental *Reappraisals* for dealing with the *Emotional Stresses* of the *Fear Dilemma*. As explained earlier in this chapter, the *Fear Dilemma* occurs when parents are worried about their child receiving poor care at the placement while simultaneously being afraid that their child might have to return home from his placement if the poor care is not ameliorated because they will not be able to secure a more appropriate placement.

One mother described the *Fear Dilemma* this way: “I've seen parents fear that because they can't have their child gone and they are so afraid of having to have their child come back, that they would leave their child in a bad situation.”

The *Fear and Worry about Our child will have to return home from his placement* manifests itself in the following excerpt:

[Bringing our child home if things got bad] wouldn't be very smart, because then we would take her out of that place where she was, she'd lose her place to go back in if she ever needed to, and meanwhile, we're getting older and older, and then where would she go? She lost her place.

Another mother explained her personal experience with the *Fear Dilemma* and also provides a glimpse at the *Reappraisals* used to handle the *Fear Dilemma*:

Well, if I would have known she was going to get bit, I would have never put her in. I would have kept her home. But then she might have ended up on a milk carton. (Laughs) I don't know. It's hard. I think they took care of her as good as they could, though; I really do. I mean, I have to convince myself of that, or I would feel too guilty to have allowed it to happen.

The *Coping Methods* parents utilized to better manage the *Fears and Worries* associated with the *Fear Dilemma* include the following two properties: (a) *There's no place that's perfect* and (b) *Our decision is fairly permanent*.

There's no place that's perfect is the *Reappraisal* that all placements have their problems. The following quotes describe why *There's no place that's perfect*: "There's some good ones, there's some bad ones. Shop around." "We found a place that we could tolerate" "One of the challenges is what do you do, because it's not like there are 20 options out there.... It wasn't like it was the best choice in the world. But, where else do you go?"

There's no place that's perfect. (Laughs) Don't expect a place that's going to suddenly make your child all healed and better. Maybe I felt a little bit that way. I felt like we wasn't (sic) doing a good enough job with our child with special needs, but we'd just put her in and- Wham! - they'd find that magic potion and our child with special needs would be all better. It doesn't happen. They do the best that they can, but they're just like we are. There's nobody that has an answer for everything, a magic potion that makes people reach their fullest capability. And realize that most people are really trying. Most of these people the kids stay with are really trying and really sincere in taking care of them. But not one of us is perfect. There's been some times that they feel frustrated that they're not doing a good job of taking care of these people.

It could be worse is a *Reappraisal* component of *There's no place that's perfect* that acknowledges that their child's placement is not perfect and focus on the fact that they are lucky that their child is not worse off. As one parent explained, "It's not that bad. It could be worse. It could be an institution." The following paragraph conveys the idea of *It could be worse*:

And, today as I look back on the whole system, I can't think of a better situation that a parent could have for their child than what we got right now. Is it perfect? Absolutely not. Lots of room for improvement. But when you look at what the alternatives would be.... But our experience with this provider has been very positive for the most part, yet there has been some wrinkles in it all. But for the most part it has been very positive and very helpful for us.

You can't protect your child from everything is another *Reappraisal* component of *There's no place that's perfect*. In the following quotation, a father eloquently explains the concept of *You can't protect your child from everything*:

Let them go. You can become obsessed almost with protecting that child because you don't think he's able to take care of himself, and all it does is drive you crazy because you can't protect them from everything, ever. Sometimes you've got to let them go, let them develop as much as they can. And you've got to reach a certain comfort level with that outside help so that you can have a life of your own.

Our decision is fairly permanent is the culmination of *Reappraisals*, similar to *It was the best decision*. When parents have considered all of the logical factors, the *Reduction or Elimination of Disadvantages*, the *Amplification or Generation of Advantages*, all of the *Reappraisals*, and the supporting voices from the *Greek Chorus*, with very few exceptions, they said that their decision about placement is fairly permanent. The following consist of the parents' responses when they were asked about the permanency of their placement decision:

"We wouldn't be able to take her back." "And to be quite honest, we can't go back." "We can't go back. We cannot take him back into our home." "My husband and I could not handle having him home - period." "It's a 100% permanent." "Basically, he is going to need care the rest of his life - he is going need to be in a placement in all of his life." "We can bring him [home], but we don't have anything for him." "We still don't have the skills, the knowledge." "Other than something happening with all the possible placements, I don't see bringing our child with special needs home as a feasible thing."

However, even with such resolute *Reappraisals*, when parents were asked if there were any circumstances that would change the permanency of their decision, almost every parent identified some situations which might cause them to reconsider placement (thus the use of the word *fairly* in *Our decision is fairly permanent*). These exceptions could be categorized as either (a) *Miracles* or (b) the *Unforgivable Sins*.

Miracles are the very low-probability improvements that parents cited would need to happen for them to consider bringing their child home again. The *Miracles* expounded upon by the parents were all of a similar vein: the child would have to improve to the degree to which most of the *Appraisals* and *Reappraisals* that the parents use for dealing with the *Emotional Stresses* of placement would become irrelevant (i.e., placement would no longer provide the *Reduction or Elimination of Disadvantages*, the *Amplification or Generation of Advantages* that render it necessary).

“If he got well enough, he could come home.” “If we saw significant improvement...where he was able to do some of the things so that he wouldn’t require so much time.” “He’d have to be somebody other than who he is.”

The *Unforgivable Sins* are serious problems that would make parents reconsider the placement. As one parent put it, “That was kind of the straw that broke the camel’s back; we said, ‘We’re looking for another provider.’ ” In fact, most parents indicated that if there were serious problems, they would seek a better or more appropriate placement; the only reason they would bring their child home would be if there were no other available placements:

“If there were something that happened that were to make me consider removing my child with special needs from his placement, I would seek out a different placement

for him.” “If our social system broke down and there was no facilities available, there’s no question that there would be responsibility there to take him and do the best work we can.... But otherwise, he’s better off [placed].”

Besides the scenario of the child developing terminal illness, parents said they would reconsider their child’s placement if they did not feel good or comfortable about the care their child is receiving at the placement. The following are the elements pertaining to the *Unforgivable Sins*: (a) *If our child seemed distressed or unhappy*; (b) *If we felt that our child was not getting the care she needs*; (c) *If we felt our child was regressing* (e.g., less independence, lost skills and abilities); (d) *If things didn’t get better after we had tried the correct channels*; and (e) *If we found out our child was dying*:

Yet, the question remains: “How do parents utilize the ideas behind the *Reappraisals* *There’s no place that’s perfect* and *Our decision is fairly permanent* to respond to the *Fear Dilemma*?” Parents demonstrated two methods for affording some emotional leeway in dealing with the *Emotional Stresses* underlying the *Fear Dilemma*: (a) parents can reduce the *Fear and Worry of Poor Child Care* by lowering expectations of care because *There’s no place that’s perfect*, *It could be worse*, and *You can’t protect your child from everything*; or (b) if the poor care becomes unacceptable (the *Unforgivable Sins*), instead of bringing the child home because *Our decision is fairly permanent*, parents can alleviate their *Fear and Worry* about *Our child will have to return home from his placement* finding a different and more appropriate placement. *Involvement*: “Anytime you’re doing something, it helps”

In addition to the *Reappraisals*, one of the primary *Coping Methods* parents used to deal with the *Emotional Stresses* of placement is *Involvement* . The idea of parents

being involved in their child's life as a means for reducing the *Emotional Stresses* of placement emerged early on from the parents' insights. Interestingly, unlike the *Reappraisals* where the most helpful quotes for establishing the *Reappraisals* as a *Coping Method* came from fathers, the quotes that provide the clearest insights to *Involvement* as a *Coping Method* come from mothers. In fact, mothers were more than twice as likely to mention *Involvement* as fathers. This clear difference between genders may perhaps be partly explained by the availability of the parents; whereas all of the fathers reported working full-time at the time of placement, more than half of the mothers reported being full-time homemakers (see Table 2); therefore, mothers may have had more time to allocate to post-placement *Involvement* in their child's life.

The first extracts from interviews are primarily mothers explaining the importance of *Involvement*:

"We refused to just let him go and be placed somewhere, and then walk away. We couldn't do that. The only way we could deal with him being placed was for us to still be totally involved." "So, we do a lot with her, a significant amount of things." "Still do that. Still take an interest in her." "As long as the families can stay actively involved, they ought to place their child with special needs." "You know what, even though your child is placed, that child is still your responsibility." "Just always stay involved." "It made me feel like I was tied in." "Anytime you're doing something, it helps... it was helpful for me because I was doing something about it."

Well, it makes you feel like you're doing something about it, instead of just sitting around and having it rain on you. At least you're putting on galoshes, or putting

up an umbrella, or something, but you're not just sitting there in the rain, you're doing something about it.

This next selection hints at the function that *Involvement* plays in reducing feelings of *Guilt*:

I think that when our child with special needs was young - that there was this idea that if you placed your child, that you were abandoning your child. And (a) that went against our values, and (b) we didn't want people to have that idea that our child with special needs was in any way abandoned. We were still very interested in what he was doing and how he was doing.

This quotation conveys the importance of post-placement *Involvement*:

Because you have the responsibility of the decision that you made, and also still watching out for the welfare of your child, you can never give that up - never, ever, ever. Never give it up to the system because they don't do right. I've seen it thousands of times. That child ends up being lost. The system ends up being important, and the child gets lost. So assuring that you will always be in charge - always.

Of the 20 families interviewed, every single one was coded for at least one form of *Involvement*. It is important to mention that the prevalence of this theme might be a function of the volunteer sample used in this study; parents who choose to remain actively involved in their child's life would more than likely also be interested in participating in a study such as this, as participation itself is a form of *Involvement*.

Just as some types of the *Reappraisals* helped parents better manage the *Fear Dilemma*, certain aspects of *Involvement* seemed to decrease two of the three *Fears and*

Worries associated with the *Fear Dilemma: Poor Child Care and Less Control*. The more parents felt involved with their child and his or her placement, (a) the more they felt in control, and (b) the less they worried about their child's care. The less *Fear and Worry* parents have about powerlessness and poor care, the less likely they are to experience the *Fear Dilemma*.

We felt more in control is a direct result of *Involvement*. One father commented, "Well we still have that constant contact where we have that reassurance that everything is okay." Another father helped shed light and understanding on how *Involvement* allowed him to feel more in charge by sharing the following:

You still want to be their parent, because he's my child and I want to have a say in what goes in his life. They met all the criteria. They made it clear that I would be control of a lot of things. I knew that I wouldn't be in control of every little thing because I wouldn't be there all the time, but major things - yes.

Our child gets better care when they know we're watching is a chief vehicle for reducing *Poor Child Care*, and as such, is one of the most important aspects of *Involvement*.

"And it is vital that you stay on top of it. Just because they live away from home that you don't let go." "Keep up with your child with special needs - follow them closely." "I keep tabs on him." "We tried to be involved wherever he was, because we felt it was really important to have people understand that he was important to someone." "We just have to pay attention - as his parents and his guardians - to what's going on in his program.... We are known to be rather 'actively involved' (laughs)." "We made a lot of fuss all the way through the whole thing." "I have to keep reminding them, 'Hey. Remember me? I want to know.'"

Three different components emerged from *Our child gets better care when they know we're watching*: (a) *The staff are the key*, (b) *Surprise! We just thought we would stop by for a little visit*, and (c) *We decided to take matters literally into our own hands*.

The staff are the key was generated from several comments by parents that the staff are perhaps the most important aspect of insuring good child care. The parents in the first passage suggest that there are staff of all kinds; the point is to make your presence felt:

Father: You're going to get good people and you're going to get bad people; and that's always something you're going to worry about. That's why you need to see your child with special needs a lot, especially if you think there are bad people that are with him, you need to let them know that-

Mother: You're watching him.

The following couple reinforce the idea that *The staff are the key*:

Father: Be very involved, and pay attention.

Mother: And demand to know.

Father: And be involved with the companies that are managing the group homes, and pay attention to the staff and to the managers, and stuff like that. The staff are the key-

Mother: The staff are the ones who have their lives in their hands.

Surprise! We just thought we would stop by for a little visit is a form of *Involvement* that operates on the idea of intermittent reinforcement: when the staff and providers don't know when the parents are going to stop by, they are more likely to maintain higher levels of child care.

“I think they don’t take as much advantage of him if they know you’re going to turn up any time and know what’s going on.” “And of course, when we put her in we made doggone sure that we’d go over and check and make sure that she was taken care of properly.” “They gave us a key, so we can go in at any time.” “And we really put our foot down. We had to really be very adamant and go and look.... We show up during the week and check things out.”

We decided to take matters literally into our own hands describes parents increasing their *Involvement* to the degree that they are once again providing care to their child in hopes of decreasing *Poor Child Care*. When one mother’s child was not receiving the physical therapy he needed, she took matters into her own hands: “I...set up a physical therapy thing with his group home, and I do that all the time.” In three out of the 20 families, the parents actually became involved in managing their child’s care for the care provider:

Things have really come around. Now I feel really fortunate - really, it’s just the way it worked out - it was never a specific plan - but now I actually manage the group home he is in. And so I see him a lot, and our relationship has really changed since I know a lot more about him. We have always maintained a weekend relationship with him for a few hours on Sunday, and that was always really nice, but I’ve learned so much more about him being able to be around him and watch him so much more. So I just really feel fortunate that that has worked out for us.

To bring discussion of the *Fear Dilemma* to a conclusion, *Involvement* helps cope with the *Fear Dilemma* by minimizing parents *Fears and Worries* about *Poor Child Care* and

Less Control. In the subsequent passage, a mother describes how she handled the *Fear Dilemma* through *Involvement*, notwithstanding bonafide *Fears and Worries* about *Our child will have to return home from his placement*:

If I felt like someone was being cruel with her, yes, that would certainly affect me. But I don't think I'd take her out of the group home. I'd go to the management and tell them. I wouldn't withdraw her because of that, because that was one of the reasons we wanted to put our child with special needs in a group home when we did, so that we could oversee things like that. And if something happened, we'd be there to do something about it! And that's the way I feel about it now. I wouldn't remove her if I did find out about cruel treatment.... I don't think there are too many group homes that would take my child with special needs with her disability.

In addition to *We felt more in control* and *Our child gets better care when they know we're watching*, five other subcategories for *Involvement* were dimensionalized: (a) *Visitation*, (b) *Custody and Guardianship*, (c) *Child's Individual Plan and Other Meetings*, (d) *Financial Involvement*, and (e) *Active at the Placement and in the Community*.

Visitation was another category of *Involvement* that seemed to assist parents in more adequately managing their *Emotional Stresses*. In fact, almost all of the parents visited their child at least weekly (which may be a function of the volunteer sample). "I think we get paid back; as in any relationship, that's just the way it is; it works both directions - you get out what you put in." "So, we do a lot with her, a significant amount

of things.” “I think the best help [for managing painful feelings] is just picking our child with special needs up and spending time with him.”

Custody and Guardianship is yet another form of *Involvement* that seemed to be beneficial for both the parents and the children with special needs. *Custody* refers to legal responsibility for a person under age 18; while *Guardianship* refers to legal responsibility for a person over age 18, and must be officially requested and obtained. Parental *Involvement* through *Custody and Guardianship* also helps reduce some of the *Fears and Worries* about *Less Control*.

“You still want to be their parent, because he’s my child and I want to have a say in what goes in his life.” “Well, we were just adamant: ‘No, we are not ever going to sign over the rights of this child. This child is always going to belong to us.’ ” “We also were not interested at all in giving up custody - we wanted to retain 100% custody.” “I wanted to make sure I still had my rights as a parent and that they would consult me and call me and I wanted to be at appointments and stuff so...” “If you get guardianship of that child...they have to consult you about everything.” “We can see him any time we want.” “We didn’t have guardianship, but we always wanted to be involved.”

Child’s Individual Plan and Other Meetings. Individual Plans or IP’s are detailed goals and programs for the child’s growth and development. Virtually all of the parents discussed their *Involvement* in meetings relating their child’s out-of-home care. The following selection provides insight to the parents’ continued involvement in routine meetings:

We try to meet on a regular basis with [our child’s service provider] and to talk about our child with special needs’ issues - where we ought to be. We meet with

the group home coordinator regularly. We talk to him weekly just to say what's happening and try to communicate our schedule and their schedule and make sure we're going where we want to go with our child with special needs and see him progress as much as he can.

Financial Involvement conveys the idea that parents are still contributing to their child: "My husband's insurance still pays for her, and I think that retains our dignity, too, because we're paying for her." "We still support her and it retains your dignity and your self-worth that you are caring for your child." "I still [pay for our child's out-of-home care] - now I'm much more in control."

Active at the Placement and in the Community is the aspect of *Involvement* that highlights lobbying, participation on specialized committees, and providing help at the placement. "They did a lot of fun things - fund-raisers and so on - and we participated in all of that just to make sure we were part of her life." "I had done a lot of civic work - volunteer work - in retardation." "We all felt the need for [creating placements], so we went to social services, and we worked through legislators."

Therapy: "Just give people a chance to explore those issues"

In addition to the *Emotional Stresses of Problematic Filial Adaptive Responses*, *Therapy as a Coping Method* is the other primary theme in the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* where saturation was not reached. Consequently, the development of the *Therapy* categories is not complete, and can be considered foundational, at best.

Therapy for Parents. While most parents reported receiving therapy for issues not directly related to their child with developmental disabilities or placement, very few

recounted experiences with therapy for issues specifically related to the adaptation to life after placement. Ironically, a significant portion of the parents either wished that they had received therapy to deal with the *Emotional Stresses* associated with placement, or indicated that they would recommend therapy to other parents considering placement.

How can *Therapy* help parents cope with the *Emotional Stresses* of placement?

The most traumatic part for any family is getting up the child and putting him in the system and placing him. If you can do something to ease that transition for the parents by informing them more, helping them go through that transition, offering parents counseling to help them through that transition so you don't go through the guilt and all the other things you do when you give up a child basically to put them into that system.

Therapy for Parents was determined to have the following four categories: (a) *We got therapy, and we're glad we did*; (b) *We got therapy, and we wish we hadn't*; (c) *We didn't get therapy and we're glad we didn't*; and (d) *We didn't get therapy, and we wish we had*.

We got therapy, and we're glad we did only appeared to apply to a handful of participating parents; therefore, there were relatively few data about this subcategory. One couple said that therapy helped them deal with some of the *Guilt* they felt after having placed their child: when one husband remarked, "I think it's really important to have that out, especially immediately after the child was placed, to get some kind of therapy to help the family deal with-," his wife interjected, "The guilt." In reference to an insight gained from therapy, one of the parents noted, "[It] helps us kind of keep on keeping on." After the following mother placed her child, she recognized some of the

signs of depression from a previous time in her life and began therapy to resolve her depression:

I then recognized how scary that depression was. And I had a real fear of ever becoming depressed like that again. And that was why I sought a therapist out and wanted some help with preventing that kind of depression. And so, it was pretty directly related to our child with special needs.

Once again, the lack of saturation provided only obscure information for the property *We got therapy, and we wish we hadn't*. The primary complaints in this subcategory revolve around the parents feeling that the therapist was not helpful due to a lack of training and experience in handling their issues relating to placement. One of the participating couples explained their experience as follows:

Mother: I'd say that it made me more mad (laughs) because of the - I don't think he [the therapist] understood, so I felt like he wasn't giving the kind of comments we needed to hear....

Father: I think also the counselors were more concerned about dealing with our relationship and the problems the two of us had, and not so much about our child with special needs.

Mother: But the thing they should have realized was that was part of it....

Father: I don't think she was trained, per say to deal with people that had handicapped children, because she had never gone through it before.... [the therapist] kind of shoved the problem aside, like it wasn't there.

The next property, *We didn't get therapy and we're glad we didn't* may be more about access to other therapeutic supports, and less about not needing any help dealing with the

Emotional Stresses of life after placement. For instance, the following couple asserts that they were each other's therapist. In response to the question, "Have either of you attended any therapy since discovering the disabilities of your child with special needs?" the husband responded, "Just between ourselves! (Laughs)" Followed by the wife's concurrence, "Yeah. We're pretty good therapists for each other. (Laughs)"

We didn't get therapy, and we wish we had is the final proposed subcategory of *Therapy for Parents*. As previously suggested, this property was the most commonly experienced of the four subcategories of *Therapy for Parents*. Several mothers lamented that they had tried to go to therapy, but that their husbands did not want to attend with them: "Earlier on it would have helped if both parties would have participated - I wanted to participate, but my husband didn't particularly want to participate in those kinds of things - I tried to get him to." In light of his own personal experience, one of the fathers who later recanted and joined his wife in therapy describe the stigma of therapy as follows:

I think it would have to be presented to parents in a way that some parents won't get the assumption that they're being called nuts or crazy -because some parents are (laughs) - and they have some opinions about mental health professionals.

Similarly, other parents recommended: "That's one thing I'd like...to suggest to the families: the parents [should] get [therapy]."

Therapy for Siblings may also help parents cope by reducing the stressors and *Problematic Adaptive Responses* of their other children. Parents would theoretically also succeed at reducing their *Emotional Stresses*, assuming that the parents perceive that their other children are adapting to life after placement more successfully as a result of the

therapy. The parents then will experience less *Fear and Worry, Sadness, and Guilt*. Perhaps the same subcategories would arise as those found for *Therapy for Parents*, but there were not enough data to even propose subcategories.

However, a substantial number of parents either had children that had been in therapy for issues relating to their sibling with developmental disabilities. One mother expressed, “We needed to ask for some support for [our other children after placement].” Another mother shared, “I had [my other son] to think of. And he was getting older.... He has some problems, and I’ve had to get him in counseling, he’s in counseling right now.... And I think it was from all this.”

The following mother conveys how she wishes someone had encouraged her to obtain therapeutic services for her other children:

If someone had said, “Children that are separated from a sibling and children that have been traumatized by whatever might need some help working through all that.” I think even if we weren’t ready to go for what we needed, if somebody said, “The indication is that your children will really benefit,” I think that would have gotten us there, because I just don’t think how much those kids [suffered] was in my awareness at least, it’s been over the years watching reactions, watching our child with special needs lose people that he is attached to, and think about how much children suffer that we don’t pay that much attention to.

Time: “It was time; passage of time”

The final *Coping Method* theme, *Time* explores the *Emotional Stresses* and parental adaptation along a continuum. As parents frequently commented, adapting to life after placement is a process that takes *Time*. A noticeable pattern emerged throughout the

interviews that solidified the ideas that humans are creatures of habit, and that it took Time for parents to make transitions, develop new routines, and figure out what to do with all of their time. “It took a lot of time, trying to get your own life together without that constant stress.”

Father: It took us a year or so to get used to the idea of leaving the house with our children - it wasn't that we just right away went off and went on a cruise - it took us a year or two just to get used to the idea of, “Boy, can we go camping?” It just didn't feel right.

Mother: We had been conditioned-

Father: Yeah, exactly, it had never been an option. It's like the elephant who as a baby is chained up, and it eventually learns to stop pulling at the chain, and so as an adult all you have to do is tie a rope around his leg, and he won't move. Well, we were an adult elephant with a rope around our leg and we didn't move, even though we could have at any time. We had just been conditioned.

One category was developed within *Time As time goes by*. In turn, two components of *As time goes by* were derived from the interviews: (a) *The more time goes by, the more we know it was the right decision*, and (b) *Does time really heal all wounds?*

The more time goes by, the more we know it was the right decision: “As time goes by, you've got to realize this was a good decision that you made.” *The more time goes by, the more we know it was the right decision* explores the frequent experience that the passing of time confirmed to parents that their decision to place was a good and beneficial one. As one father indicated, “You don't know what your going through until

you've already sort of done it." Each of the following selections emphasizes various aspects of *The more Time goes by, the more we know it was the right decision*:

The more the time goes by, the more you see your child progress and where they're at, and the more you see your family life improve - both when the child is with you on a visit or when their not with you, with your other children - you realize you made the right decision.

I think that if somebody would have come up and said, "This is great, you're making the decision, but you're going to have to realize that you're going to have to go through a period of adjustment, and your kids are going to go through a period of adjustment, and you're going to be wondering whether you made the right decision or not, and you're going to have to handle a lot of guilt feelings for a while. But if you can get by that, get past that time, it's going to be great." If somebody could have come up and told us, "At first this is going to look like maybe it was a bad decision, but as time goes by, you've got to realize this was a good decision that you made."

Does time really heal all wounds? Sadly enough, unlike a Hollywood ending, some parents reported that the pain (*Emotional Stresses*) resulting from placement did not decrease over time; however, parents' levels of enduring pain seemed to fall all across a spectrum, and other parents indicated that they had no *Emotional Stresses* relating to placement. These differences may perhaps be somewhat accounted for through comparisons with divorce and death; some people report the pain never goes away, some say it fades with time, and still others claim to have not really been affected by the event and subsequent transition.

The following quotes were selected to represent various points along the continuum:

“But I think it’s just over time. It took a lot of time.” “I think just time was one of the big things.” “Initially, you feel very guilty.”

“Well, the pain never goes away.” “Emotionally, we struggle every day.” “Sometimes I still struggle, feeling like it’s my fault” “I still feel guilty enough.” “We still feel awful.” “I am always sad” “She’s been there for a year and a half, and the pain is no different today than it was the day we dropped her off.” “It’s always hard to leave, and there hasn’t been a time when I haven’t been crying half the way home.” “It’s still hard - absolutely. We still get teary eyed when we take him back after a visit.”

Well, I felt like a failure to place him; I felt like I failed him as his father, and failed my family because I wasn’t able to keep him at home. Time helps a little with that, but there are times it is still really hard.

It wasn’t like a lot of easy emotions, and it’s a separation, and it’s like a death in the family. And then there’s time - it takes time to overcome that. And I think that when I look at the process, it still would have taken time to adjust to that emotionally as well.

In response to his wife’s statement, “[We feel] very comfortable with [our placement decision],” the husband clarified, “Well, very comfortable with it, but it still gives us grief.” “So, even though it’s very difficult and still is painful, I think it was the best decision that I could have ever made.”

It’s going to happen - the feelings are going to be there, and just realize it takes time. I mean, it’s something that’s not going to be cured overnight, and it’s

something you just have to kind of have go through. I don't know that there's anyway of preventing that in saying, "I can tell you something and you're not going to feel these feelings," yeah, you're going to feel those feelings, and it does take time. And there comes a time when you kind of get used to things: "Things are ok," "Ok, it's working out," "Things are all right," and, "This is good," and you see benefits, and things will work out. Just a reassurance that there's some pain involved with doing it, but with time that will resolve.

"It was better for everyone, but it was a long time before I admitted it." "There are times when it's harder than others. For the most part, it's just not a hard thing." "Even now there's times it gets to be a little bit long, but not very often." "Well, anytime a child leaves home, it's an empty spot in the home, until you kind of get used to it."

At the emotional level, now it's okay; at first, it was hard. Now, we're kind of used to it. It was just like having my son away at college - first I missed him a lot; now he comes home every once in a while, we enjoy seeing him, and when he goes back, it's okay.... It's a natural transition; so you get used to it about anything.

And it took me a full year to get me where I was able to see that he was actually in an environment that was better for him because it was more structured for him. He was having some successes and making some changes, and they were doing things...so, for me it was just a passage of time to see that in reality they could make a world for him that was better than the world we could make for him, and just to get over my own guilt trip that I placed myself under. But that's, it was passage of time, seeing the results.

“It was more than a year. It took a long time, you know.”

“Oh, it’s fine. I’ve totally adapted to it.” “I’ve learned is that everything at some point - what’s the old saying? ‘This, too, shall pass.’ Everything will pass sooner or later.”

One of the parents who placed her child when here child was in her early 20s seemed to be an exception:

I guess, maybe that’s awful, I don’t know (chuckles), but I did not [have feelings of guilt] and I have never been sorry that we did what we did.... I hope I don’t sound cold-hearted, but it wasn’t traumatic - it just was not!... I’ve *never* been sorry.

Hence, in connection with the *Reappraisal Leaving home is a developmental norm*, the age of child at placement (i.e., whether or not the child was placed before or after adulthood) may make account the difference of (a) the intensity or magnitude of the *Emotional Stresses* (b) the frequency (e.g., episodic cycling) of the *Emotional Stresses*, and (c) the duration of the *Emotional Stresses*.

Finally, consider this passage that nicely sums up major portions of the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities*:

You don’t know what you’re going through until you’ve already sort of done it, then you can give people insight on what to expect, and what might happen, and kind of prepare them for first the guilt feelings, and then maybe the adjustment that goes on in the family, and then realize that finally, after so much time, that it’s [placement] a pretty good idea.

Verification

While standards of quality have yet to be firmly established in qualitative research designs, several verification processes exist for the purpose of increasing reliability and validity (Babbie, 1999; Creswell, 1998). In grounded theory, verification helps create theory that fits with reality, provides accurate understanding, and has significant utility (Strauss & Corbin, 1998).

Although verification processes vary among qualitative researchers, the following are commonly practiced procedures: (a) *sustained engagement and diligent observation*—the researcher spends enough time in the field to develop a sense of culture and salient issues on which to focus analysis; (b) *negative case analysis*—working hypotheses constructed from invalidating and negative evidence; (c) *triangulation*—the employment of multiple investigators (e.g., consensus and inter-rater reliability), methods, sources of data (e.g., observation, interview, quantitative components), and established theories; (d) *peer review*—checks and balances by external researchers that keep principal investigators honest; (e) *external audits*—persons not connected to the study are invited to review both procedures and results for accuracy; (f) *member checks*—verification through participant feedback on findings; (g) *intersubjectivity*—the researcher reflects on personal feelings and thoughts about the correctness of study results and limitations; (h) *researcher bias*—the researcher seeks to make personal bias transparent to readers; (i) *rich descriptions*—detailed information allows readers to make their own conclusions and examine bias (that of the reader as well as the researcher) (Babbie, 1999; Creswell, 1998). All of these procedures have been or will be implemented to some degree.

Sustained Engagement and Diligent Observation

Prior to designing the original study in which the data were collected, the interviewer worked in a residential care center, allowing him to have first-hand experience with the important issues facing parents of children with developmental disabilities. This was coupled with a thorough review of relevant research.

Negative Case Analysis

Throughout the process of analysis, outliers, exceptions, and disconfirming evidence were used to guide the formation of themes and categories. For instance, statements made by participants that seemed to run counter to what the earlier stages of the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* would indicate were used to modify existing hypothesis and/or categories, and in some situations, create new ones. For example, when one or two parents reported experiencing markedly fewer *Emotional Stresses*, the researcher hypothesized that when placing a child during adulthood the parents tend to experience fewer stressors because it is normal for children to leave home by that age. This resulting hypothesis eventually led to the formation of *Time as a Coping Method*. This process was continued until it was possible to categorize all experiences (Cresswell, 1998).

Triangulation

During the coding stages of analysis, the genders of the children and of the parents, type of placement, amount of time elapsed between placement and the interview, social class, and other participant demographics were utilized for internal triangulation (i.e., to see if there were differences among parents' experiences as a function of these characteristics). A key example is using the types of placement to verify the various

Appraisals and Reappraisals. At one point, the researcher began to wonder if *Nobody loves, knows, or can care for my child like me* was primarily a fear of being replaced that was experienced by parents whose children were in professional parenting care; however, triangulation with parents whose children were in residential care centers and group homes indicated that the experience was pervasive among all types of placement. Toward the final stages of analysis, the other scholarly research, like stress and coping theories, were used to verify the credibility and transferability of the findings.

Peer Review

At various stages of model development, Dr. Susanne F. Olsen, an expert in the field of disability and a member of the thesis committee for this project, was consulted about the organization and presentation of the results.

External Audits

The three other professors on the thesis committee, Dr. Norman B. Epstein, Dr. Sally A. Koblinsky, and Dr. Carol A. Werlinich, reviewed the methodology and results to increase the veracity of the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities*.

Member checks

All of the participating parents indicated that they would like to receive a copy of findings related to the research. Member checks will be made possible by sending all of the participants copies of the results from this study, and allowing them to provide their reactions and feedback. This will occur after submission of this thesis and before publication.

Intersubjectivity

The researcher's use of self was a constant presence all through the data analysis procedures. Partially facilitated by writing memos, the researcher reflected on how themes and categories seemed to relate to one another, in light of what it seemed parents were experiencing and indicating. The problems and limitations of this study are addressed in the following section, as well as in the Discussion section.

Researcher Bias

In order to make personal bias as transparent as possible to readers, the researcher has included the following discussion of potential bias. The researcher had no agenda other than the organization, summarization, and dissemination of the participating parents' experiences to parents and service providers of children with developmental disabilities. Beyond experience working a residential care center for children with developmental disabilities, the researcher does not have any developmental disabilities, does not have immediate or extended family with developmental disabilities, and has no other personal connections that might bias the results of this study. The researcher did not experience feeling "right" or "wrong" about what participating parents had either done or said, and did not find himself identifying more with one particular parent or groups of parents (e.g., age, gender, race, SES, religion); however, for the purpose of being as transparent as possible, the researcher is a 28-year-old Caucasian male who is a member of the Church of Jesus Christ of Latter-day Saints (LDS or Mormon) who comes from an upper-middle class background. The researcher has no children of his own, and is indifferent about the decisions to place a child with developmental disabilities or to continue to care for the child at home. The only personal biases of the researcher that

could have potentially affected the analysis and write-up were beliefs that (a) people ought to be happy, (b) children with developmental disabilities deserve quality care, and (c) families should remain involved with their child after placement.

Rich Descriptions

Finally, the principal investigator went to great lengths to provide readers with enough direct quotes from participating parents so as to (a) minimize the loss of the fine nuances of the parents' experiences, and (b) to provide readers access to enough data that they can arrive at their own personal conclusions.

Limitations

Internal Validity

The nature and purpose of qualitative research yields more robust internal validity than quantitative measures (Babbie, 1999). Although there are still many things an investigator can do that can influence the data, the potential for demand characteristics is also quite high. As all of the data have been acquired through retrospective parental report, maturation (change over time) is the most pervasive threat to internal validity in this study. Parents may not remember correctly specific aspects of their experience. According to Cole (1986), parents tend to defend their previous decisions, which poses threats to this study as some of the *Appraisals* and *Reappraisals* parents shared could possibly be to defend their decision to place their child in out-of-home care to others, instead of cognitions used to defend their decision to themselves. Hill et al. (1997a) indicated that participants are likely to report a negative event differently if it was resolved than if it was not. Parents who had adapted more to life after placement may

have underreported and/or downplayed both previously-experienced *Emotional Stresses* as well as previously-utilized *Coping Methods*.

History is another possible threat to internal validity. For instance, because of the changes in the quality of out-of-home care over the past several decades, parents who placed their child three decades ago might have different *Reappraisals* about how good their child's current placements are compared to parents who only placed a year or two ago.

Internal validity may also have been affected by the fact that most of the participating parents were interviewed with their spouse. On the one hand, this could increase internal validity by motivating people to report accurately because their spouse could correct them and tell the interviewer that what was said was inaccurate, or even criticize the person privately after the interview; on the other hand, the presence of the partner may inhibit some people from being fully honest (i.e., the person may choose to not disclose certain information because of how he or she thinks his or her spouse may respond).

The structured questionnaires were completed by the participating parents after the interview so that the content of the questionnaires (e.g., rating the degree to which various factors influenced the decision to place) would not have had an effect on what the parents thought of discussing during the interview. Furthermore, only face and content validity were established for the interview questions, and only face validity for the questionnaire. However, as previously indicated, internal validity in qualitative research tends to be inherent and relatively high (Babbie, 1999).

External Validity

Qualitative designs seek to understand the meanings that individuals give to certain experiences by searching for patterns and themes among participants' perceptions of their experiences. It is important, yet difficult, to find a balance between the generalizability and value of findings. Guba and Lincoln (1981) note that as generalizability increases, it also becomes less helpful in understanding and/or predicting human behavior. Accordingly, the more homogeneous the sample, the less one can safely generalize the themes and theories observed to the broader population of families who have experienced placement of a disabled child.

It is anticipated that the generalizability of this study is limited in its range. As with all research, the external validity will be most high for people beyond this study's sample who meet all of the selection criteria and none of the exclusion criteria used for the sample.

In addition to the selection criteria, other factors may affect the external validity of this study. Utah has relatively low racial and ethnic diversity; although no inclusion or exclusion criteria impeded the participation of people belonging to racial or ethnic minorities, the prevalence of participants in the sample representing such groups is low. Also, because services for people with disabilities are administered at the state level, policies and services tend to vary significantly from state to state (Richardson et al., 1989), which may limit generalization to similar populations in other states. Consequently, the evident threats to external validity may limit the generalizability of the findings from the sample population to other related populations.

However, it is important to note that the target population for this study is, in fact, parents of children with developmental disabilities in out-of-home placements in the state of Utah. The original study was supported by state and private agencies in the anticipation that the results will be relevant and helpful for developing policies affecting the management of care for children with developmental disabilities.

Furthermore, the purpose of grounded theory research is to generate theories that can then be tested with more heterogeneous samples or homogeneous samples along other variables (e.g., geographic location, race, socioeconomic status); in other words, obtaining valid findings in a more limited sample is valuable because it allows for the replication in more diverse samples to test generalization. Thus, this study has provided researchers in the field with a model for understanding post-placement parental stressors and coping methods associated with placing a child with developmental disabilities in out-of-home care that can be validated through further additional qualitative and quantitative means.

Reliability

Whereas the level of internal validity in qualitative research is inherently high, inauspiciously, the contrary tends to be true for the associated level of reliability (Babbie, 1999). The data are filtered via the subjective perspectives of the researcher, which threatens reliability (Babbie, 1999; Hill, Thompson, & Williams, 1997b). How researchers choose to code a specific comment may vary significantly from researcher to researcher, assuming that the particular comment is even selected from the transcription in the first place. Due to the volume of data coded, the length of time necessitated for the analysis, and the fact that the researcher was the only coder, it is possible that the

researcher's standards and judgments changed over time; consequently, the researcher as the measurement instrument, is also a threat to reliability. These threats to reliability are partially ameliorated by the implementation of verification procedures. (See Verification.) It is important to note that inter-rater reliability, while generally difficult and complex to establish in qualitative research, was not used in this current study, as the principal investigator was the only researcher available for coding the transcripts. Thus, even with the utilization of verification processes, the personal perceptions and interpretations of the principal investigator were not controlled for via inter-rater reliability procedures.

Trustworthiness

While validity and reliability are the standards by which research is evaluated, it is paramount to note that these concepts are more specifically tailored for evaluating quantitative research; therefore, equivalent qualitative counterpart standards are emerging from the efforts of qualitative researchers and theorists. The following is a brief description of these standards, along with their application to the results of this study.

Lincoln and Cuba (1985) use the following terms and verification procedures to ascertain the trustworthiness of the data. *Credibility* (internal validity) is brought about by sustained engagement and diligent observation, negative case analysis, and triangulation of data, all of which were implemented as part of the verification process (see *Verification*). *Comparability, translatability, or transferability* (external validity) is facilitated by the use of rich and thick descriptions; hence the justification for the inclusion of multiple supporting quotes in this study. *Dependability* (reliability) and *confirmability* (objectivity) are made possible through the various audits performed on

the results (i.e., member checks, peer review, external audit, intersubjectivity, and transparent researcher bias), as criticism is seen as a vehicle for increased understanding.

Therefore, although the quantitative standards for verifying results render the validity and reliability of the results from this study somewhat suspect, the application of the qualitative procedures for determining the trustworthiness of the results are more appropriate and effective. As such, it is expected that these results, which are rich and extensive, will allow for new insights about parents' experiences after they have made the decision to place a child with developmental disabilities. Given how little attention has been paid to the post-decision process in prior research, the present study has the potential to make an important contribution to our understanding of family experiences with out-of-home placement.

CHAPTER 4

DISCUSSION

Summary of Major Findings

The *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* presented in the preceding chapter seeks to shed light on the processes that parents go through after placement. Families appeared to implement cognitive (*Appraisals* and *Reappraisals*), emotional (*Relief*), and behavioral (*Involvement*) *Coping Methods*. The unique organization of the post-placement stressors and advantages experienced by parents into categories of emotions was brought about by the language and patterns in which parents described the challenges and benefits associated with having placed a child. These categories included five *Emotional Stresses* (*Guilt, Sadness, Fear and Worry, Anger & Frustration, and Uncertainty*) and one primary *Emotional Advantage* (*Relief*). The emotions that parents experienced were markers and manifestations elicited by the parents' particular ways of interpreting (*Appraisals* and *Reappraisals*) a major stressor event (placement) in their lives.

In addition to the identification of the *Emotional Stresses and Advantages*, the following main themes and categories were recognized and incorporated in the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities*. The *Greek Chorus* and parents' interpretations of desirable and problematic adaptive responses of the child with developmental disabilities and her or his siblings were determined to affect *Emotional Stresses* for parents. The principal *Coping Methods* that parents employed to manage the *Emotional Stresses* of placement were established as *Reappraisals* (cognitions centered around the cost-benefit analysis of placement),

Involvement (an attempt by parents to remain an active part in their child's life), *Therapy* (a potential resource for accelerating the process of parental adaptation to life after placement), and *Time* (a significant gauge of adaptation). Other unique findings include the emergence of *Invisible Advantages*; *Guilty Relief*; the *Greek Chorus* ; and the *Fear Dilemma*.

All of the parents interviewed had experienced some *Emotional Stresses* and used some *Coping Methods*, which demonstrates the inclusiveness of the model. Finally, the items contained within the model represent a conglomerate of the participants' experiences. The model was constructed to be as inclusive as possible in order to provide the most comprehensive understanding possible.

Good parenting has specific characteristics (e.g., affection, control, involvement, nurturance, warmth) that have been organized within the theoretical and empirical literature into three constructs: control, structure and support (Koblinsky, Morgan, & Anderson, 1997; Maccoby & Martin, 1983; Rollins & Thomas, 1979; Slater & Power, 1987). The data for this study suggest that parents cope with the stressors associated with post-placement life by staying in control (control), being involved (structure), and perceiving that they still provide affection and nurturance to their child (support). Because these are factors associated with good parenting, such *Coping Methods* enable parents to maintain their feelings of being a good parent, even though their child with developmental disabilities has been placed outside of the home.

Despite the high religiosity of the sample, the participating parents overwhelmingly reported that their religious beliefs did not affect their decision to place; whether or not their religious values affected their experience of the *Emotional Stresses*

and Advantages and *Coping Methods* was noticeably less clear. Interestingly, because of the LDS (Mormon) emphasis on the importance of family, several of the LDS parents expressed that they believed they felt more guilt for placing their child than they would have if they espoused different religious values.

It is not possible to describe how the findings within the model are similar to or different from findings of previous quantitative and qualitative studies because, as previously indicated, no other research on post-placement parental adaptation could be located. However, some comparisons with literature on pre-placement responses may be drawn. For example, the cognitive subcategories, components, and elements of *Reducing or Eliminating Disadvantages* echoed many of the findings from research on issues leading to placement, such as the high levels of parental stress, safety concerns, and negative impacts on familial relationships (Blacher, 1984; Blacher & Baker, 1994; Cole, 1986; Crnic et al., 1983; Dunst et al., 1987; Martin & Colbert, 1997; Sherman, 1988; Sherman & Coccozza, 1984). Another example is that most of the *Emotional Stresses*, particularly *Guilt*, have been previously considered factors associated with placement and the placement decision (Bromley & Blacher, 1989; Martin & Colbert, 1997).

Likewise, the *Anger and Frustration of Bureaucratic Stresses* appears to mirror some of the problems that parents experience with red tape prior to placement (Bernheimer et al., 1983; Martin & Colbert, 1997). Furthermore, the availability of support services, a factor that increases the likelihood of placement (Bruns, 2000; Cole, 1986; Sherman, 1988), is consistent with the current study's *Reappraisal: We could have kept our child home IF...* Thus, although no direct comparisons with prior research are

available, assessments based on related research seem to corroborate many of the findings of this study.

The *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* has apparent similarities to established stress and coping theories. The *Double ABCX Model of Family Stress and Adaptation* (McCubbin et al., 1982) has been extensively applied in the field of family research, and it has been successfully utilized in a few studies on family adaptation to the stresses of living with a family member who has developmental disabilities (Cole, 1986; Florian & Dangoor, 1994; Saloviita, Itälina, & Lenonen, 2003).

The *Double ABCX Model* (Lavee et al., 1985; McCubbin et al., 1982) seeks to explain adaptation in two stages: the pre-crisis phase and the post-crisis phase. The pre-crisis phase (e.g., pre-placement family life) examines how perceptions of stressors (parental perceptions of caring for a child with developmental disabilities) and the availability of preexisting resources (e.g., family and child supports) produce crisis, which necessitates family change (e.g., placement). Most of the research in the field of placement for children with developmental disabilities has focused on this first phase.

This project focused on the post-crisis phase (e.g., post-placement family life). In the second phase, the *Double ABCX Model*: (a) accounts for the accumulation of stressors and demands (e.g., *Emotional Stresses which can become magnified by Problematic Filial Adaptive Responses and Critical Greek Chorus Voices*); (b) considers adaptive resources obtained by the family (e.g., *Therapy*); reflects the relevant interpretations and coping strategies employed by the family (e.g., *Reappraisals and Involvement*); and (d) indicates the degree of adaptation along a continuum of time (e.g., *Time*). Therefore, the

apparent congruence and consistency between the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* and the *Double ABCX Model* lends further validation to the model.

No major problems were encountered during the analysis. The research process for this study was lengthy, expensive, and arduous. However, in a cost-benefit analysis, the efforts required to execute this qualitative study facilitated the formation of the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities*, a result that would not have been fully possible using more traditional quantitative survey methods. The stories and descriptions, which are unique to qualitative methods, not only grounded the development of the model, but are also a key aspect of the model that has intrinsic potential to help parents of children with developmental disabilities.

Implications of Results

Parents

The *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* presents and identifies information that can be helpful in assisting (a) parents who have placed, and (b) parents who are considering placing or will face the decision of placing a child with disabilities in some form of out-of-home care in the future. Parents who have already placed a child may feel that their experiences are validated. This normalizing effect may help (a) reduce stressors by raising awareness, and (b) expose parents to coping methods that had not been utilized, further enabling parental adaptation to life after placement. Parents who will be evaluating whether or not to place a child could potentially be aided by this model as it could allow them to (a) make a

better informed placement decision with a glimpse into the future, and (b) have an idea of what to expect should placement be their decision.

Policy Makers and Administrators

The results of this study may also be beneficial to human service departments as the findings associated with this research could be useful to program administrators in modifying and developing programs and procedures to more effectively facilitate the needs of parents of children with disabilities or special needs, and generating greater empathy for parents' experiences among service providers. Because "developing and maintaining effective support systems for families of handicapped children can have positive influences on parent and family functioning" (Dunst, Cooper, & Bolick, 1987, p. 17), this model may guide service providers and policy makers in making appropriate and well-tailored services available to families who have placed a child. Resources offered might include information, training (e.g., disability education and child behavior modification training for parents, sensitivity and group therapy/support group training for therapists) and therapeutic services (support groups and/or group therapy for parents and for siblings, marriage and family therapy, parent mentors who have adapted to life after placement for parents who are considering placement or who have recently placed a child). In addition, the need to streamline bureaucratic processes to reduce *Emotional Stresses* and the value of fostering *Involvement* (e.g., more parental control over child-related decisions, improved communication and responsiveness, more parent-friendly navigability, additional parental opportunities for continued limited and volunteer involvement with the child, and improved working conditions for caregivers like better pay and adequate staffing to reduce turnover) might be acknowledged and promoted.

Therapists

Additionally, this study may also have clinical applications for counselors and therapists who work with families of people with disabilities or special needs. Some of these applications might include new insights regarding (a) the stressors experienced by parents of people with disabilities or special needs, and (b) the coping methods most frequently employed to deal with those stressors. The acquisition of such knowledge could be used to enhance current therapeutic methods for aiding and assisting parents who have placed.

For example, in the current study, some parents regretted the fact that their therapist was not sufficiently trained (i.e., not knowledgeable about the issues and circumstances that parents face after placing a child with developmental disabilities in out-of-home care) to work with families of children with disabilities. The parents also felt that their therapist minimized their stresses and concerns surrounding their child. Interestingly enough, many therapeutic processes across different models of therapy seem consistent with the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities*. For instance, therapy is doing something, a behavioral response (*Involvement*), about the *Emotional Stresses* of life after placement. Moreover, therapy often provides new ways of understanding situations, a cognitive assessment (*Reappraisals*), and provides diverse avenues for *Coping*. Therapy can be an additional *Supportive Greek Chorus Voice*. And therapy usually takes *Time* for important changes (*Adaptation*) to occur. Cognitions, behaviors, and emotions are areas for change that can be addressed in the therapeutic setting.

Furthermore, the results of this study can help sensitize therapists to issues surrounding raising a child with developmental disabilities, particularly the problems faced by parents who have chosen to place their child. If therapists are more knowledgeable about the process that parents go through after placing a child in out-of-home care, the therapists will be able to more appropriately address parents' challenges and more adequately provide empathy for the parents' situation. For example, therapists could increase their empathic knowledge base by having the parents educate them about their child's disability or disabilities, and their child's placement (e.g., factors that might affect *Involvement* and *Fear and Worry*, such as rules, limits, problems with care).

Additionally, awareness of the *Emotional Stresses* associated with placement may guide therapists in implementing more effective interventions (e.g., therapeutic methods for managing grief and loss). Therapists could also help parents identify *Invisible Advantages* that the parents had not been previously perceived.

Information Dissemination

It is expected that the results of this study will be disseminated to professionals in the field through publication in professional journals, for the purpose of educating those in the field and defining areas for future research. Results will be made available to service providers via an organization that funded the primary data collection with the intention of providing feedback for modifying and developing programs to meet the families' needs more effectively. Finally, the results will potentially be distributed to parents of children with developmental disabilities in brochures and topic-related newsletters with the intent of providing useful information for families who have placed or who will face placement decisions in the future.

Several potential problems exist in providing parents the results of this study. First, the parents may have a hard time remembering that the list is not a prediction of all the experiences to come; this study was a compilation of common experiences. In other words, although some parents experienced most of the aspects of the model, others experienced fewer. However, with the exception of *Therapy* and the *Problematic Filial Adaptive Responses*, all of the parents appeared to have had experience with at least a subcategory, component, or element within each theme. Second, when reading through the findings, parents who have placed a child may feel more *Guilt* and *Emotional Stresses* if they perceive that their experience does not seem as difficult as other parents' experiences. Moreover, parents who are considering placement might feel guilty that their situation does not seem as challenging as that experienced by other parents, thus questioning if placing their child is truly merited. Steps will be taken in an attempt to minimize these possibilities, yet still insure that results are presented in a manner to assist parents who have placed, and help parents contemplating placement, to make a more-informed decision.

Recommendations for Future Research

It is anticipated that this study may serve as a catalyst or springboard for future research. More research is needed to increase the transferability and dependability of the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities*. Subsequent studies may be designed with a heterogeneous or more diverse sample for the purpose of confirming or disconfirming results of this initial research (Creswell, 1998). Specific pathways to accomplish this goal include: (a) additional qualitative work with samples that are homogenous along different variables (e.g., race,

religion, and geographic location), and (b) additional qualitative work with more heterogeneous samples.

For example, exploration and verification of the trustworthiness of the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* with parents of children whose placements were mandatory (not voluntary) would be an important extension within a different type of homogeneous sample. An additional promising study would consider the adaptation processes of parents who have placed children with mild or moderate developmental disabilities. A possible research question could be: Are the cognitive *Appraisals of the Reduction and Elimination of Disadvantages* effective for coping with *Emotional Stresses* among parents of children with mild or moderate developmental disabilities experience?

Furthermore, additional research is needed to increase understanding of (a) how parents *perceive* their children (i.e., the child with developmental disabilities and any other children) adapt to placement, and how those perceptions affect parental adaptation to placement; and (b) why therapy seems to be underutilized by families who have placed, and how therapy might be employed to assist parents and their children prior to and after placement.

Developmental Factors in Child Placement and Parental Adaptation

Another area of future research could include looking at differences among coping methods along the continuum of time. A first recommendation is that researchers attempt to answer the question, *Does time really heal all wounds?* This could be accomplished by exploring how the stressors and the associated coping mechanisms (such as *Uncertainty* and *As time goes by*) change over time. The results of such research

would be invaluable for parents who have placed a child in out-of-home care, as greater understanding of the effects of *Tim* through longitudinal research might assist in raising awareness, increasing normalization of experiences, and creating more realistic expectations regarding the *Emotional Stresses* and adaptation.

A second recommendation is that researchers examine how the age of the child at placement (i.e., whether or not the child was placed before or after adulthood, in other words, whether placement is perceived as an on-time or off-time normative event) accounts for differences in the intensity, frequency, and duration of the *Emotional Stresses*. For example, does the fact that it is a developmental norm to leave home when one becomes an adult reduce the *Emotional Stresses* experienced by parents who place their child in early adulthood? Are the *Emotional Stresses* that are experienced by parents who place their child in early adulthood managed more quickly?

Child and Sibling Adaptation Processes to Placement

Future research is also needed to explore the adaptation processes to out-of-home placement for children with developmental disabilities and siblings of children with developmental disabilities. Of all of the themes that the model generated from the data, this area was possibly the most “gray” and the least developed. Future research might explore more fully the common experiences and perhaps even stages of children’s adaptation to placement. It also will be important to examine the relative effectiveness of different coping strategies, as well as what works best for whom. Furthermore, the stresses experienced by siblings who do not have the cognitive capacity to see all sides of an issue (e.g., the subcategory *Worry: Will I have to go somewhere else, too?* in the present study) also merit additional exploration.

Whereas all of the data used in this study were based on parent perspectives, future research in the area of adaptation could also be collected from the siblings and the child with disabilities. Obtaining self-reports from the siblings does not impose the same kinds of limitations that exist in interviewing the children with developmental disabilities. However, children with developmental disabilities are considered a vulnerable population, creating additional obstacles for access. Furthermore, as many parents in this study indicated, the majority of their children with developmental disabilities had restricted communication abilities; consequently, samples may need to consist of children with mild and moderate disabilities.

Therapy

Similar to seeking saturation for the adaptation processes to placement of children with developmental disabilities and their siblings, further research should also attempt to saturate the theme of *Therapy* in the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities*. Such saturation may provide a better understanding of how therapeutic services can be employed to assist parents and their children prior to and after placement.

Invisible Advantages and The Fear Dilemma

Both *Invisible Advantages* and the *Fear Dilemma* are concepts unique to this model. Anytime a new concept emerges, it calls for additional research and study. By creating interview questions to target these categories more adequately, future research could provide more detailed descriptions and understandings.

Gender Differences

Future research should also explore some of the gender differences observed and reported in this study. For example, (a) What accounts for the fact that mothers seemed to report engaging in coping methods more frequently? Do mothers experience more stressors than fathers, or are mothers only more likely to discuss them? (b) Why were fathers more likely to mention *Reappraisals* as a *Coping Method* and mothers more likely to zero in on *Involvement*? and (c) Given the gender prevalence of depression and the number of mothers reporting depression, it would have been anticipated that some of the fathers would have experienced depression, yet none of the fathers reported depression. What accounts for this discrepancy? Are fathers less likely than mothers to develop symptoms of depression in relation to placing a child in out-of-home care? Can it be explained by a phenomenon where one parent (the father) feels compelled to diminish the appearance his *Emotional Stresses* in an attempt to provide support for the other struggling parent (the mother), or by greater levels of father outside employment? Did the male gender of the interviewer have a moderating effect? Variables such as gender roles and socialization, gender coping styles, and machismo may be relevant for answering these questions. It would also be important for future research to tie in findings about gender differences in social support in family relationships and care-giving activities.

Marital Relationships

Although the negative effects of raising a child with developmental disabilities (e.g., childcare demands, unequal distribution of caregiving, lack of free time) on marital satisfaction have received some attention (Martin & Colbert, 1997; Taanila, Kokkonen, & Jaervelin; 1996), more research is needed to understand the positive effects, as well as the

negative. In addition, this study found that in some cases placement led to feelings of *Anger and Frustration* that parents attributed to their *Marital Relationship* (i.e., *We disagreed about placement* and *We had different coping methods*). Therefore, future research should attempt to better understand how the decision to place and post-placement life influence parental perceptions of marital satisfaction and distress.

Related Areas

Divorce, Grief and Bereavement, and Empty Nesting

As mentioned at various times in the results chapter of this thesis, several of the findings appeared to have overtones similar to those of divorce, grief and bereavement, and parental experiences of empty nesting. Accordingly, future research in the area of post-placement adaptation should examine literature in these three areas. Researchers could draw comparisons between the established models in the areas of divorce, grief and bereavement, and empty nesting with the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities*. Such comparisons might prove useful in evaluating the model and in generating hypotheses for future testing through further research.

Placing Aging Family Members

Many aspects of the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* are similar to the process of adapting to placing elderly parents in out-of-home care. For example, Aneshensel, Pearlin, Mullan, Zarit, & Whitlach (1995) found that children are usually very involved in the lives of their placed aging parents after placement. As is the case with adaptation to life after placing a child with developmental disabilities, although substantial attention has been devoted to the

stresses of providing care to elderly family members, there appears to be a scarcity of research on adapting to life after placing an aging parent in out-of-home care. Even though placing an elderly parent may be more of an on-time normative transition than placing a younger child, future research might apply the model developed in this study to the experiences of families who have placed an aging member in out-of-home care.

Conclusion

As Glaser and Strauss (1967) so adequately posit, good theories are always changing and developing:

When generation of theory is the aim, however, one is constantly alert to emergent perspectives that will change and help develop [the] theory. . . . So the published word is not the final one, but only a pause in the never-ending process of generating theory. (p. 40)

Therefore, the researcher does not wish to insinuate that the *Model of Parental Adaptation to Life After Placing a Child with Developmental Disabilities* is a complete and comprehensive model. Rather, it is an initial attempt at developing a better understanding and providing improved assistance to those who merit it. It is the hope of the researcher that the model will help address to some degree the issues ardently raised by one of the participating parents:

The most traumatic part for any family is giving up their child and putting him in the system and placing him. If you can do something to ease that transition for the parents by informing them more, helping them go through that transition, offering parents counseling to help them through that transition so you don't go through

the guilt and all the other things you do when you give up a child basically to put them into that system.

APPENDICES

Appendix A

Utah Division for People with Disabilities Form 19

ID # _____

- ❑ **1. Self Care.** A person who requires assistance, training, and/or supervision with eating, dressing, grooming, bathing or toileting. (*Age appropriate activities must be considered.*)
- ❑ **2. Expressive and/or Receptive Language.** A person who lacks functional communication skills and/or requires the use of assistive devices to communicate or does not demonstrate an understanding of requests or follow two-step instructions. (*Age appropriate activities must be considered.*)
- ❑ **3. Learning.** A person who has obtained a valid and reliable IQ score of two standard deviations or more below the mean on an individually administered standardized intelligence test (*e.g., a score of 70 or below on the Wechsler Intelligence Scale for Children or Adults [WISC III or WASC III] or a score of 68 or below on Stanford-Binet, Fourth Edition*). IQ test cores over the developmental period should consistently yield scores two standard deviations below the mean.
- ❑ **4. Mobility.** A person with a mobility impairment who requires the use of assistive devices to be mobile and who cannot physically self-evacuate from a building during an emergency. (*Age appropriate activities must be considered.*)
- ❑ **5. Capacity for Independent Living.** A person who is unable to locate and use a telephone, cross streets safely, or understand that it is not safe to accept rides, food or money from strangers. An adult who is unable to complete basic survival skills in the areas of shopping, preparing food, housekeeping or paying bills. A person who is a significant danger to self or others without supervision. (*Age appropriate activities must be considered.*)
- ❑ **6. Self-Direction.** A child (age 6-18) who is significantly below average in making age appropriate decisions. An adult who is unable to provide informed consent for medical/health care, personal safety, legal, financial, habilitative, or residential issues and/or who has been declared legally incompetent. (*Age appropriate activities must be considered.*)

The Economic Self-Sufficiency Functional Limitation Definition Applies Only to Adults (age 18 or older)

- ❑ **7. Economic Self-Sufficiency.** An adult who receives disability benefits and who is unable to work more than 20 hours a week or is paid less than minimum wage without employment support. (*Age appropriate activities must be considered.*)

Appendix B

Interview Questions

Stressful Factors on Home Life

Tell me about your child with special needs.

Tell me about how having your child live at home affected your lives.

- Benefits
- Limitations

Tell me about how having your child at home affected your marital relationship.

Tell me about the kinds of things you did together as a family before you placed your child.

How much one-on-one time was spent with the child with special needs at home before entering the resident-care home?

What kind of impact, if any, did having one child with disabilities have on your decision to have subsequent children?

Why Placement was Considered

How old was your child when you began to consider placement?

Tell me about the factors (things) that influenced you to begin considering placement?

Is there one particular event that caused you to consider placement?

How did you initially feel about placement?

- If negative feelings existed, how did you overcome them?

What things had you read or been told by others about placing a child in an out-of-home care?

The Decision-Making Process

How did you go about making the decision to place your child?

What were some of the advantages and disadvantages of placement?

How did your personal values influence your decision making process?

How did your religious beliefs and convictions influence your decision making process?

What factors influenced you to choose the kind of program you did?

- Did you ever consider any other type of placement?
- How did you learn about the resident-care home where you have placed your child?
- Who was most helpful in providing information about available placements?
- How did you investigate or research the placements you were considering?
- How many potential placements did you visit before deciding on the one in which you placed your child?

How was the final decision reached?

How did you feel about your final decision?

Describe what it was like when you told your other children about the decision you had reached.

Supports

Support Services

What kind of support services are most needed by your child?

When your child was at home, were there any additional support services needed by your *family*? What were they?

Tell me about your experience in obtaining support services (including placement) for your child.

If your family had received all of the services needed by your child, would that have affected your decision to place your child? In what ways?

Influential Systems of Support

What was your children's initial reaction to the idea of placement?

How did your extended family members react to the idea of placement?

How did your close friends and neighbors react to the idea of placement?

Support Groups

Have you ever thought about attending a support group for parents in your situation?

Are you aware of any support groups for parents of children with special needs that operate in the area? How did you find out about it?

Were you able to attend some form of support group before, during, or after you made your decision about placing your child?

Did your caseworker mention the possibility of attending a support group? If so, what did they tell you?

How helpful or valuable do you think attending a support group has been/would be for you?

What would the ideal support group be like?

The Placement Program

Tell me about your child's condition when he/she was placed.

Describe the placement program your child is in.

What kind of interaction do you and your family have with your child now that he/she has been placed?

Effects of the Decision to Place on the Family

How do *you* feel about the decision you made now?

What have been some of the positive effects of your decision on your family?

Have there been any negative effects of your decision on your family?

When you compare your life now to the way it was prior to placement, what differences or changes come to mind? (In what ways has your family changed since you placed your child?)

- Have the changes you expected occurred
- Have the things you thought would remain the same stayed the same?

Has the absence of your child had any effect on the overall atmosphere in the home?

- What kind of an effect?

How do your children feel about the placement of their sibling now?

Do you think the placement of your child has affected the lives of your other children? If so, how?

What is it like when you go to visit your child at the placement?

What is it like when your child comes home to visit?

What is it like when you take your child back to the placement after a visit at your home?

Therapy

Have you received any counseling or therapy before or after you placed your child?

If no: Why not?

If yes:

- What kind of counselor or therapist did you see?
- What was the therapy/counseling like?
- Did you feel the counselor/therapist was well informed on how to help people in your situation?
- How beneficial do you think the therapy was?
- What was the duration of the therapy?

Has anyone (else) in your family received any counseling or therapy before or after you placed your child?

- What kind of counselor or therapist did they see?
- What was the therapy/counseling like?
- Did you feel the counselor/therapist was well informed on how to deal with your situation?
- How beneficial do you think the therapy was?
- What was the duration of the therapy?

How readily available have social services like counseling or therapy been to you?

Retrospect

How permanent is your decision?

What kinds of things might make you consider removing your child from the resident-care home?

How effective do you feel your approach to determining placement was?

If you could go back and make the decision again, would you go about making it with the same method/process/way or differently? Why?

Can you think of any advice that was given to you that helped you in making your decision?

What things do you wish someone had told you when you were trying to make your decision?

What steps do you believe would have helped you to make the decision more easily?

What advice would you give to parents who were trying to decide about placing a child?

What would you tell other parents they might expect?

What advice would you give other parents about *coping* with the placement decision?

Appendix C

Questionnaire

ID # _____

Please try to answer every question as honestly and objectively as possible without consulting with your spouse or partner. We would also ask that you try your best to answer every question. Unless otherwise specified, please answer all questions with ***the time of initial placement as your frame of reference***. If you are unsure about any part of this survey, please feel free to ask for clarification. Thank you for your help and cooperation.

Survey I

Characteristics of the person with special needs at the time of placement

Age of son/daughter: ___ years old

Gender of son/daughter: Male Female

Height of son/daughter: ___ ‘ ___ “

Weight of son/daughter: _____ lbs.

Location of your son or daughter with special needs in birth order (please circle one):

1st 2nd 3rd 4th 5th 6th 7th 8th

For the following 11 questions, please rate your son's or daughter's need for support at the time of placement in the following areas, based upon the following criteria:

1 = Intermittent: Supports are provided on an "as needed" basis, temporary, infrequent, or short term, in a few settings.

2 = Limited: Supports are provided on a regular basis for a short period of time, in several settings.

3 = Extensive: Supports are needed regularly (e.g., daily) in several settings and may extend over long periods of time.

4 = Pervasive: Supports are constant and intense in all settings; they may be life-sustaining.

- _____ (1) Communication (understanding others and expressing self)
- _____ (2) Self-Care (toileting, eating, dressing, hygiene, grooming)
- _____ (3) Home Living (clothing care, housekeeping, cooking, home safety)
- _____ (4) Social Skills (interacting with others, coping with demands, obeying rules, accepting peers)
- _____ (5) Community Use (traveling, shopping, using public facilities, church)
- _____ (6) Self-Direction (making choices, following a schedule, seeking assistance, resolving problems)
- _____ (7) Health & Safety (eating, illness identification, basic first aid, physical fitness)
- _____ (8) Academics (writing, reading, math, science, health, geography, social studies)
- _____ (9) Leisure (playing, recreational activities, personal choices)
- _____ (10) Work (part or full time job, related work skills, money management)
- _____ (11) Mobility (ability to get from one place to another)

ID # _____

What was your son's or daughter's primary diagnosis at the time of placement?

Please circle all of the diagnoses below that applied to you son or daughter at the time of placement:

Cerebral Palsy	Mental Deficiency	Traumatic Brain Injury
Epilepsy	Developmental Delay	Communication Disorders
Behavior Disorders	Autism	Orthopedic Impairments
Hearing Impairments	Visual Impairments	

Please list any additional diagnoses:

Please rate the level of your son's or daughter's disability at the time of placement

(please circle one):

None Mild Moderate Severe

Behavior problems at the time of placement (please circle one)

None Mild Moderate Severe

Please list:

ID # _____

For the following questions, please think about your lifestyle *before* your son or daughter was placed

How much one-on-one time was spent with your son or daughter with special needs at home before he or she was placed?

_____ hours a day (average time spent per day by father).

_____ hours a day (average time spent per day by mother).

_____ hours a day (average time spent per day by one sibling).

For the following questions, please think about your lifestyle *after* your son or daughter was placed

How pleased are you with the care your son or daughter is currently receiving?

(Please circle one)

Extremely satisfied	Very satisfied	Moderately satisfied	Satisfied
Dissatisfied	Very dissatisfied	Extremely dissatisfied	

How permanent is your placement decision? (Please circle one)

Temporary Undecided Permanent

Survey II

How much of an impact did each of the following have in *discouraging* you from placing or *encouraging* you to place your son or daughter in an out-of-home-care program at the time of placement?

- 4 = Had a **strong** impact in **discouraging** me from placing
- 3 = Had a **moderate** impact in **discouraging** me from placing
- 2 = Had a **slight** impact in **discouraging** me from placing
- 1 = Had the **same** impact as anything else in **discouraging** me from placing
- 0 = Had **no** impact on my decision to place
- 1 = Had the **same** impact as anything else in **encouraging** me to place
- 2 = Had a **slight** impact in **encouraging** me to place
- 3 = Had a **moderate** impact in **encouraging** me to place
- 4 = Had a **strong** impact in **encouraging** me to place
- N/A = **Not applicable**

- _____ 1. My religious beliefs
- _____ 2. Finding a nice enough placement
- _____ 3. The way in which raising this child compared to raising my other children
- _____ 4. My child's particular behavior problems
- _____ 5. Advice from professionals
- _____ 6. Thoughts and feelings I experienced regarding the idea of placement
- _____ 7. Concerns about how my child would understand and perceive placement
- _____ 8. Availability of respite care
- _____ 9. Availability of appropriate schooling for my child
- _____ 10. Availability of placements for my child
- _____ 11. Thoughts about someone else raising my child
- _____ 12. Availability of babysitters
- _____ 13. Knowing how to go about getting a placement for my child
- _____ 14. My spouse's attitude toward placement
- _____ 15. The way in which my children without special needs interacted with their sibling with special needs
- _____ 16. The frequency and length of visits with my child provided by the placement
- _____ 17. Concerns about how my child would understand and perceive my love for him or her
- _____ 18. The skills and abilities my child had learned or developed prior to placement
- _____ 19. The degree to which my spouse helped care for our child with special needs
- _____ 20. My attachment to my child
- _____ 21. Advice from friends

ID # _____

Survey III

Your relationship to the child with special needs (please circle one):

Father Mother Aunt Uncle Grandparent Sibling other:

Are you the child's primary provider? Yes No

If you answered no to the above question, who is the child's primary provider?

Your gender (please circle one): Male Female

Your ethnic background (please circle one):

African Asian Caucasian Hispanic Native American Pacific Islander

Other: _____.

Your religious orientation at the time of placement (please circle one):

Atheist Agnostic Baptist Catholic Jehovah's Witness

Jewish Islamic Lutheran Methodist Mormon

Seventh-Day Adventist No religious preference

Other: _____

ID # _____

Your marital status at the time of placement (please circle one):

Married Divorced Separated Co-habitation Single Widowed

Are you a biological parent of the child with special needs? Yes No

___ Your age at the time of initial placement

Is your spouse or partner a biological parent of your child with special needs? Yes No

___ Your spouse's or partner's age at the time of initial placement

___ years The length of your marriage or co-habitation at the time of placement

___ children Number of children in your family (including child with special needs) at the time of placement

The gender and ages of your children living at home at the time of placement:

1st child: Male Female ___ years old

2nd child: Male Female ___ years old

3rd child: Male Female ___ years old

4th child: Male Female ___ years old

5th child: Male Female ___ years old

6th child: Male Female ___ years old

7th child Male Female ___ years old

8th child: Male Female ___ years old

ID # _____

Your highest level of education at the time of placement (please circle one):

Less than high school	Completed high school	Some college
Undergraduate degree	Graduate degree	Doctorate degree

Your spouse's or partner's highest level of education at the time of placement
(please circle one):

Less than high school	Completed high school	Some college
Undergraduate degree	Graduate degree	Doctorate degree

The current degree of marital satisfaction (please circle one):

Extremely satisfied	Very satisfied	Moderately satisfied
Satisfied	Dissatisfied	Very dissatisfied
Extremely dissatisfied		

If you had any health problems at the time of placement, please list them in the space provided below:

If your spouse or partner had any health problems at the time of placement, please list them in the space provided below:

ID # _____

Your employment status at the time of placement (please circle one):

Full-time Part-time Homemaker Unemployed Retired

Your spouse's or partner's employment status at the time of placement

(please circle one):

Full-time Part-time Homemaker Unemployed Retired

Annual family income at the time of placement (please circle one):

Under \$10,000	\$10,000-\$19,999	\$20,000-\$29,999
\$30,000-\$39,999	\$40,000-\$49,999	\$50,000-\$59,999
\$60,000-\$69,999	\$70,000-\$79,999	\$80,000-\$89,999
\$90,000-\$99,999	\$100,000 +	

Appendix D

Letter for Initial Contact from DSPD

Date

Dear Parents,

I am the Associate Director of the Utah State Division of Services for People with Disabilities. Researchers from the School of Family Life at Brigham Young University are conducting a study on the decision making process that parents go through when considering an out-of-home placement for their child with a disability. We hope that the results of this study will provide valuable information and assistance to families who are in the process of making this decision as well as to families who may face the decision to place their child in an out-of-home program in the future. It is felt that the best way to help parents who are considering this decision is to talk to those who have already experienced it.

I'm contacting you to see if you would be willing to be contacted by one of the researchers at BYU. They would like to call you to explain the study further and to see if you would be willing to be a participant.

Please be aware that your participation in this study is **totally voluntary** and will not affect the supports or services your child receives. If you agree, simply sign the bottom of this letter and fill in your telephone number. Use the enclosed postage paid envelope to return it to me. If you return this to me, I will pass your name and telephone number to the researchers at BYU and they will contact you. Thank you for your consideration.

Sincerely,

George Kelner, Ph.D.
Associate Division Director

[] Yes, I am interested in being contacted to learn more regarding this study. I understand that when I am contacted I will, at that time, be able to determine whether or not to participate in this study.

Name
(please print)

Phone Number
(with area code)

Appendix E

Letter for Initial Contact from Organizations Other Than the DSPD

Date

School of Family Life
Brigham Young University
1036 SWKT
Provo, UT 84602

Dear Parents,

A student and faculty member of Brigham Young University's School of Family Life are conducting a study on the decision-making processes parents go through when considering some form of out-of-home placement for children with special needs or developmental disabilities. The researchers feel that the best way to help parents who are considering placement is to talk to those who have already experienced it. Ultimately, it is hoped the results of this study will provide valuable information and assistance to families who will face similar decisions regarding placement of children with special needs or developmental disabilities in the future. This project has been reviewed and approved by professionals at Brigham Young University and the State of Utah's Division of Services for People with Disabilities.

Please note that your participation in this study is **completely voluntary** and will not affect the supports or services your child receives. If both you and your spouse are interested in being contacted by a researcher to learn more regarding this study, please complete and return the bottom of this letter in the provided postage-paid envelope, and you will be contacted shortly by a researcher with this study from Brigham Young University. Your name and phone number will be kept strictly confidential. Thank you for your thoughtful consideration.

[] Yes, I am interested in being contacted to learn more regarding this study. I understand that when I am contacted I will, at that time, be able to determine whether or not to participate in this study.

Name
(please print)

Phone Number
(with area code)

Appendix F

Telephone Protocol for Initial Consent

“Hello, my name is Jeff Jackson, and I’m doing research for my master thesis at the University of Maryland concerning children with special needs. I was referred to you by _____ who suggested that I contact you and your spouse or partner to determine if you would like to participate in this research.

We want to understand the decision-making process parents go through when considering out-of-home placement. Ultimately, we hope the results of this study will provide valuable information and assistance to families who are in the process of making the decision and those who will face the decision to place their child in an out-of-home-care program in the future. We feel that the best way we can help parents who are considering this decision is to talk to those who have already gone through the process.

If both you and your spouse or partner consent to participate in this study, you would be providing valuable information that will be helpful to parents who find themselves in similar situations and facing similar decisions. Participation in this study will entail an interview with both you and your spouse and the completion of three short written questionnaires which would both take place in your home or at some alternative location, according to your preference. The time required for each of you to complete the interview and questionnaires is approximately 2-4 hours. Would you both be willing to participate in this research?”

- > If they say **no**: “Thank you for your time. Have a nice day.”
- > If they say **yes**: “I appreciate your willingness to help. Do you or your spouse (partner) have any specific questions about this study that you would like to ask me?” (Have consent form readily available in order to discuss relevant areas of question or concern with them.)

After all questions have been answered:

“When could I meet with both you and your spouse (partner) for about 2-4 hours?”

“Would you prefer to meet in your home or at some alternative location?”

If they say they would prefer to meet at their house:

“What is your address?”

“Could you please give me directions to your house?”

If they say they would prefer to meet at some other location:

“Where would you like to meet?”

“What is the address?”

“Could you please give me directions?”

Appendix G

Study Summary for Use During Telephone Initial Contact

About This Study

- This study has been approved by both Brigham Young University and the Utah Department of Human Services.
- The purposes of this study are to
 - (a) identify the overall patterns evident in the processes involved in deciding to place a family member with special needs in some form of out-of-home care;
 - (b) examine parental perceptions regarding the effectiveness of those processes
 - (c) investigate the effects of this decision on the family;
 - (d) evaluate the effectiveness of counseling available to families.

Participant Selection

- Prospective participants for this study were selected on the basis of being parents of a child with special needs who is currently residing in an out-of-home-care program.
- Approximately 20 families will participate in this study.
- Participation in this study is completely voluntary; refusal to participate will not involve any kind of penalty.
- Participants may discontinue at any time.
- The researcher may terminate your involvement in this study if he determines that your family does not meet this study's criteria for selection.

What Participation in This Study Entails

- The entire meeting should last approximately 2 to 4 hours.
- The meeting may either take place in the participants' home or at some alternative location.
- The meeting consists of both an informal interview and three short written questionnaires that are to be filled out before the interviewer leaves.
- Participants will be interviewed regarding the way their family went about deciding whether or not to place their child in an out-of-home-care program and how they feel this decision has affected their family.
- The interviews will be audio taped.
- Both parents will be interviewed and asked to fill out the questionnaires and a consent form.

Confidentiality

- Both names and all information disclosed during the interview or in the surveys will be kept strictly confidential.
- The manner in which the results of this study will be reported will assure confidentiality by preventing individual identification and assuring anonymity.
- After the interviews have been transcribed word for word, the tapes will be destroyed.

Risks & Benefits

- The only perceived potential risks and discomforts associated with this study may be due to the emotional content of the topics to be discussed.
- Participation in this study may benefit participants directly by providing an opportunity to reflect upon, gain valuable insights about, and reconfirm the decision that they made regarding the placement of their child.
- The information provided by participants might prove instrumental in aiding and assisting other parents of children with special needs when they are faced with the decision of whether or not they should place their child.
- No financial or other forms of compensation will be provided to the participants of this study.

Appendix H

Potential Participant Information Sheet

Family Contacted:

Father's Name: _____

Mother's Name: _____

Child's Name and Gender: _____

Phone Number: _____

Selection Criteria

- Have you ever placed a child with special needs in some form of out-of-home-care?
- Was the placement mandatory (e.g., court mandated)? (Exclusionary)
- How many years has it been since your child was first placed in some form of out-of-home-care? (1-45 years)
- How old was your child when the initial placement decision was made? (2 - 30 years of age)
- What was your marital status at the time of the initial placement?
- The next couple of questions are to assess the types and levels of your child's special needs at the time of initial placement. (Use Form 19 [Appendix F] – the score must be 3+/6 if the child was placed after turning 6 and 3+/5 if placed before turning 6. Score: ___/___)

Additional information

Is your child currently placed in some form of out-of-home care?

What is your current marital status?

Are you (and spouse/partner) the biological parents?

Participation in the Study:

- Yes.** Participant(s) verbally consented over the phone to meet with researchers from Brigham Young University.
- No.** Participant(s) wishes not to participate in the study.

Meeting Place:

- Home of participant
- Alternate location

Address:

Directions:

Contact made by:

Jeffrey B. Jackson

Signature

Date

Appendix I

Consent To Be a Research Participant

ID # _____

You were selected for participation in this study because you are the parent of a son or daughter with special needs who is currently in an out-of-home-care program. Approximately twenty other families will be participating in this study. The purposes of this study are to (a) identify the overall patterns evident in the processes involved in deciding to place a family member with special needs in some form of out-of-home care, (b) examine parental perceptions regarding the effectiveness of those processes, (c) investigate the effects of this decision on the family, and (d) evaluate the effectiveness of counseling available to families.

Participation in this study is completely voluntary; refusal to participate will not involve any kind of penalty. You may discontinue participation in this study at any time; just notify the researcher that you no longer wish to be included in the study. The researcher may terminate your involvement in this study if he determines that your family does not meet the selection criteria for this study.

If you agree to participate in this study, you will be interviewed regarding the way your family went about deciding whether or not to place your son or daughter in an out-of-home-care program and how you feel this decision has affected your family. These interviews will be audio taped; after the interviews have been transcribed word for word, the tapes will be stored for a period of five years before they are destroyed. In addition to the interview, you will be asked to fill out three brief written surveys. The interview and questionnaires take approximately 2 - 4 hours to complete.

All information disclosed by you either during the interview or in the surveys will be kept strictly confidential, as will be your name. The manner in which the results of this study will be reported will assure confidentiality by preventing individual identification and assuring anonymity. Utah law requires the reporting of any suspected or actual abuse, neglect, or exploitation of a child, an adult 65 or older, or an adult who has a mental or physical impairment that affects the person's ability to provide for or protect him/herself. If the researcher has reason to believe that such abuse, neglect, or exploitation has occurred, the researcher will report this to Child Protective Services, Adult Protective Services, or the nearest law enforcement agency. Any disclosure of illegal acts or any suspected illegal acts will also be reported to the appropriate authorities.

The only perceived potential risks and discomforts associated with this study may be due to the emotional content of the topics to be discussed. Participation in this study may benefit you directly by providing an opportunity to reflect upon, gain valuable insights about, and reconfirm the decision that you made regarding the placement of your son or daughter. Participation in this study may benefit other parents of children with special needs because the information you provide might prove instrumental in aiding and

assisting them when they are faced with the decision of whether or not they should place their child.

This study is being conducted by Jeffrey B. Jackson, M.S. candidate in Marriage and Family Therapy at the University of Maryland and B.S. in Marriage, Family, and Human Development from Brigham Young University. If you have any questions regarding this research project, you may contact Jeff Jackson at (301) 483-0909 or (801) 272-3139.

If you have questions regarding your rights as a participant in a research project, you may contact Dr. Shane Schulthies, Chair of the Institutional Review Board, Brigham Young University at (801) 422-5490, or Mary Caputo, Chair of the Department of Human Services Institutional Review Board (DHS IRB) at (801) 538-4295.

I have read, understood, and received a copy of the above consent information, and agree to participate in this study.

Research Participant Signature

Date

Witness Signature

Date

Appendix J

Future Contact Form

ID # _____

In the event that it becomes necessary to clarify certain aspects of this study or gather additional information, would you be willing to complete and return an additional survey that would be mailed to your home?

- Yes, I would be willing to fill out an additional survey.
- No, I would prefer that I not be sent an additional survey.

We would be more than happy to send you a copy of the results from this study. Would you like to receive a copy of the results?

- Yes, I would like to receive a copy of the results of this study.
- No, I would prefer that I not be sent a copy of the results from this study.

We will be transcribing the interview portions of this study. We would be more than happy to send you a copy of the transcription of your interview. Would you like to receive a hard copy of the transcription of your interview?

- Yes, I would like to receive a hard copy of the transcription of your interview.
- No, I would prefer that I not be sent a hard copy of the transcription of your interview.

If you answered “YES” to any of the above questions, please provide the requested information on the following lines:

Name: _____

Current address: _____

Current phone number: (____) _____

Appendix K

Confidentially Agreement For Transcribers

The following paragraph contains the policies to which the participants in this study agreed. Please read it carefully as you will be required to help us protect the confidentiality and rights of the study participants.

All information disclosed by you either during the interview or in the surveys will be kept strictly confidential, as will be your name. The manner in which the results of this study will be reported will assure confidentiality by preventing individual identification and assuring anonymity. Utah law requires the reporting of any suspected or actual abuse, neglect, or exploitation of a child, an adult 65 or older, or an adult who has a mental or physical impairment that affects the person's ability to provide for or protect him/herself. If the researcher has reason to believe that such abuse, neglect, or exploitation has occurred, the researcher will report this to Child Protective Services, Adult Protective Services, or the nearest law enforcement agency. Any disclosure of illegal acts or any suspected illegal acts will also be reported to the appropriate authorities.

I, (*print name*) _____, understand that through the experience I will have in working on this research study, that I must maintain strict confidentiality as to any identifying information of the study participants: any information as to the participants and/or their families must remain within strictest confidence in order to protect the privacy, rights, sensitivities, and feelings of the participants involved in this study.

My signature below signifies that I will abide by this confidentiality agreement.

Signature

Date

Appendix L

Transcription Instructions

Word Processor: Microsoft Word must be used

Verbatim: The transcription should be verbatim with the following exceptions:

- Words like "um," "ok", "um hm," "you know," etc.
- Stutters and repeated phrases (e.g., "I, I, I think we should, we should...")
- Portions that are verbally indicated as not to be transcribed.
- Proper names and places should be indicated with the first capital letter followed by a dash (2 hyphens together) e.g., Tiny Tots = T-; Rise = R-; Jack = J-; etc.
Exceptions include:
 - Professional parenting care
 - If the husband refers to his wife by name, please indicate this by stating "wife" and vice versa
 - When either of the parents refer to their child with disabilities by name, please indicate this by typing (our/my) "child with special needs." If either parent refers to a child other than the child with disabilities, please refer to that child by using the first letter of the child's name as explained above followed by "(child)" instead of the dash. If two children should have names starting with the same letter (e.g., Tim & Tom), please indicate this by using ordinal numbers after the first letter and then the parentheses: e.g., T1 (child) & T2 (child).

If you are unable to understand a portion of the interview, please indicate this by an asterisk (*).

If the interviewee does something that may not be captured by transcription (e.g., laugh, cry), please indicate this in the transcription by including it in parentheses.

Structure:

Start a new paragraph each time someone else begins to speak (even if it is a one-word interjection). Then indicate the responses with 2 hard returns between each as can be seen in the example (RH = response of husband; RW = response of wife, CI = comment by interviewer, Q = question by the interviewer). Use brackets [CI] without italics if the interviewer interjects anything that is not used as a question (e.g. comments, supplying words for participants when they are stuck, etc.). If one spouse or the interviewer interrupts whoever is speaking, indicated this by a dash at the point where the person speaking was cut off, and then start a new paragraph.

Please use the following guidelines for color-coding:

Green = Question [Q] (in italics)

Red = Response of Wife [RW]

Blue = Response of Husband [RH]

Pink = Response of a Child [RC] will be very rare

Black = Comments by Interviewer [CI]

Please keep a running legend or key in ALPHABETICAL ORDER at the end of the transcription for the purpose of decoding.

E.g.: J- = Jack

R- = Rise

T- = Tiny Tots

T1 (child) = Tim (oldest child)

T2 (child) = Tommy (3rd of 5 children)

Finally, please add 1-2 paragraphs of your reactions to and observations of the parent(s)/family.

Example Transcription

[Q] *So how did you find babysitters for your child with special needs?*

[RH] It was really hard to find any qualified enough to do the babysitting. We didn't feel good about leaving our child with special needs alone at home. It was mainly a matter of -

[RW] Trust.

[RH] Yeah, trust and inaccessibility. You just can't have the 13 year-old girl from down the street come. You need someone with training and experience, and consequently you can't pay them what you would the neighborhood girl, which we could not afford. It was very hard on our marriage because we couldn't get out very often.

[RW] Probably only two times each year.

[CI] That must have been hard.

[RH] You know what, it was.

[RW] Yeah, like my husband said, it was really stressful to try to find a babysitter. Every now and then used to go have picnics in the park (chuckles). Our child with special needs loved being pushed on the swings by anyone in the family. In fact, one of the best things about having our child with special needs at home was the amount of cooperation it inspired among our other children.

[RH] When she was born, C (child), our oldest, was really probably the one that got the most neglected and it certainly wasn't an intentional thing, but we just, most of our attention was going to our youngest because she was obviously a baby and to our two children with disabilities and a we found that C (child) started to have rebelliousness, I mean she wasn't super rebellious, but she certainly *. I kind of found out that she was having thoughts of running away, this was right before we placed Child with special needs, this would have been two years ago, but a she was having thoughts of running away, she was having thoughts of wanting to stab her brother, so anyway, that obviously causes a lot of concern. So I mean there are certainly good things about having Child with special needs at home, you know, he's very loving in nature and it helped us I think to maintain, if you yell around Child with special needs, he gets upset and cries, so obviously we tried to maintain a more even atmosphere, I mean not that we don't do that now, but obviously with him in the family it required us to do more of that I think.

Legend

Child with special needs = Barbra

Husband = Tom

Wife = Sandra

C (child) = Christy (oldest child of four)

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