

EFFECTS OF RESPITE CARE ON THE
POTENTIAL FOR ABUSE AND
FAMILY FUNCTIONING

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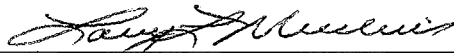
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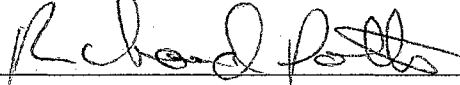
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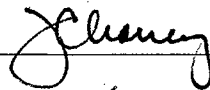
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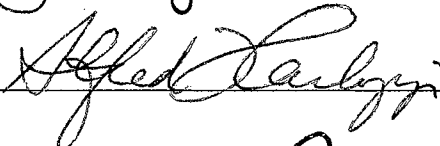
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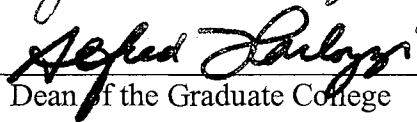


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CHAPTER I

INTRODUCTION

The United States Department of Health and Human Services estimates that almost four hundred thousand children were physically abused in the United States in 1993, a 42% increase from 1986 estimates (U. S. Department of Health and Human Services, 1996). Developmentally disabled children represent a disproportionately large segment of the population at risk for abuse (Ammerman, Van Hasselt, & Hersen, 1988). Although only estimates can be made regarding the actual number of disabled children that are abused, the National Center on Child Abuse and Neglect (as cited in Baladerian, 1994) suggests that disabled children suffer at least twice and up to ten times the rate of abuse that is experienced by the general population.

Many hypotheses have been considered regarding the reasons behind the disproportionate amount of abuse suffered by disabled children. Kirkham, Schinke, Schilling, Meltzer, and Norelius (1986) proposed that the demands of caregiving and related responsibilities reduce opportunities for community contact for the caregiver, thus increasing social isolation for both the parent and the child. Additionally, Kirkham et al. (1986) suggested that these parents suffer from high levels of stress and frustration due to the additional challenges placed upon the caregiver of a disabled child. Marchetti and McCartney (1990) hypothesized that abusers see disabled children as more vulnerable because they are often cognitively impaired. This vulnerability of the disabled child also

reduces the likelihood that the child will report the abuse (Ammerman, Hersen, Van Hasselt, Lubetsky, & Sieck, 1994).

Although the aforementioned issues represent key factors that can lead to abuse, research has shown that caregiver variables represent only a portion of the factors that contribute to physical abuse. Indeed, several child characteristics have been identified as contributors to heightened child abuse as well (Kolko, Kazdin, Thomas, & Day, 1993). These qualities include troublesome temperament, poor attachments, and behavioral and emotional difficulties, which are thought to actually elicit abuse from caretakers who have the potential to abuse (Kolko et al., 1993). Research has shown that parents who feel their children are difficult to manage may be at higher risk for physical abuse (Ammerman et al., 1998). Although children who possess such characteristics may face heightened risk for child abuse, those who are developmentally disabled are at even greater risk. Other child characteristics that contribute to the abuse of developmentally disabled children include premature birth, mental retardation, increased need for care and supervision, and behavior problems (e.g., self injurious behavior, aggression) (White, Benedict, Wulff, & Kelley, 1987; Zirpoli, 1986).

Not only does a developmental disability directly effect the afflicted child and their caregiver, but many studies have focused on the indirect manner in which the presence of a disabled child influences family functioning and family characteristics, thereby raising the potential for abuse. The amount of care required by a disabled child appears to impact all aspects of family functioning and all members of the family (Folden & Coffman, 1993). As families attempt to care for a disabled child in the home, the effects of this responsibility on the family can range from total disruption of the family to

the growth of strength and cohesion within the family system (Folden & Coffman, 1993). More attention is being paid to the challenges facing families caring for a child with a disability and has resulted in heightened efforts to augment the services and resources available to this population.

One approach that has been increasingly utilized to alleviate stress on the family of the disabled child is respite care. Cohen and Warren (as cited in Folden & Coffman, 1993) defined respite care as “the temporary care of a disabled individual for the purpose of providing relief to the primary caregiver”. Since the 1970s, the typical concept for care of a disabled child was based upon “normalization”, defined as promoting deinstitutionalization of children with disabilities (Folden & Coffman, 1993). This concept supported deinstitutionalization based on the premise that the home environment provides an atmosphere that best promotes growth and development for the disabled child. However, the increased amount of stress placed upon families caring for a disabled child within the home prompted a concomitant need for community services to alleviate the strain of caregiving (Short-DeGraff & Kologinsky, 1988). Thus, respite care is an increasingly utilized form of support services for specialized care for the developmentally disabled, as well as other populations in need (Short-DeGraff & Kologinsky, 1988). Notably, Cohen and Warren have found that families utilizing respite services reported greater life satisfaction, increased hope for the future, improved approach toward caregiving, and an heightened ability to cope (as cited in Folden & Coffman, 1993). Additionally, Caradoc-Davies and Harvey (1995) found that families used respite care in order to provide opportunities for vacations, rest from caregiving, business, and surgery,

and that 78% of parents surveyed felt that respite care was a necessary service in order to maintain caregiver mental health.

Although there is growing emphasis placed upon the importance of respite services, there is little available literature of methodologically sound quality that assesses the impact of respite care for family members of developmentally disabled children (Folden & Coffman, 1993). Importantly, there is virtually no information available regarding the influence of respite care upon the families of disabled children and abuse potential. Thus, the purpose of the current study is to identify the influence of respite care upon caregivers' potential for abusing disabled children in their care, and to examine the effects that respite care has on the entire family and its functioning. Parents of children with developmental disabilities admitted for respite care and short-term hospitalization, a form of respite care, to a center for developmental disabilities will be administered measures of abuse potential and family functioning at admission, discharge, and at two months follow up. Such research will provide important information regarding the influence both respite care and short-term hospitalization may have upon the potential for caregivers to physically abuse children with a disability. Further, the current study will allow investigation of how these forms of respite care may alter the quality of family relationships.

In the following sections, the impact of a developmental disability upon the child and their family will be discussed. First, the physical, emotional, and psychological complications associated with children with disabilities will be considered. This section will be followed by a discussion of the impact of stress upon families caring for children with disabilities. Subsequently, the incidence of child physical abuse will be outlined,

along with research focusing on abuse and children with disabilities. Last, literature regarding trends in respite care will be evaluated, and studies of the effectiveness of such services will be assessed.

CHAPTER II

REVIEW OF THE LITERATURE

The Child with a Developmental Disability

Disabilities are conditions that can impart moderate to severe limitations in physical functioning, as well as restricting social relationships with family and friends. It has been estimated that 10% of all children in the United States are afflicted with some type of disability and experience related complications in functioning (Wallander, Varni, Babani, Banis, & Wilcox, 1989). Not only do children with disabilities suffer from mobility and sensory impairments, but they also must endure recurrent hospitalizations and medical procedures and adhere to physical therapy regimens (Kazak, 1986). Research shows that disabilities impact social relationships of children by reducing social contact and the range of interactions, along with the number of individuals in the child's social network (Lyons, Sullivan, Ritvo, & Coyne, 1995).

Although type of disability and degree of impairment vary substantially in children with a developmental disability, the psychological, emotional, social, and financial costs the children and their families endure is considerable. When compared to their peers, children with developmental disabilities are more likely to evidence psychological and behavioral problems in addition to the physical complications

they must face (Boyce, Behl, Mortensen, & Akers, 1991; Gallagher, Beckman, & Cross, 1983).

The psychological and emotional problems found in many children with disabilities can be associated with the children's inability to achieve developmental milestones at the same rate as their normal peers (Kazak, 1986). To add to the child's difficulties, it has been established that as the age of the child increases, the differences between the child and his or her peers become increasingly noticeable (Gallagher et al., 1983). In a study of 270 chronically ill and disabled children, Wallander, Varni, Babani, Banis, and Wilcox (1988) compared subjects' scores on the Child Behavior Checklist (Achenbach & Edelbrock, 1983) to those scores from physically healthy cohorts. Results showed that the chronically ill and disabled children represented an at-risk group for psychological adjustment problems. Thus, adjustment to the disability creates difficulties for children in areas of both psychological and emotional health.

It has been established that social support networks also influence a child's adjustment to their disability. In a survey study of 137 parents of disabled preschool children, Dunst, Trivette, & Cross (1986) found that diagnosis and the number of social support sources were significantly related to physical complications. In a related study, Varni, Wilcox, & Hanson (1988) surveyed 23 families with children suffering from juvenile rheumatoid arthritis (JRA). Results showed that family social support tended to decrease the incidence of mood disorders (i.e., depression, anxiety) and problem behaviors (i.e., aggression, hyperactivity). Further, Wallander et al. (1989) surveyed the mothers of 153 chronically ill and handicapped children regarding family resources as resistance factors for child psychological maladjustment. The results indicated that

children's adjustment, particularly social adjustment, was significantly related to family resources, both psychological and utilitarian (i.e., financial resources). Thus, regardless of developmental status, better functioning was evidenced based upon the amount of social support received by the child with a disability.

Estimates suggest that approximately 50% of children with a disability have problems with destructive, aggressive, and overactive behavior (Quine, 1986). Children with more problematic behavior disorders have been found to have fewer self-help skills and poorer communication skills when compared to children without behavior disorders (Quine, 1986). In a study of handicapped children with behavior problems, 200 families were surveyed regarding handicap severity and family circumstances. Quine (1986) found that a significantly greater number of children from single-parent homes evidenced behavior problems than those from two-parent homes, although the author states that the cause of this difference is difficult to determine. Notably, these behavior problems may produce greater parental distress in these single-parent homes possibly due to the lack of spousal support and the burden of caregiving placed upon one parent instead of two.

Children with developmental disabilities must also combat the physical complications that are inherent with their diagnosis. Issues that must be dealt with include the chronicity of the disability, symptom course, pain and physical discomfort, and functional loss (Lyons, Sullivan, Ritvo, & Coyne, 1995). Additionally, the child must also contend with treatment and rehabilitation that serve to alleviate the effects of the disability. These services can be quite time consuming and create financial strain on the child's family.

Thus, children with disabilities place a greater demand upon their caregivers not only due to the increased burden of caregiving, difficulty managing the disability, the child's dependence, and poor communication skills, but also because of emotional and behavioral complications, time, and financial pressure (Kazak & Simms, 1996; Quine, 1986). These factors culminate to create an environment of considerable stress for the families of children with disabilities.

Stress and Families with a Developmentally Disabled Child

Many research studies have emphasized the significant amount of stress that parents who care for a child with a disability experience (Failla & Jones, 1991; Gallagher et al., 1983; Gross, 1988; Kazak & Simms, 1996; Tunali & Power, 1993). Historically, increased levels of family stress have been identified as an almost inevitable result of having a child with a developmental disability (Boyce et al., 1991; Dyson, 1991). The characteristics of the child (level of care, social skills, disposition, disability, prognosis uncertainty), as well as social networks, spousal support, marital satisfaction, financial stability, family relations, and parental characteristics, all appear to significantly impact the level of stress experienced by parents (Boyce, 1991; Gallagher et al., 1983; Murphy, 1982; Tunali & Power, 1993). Additionally, parents experience anxiety, depression, fear, guilt, and helplessness related to the uncertain conditions that surround their child's disability (Donnelly, 1994).

Gallagher, Beckman, and Cross's study (as cited in Gross, 1988) stated that although characteristics of the parents, including age, personality, occupation, and values influenced their perception of stress, the number of care-giving demands required by the

child's disability, other child characteristics, and related caregiving burdens also have a significant influence. Parents of children with disabilities often report experiencing difficulties in their ability to work due to taking time off for the child, lack of social contact, and restricted time for personal and leisure activities (Carpiniello, Piras, Pariante, Carta, & Rudas, 1995). The social stigma of having a child with a disability has also been identified as a stressor for parents (Flagg-Williams, 1991). Parents' stress level is reportedly higher when the child's ability to communicate is relatively low (Frey, Greenburg, & Fewell, 1989). Additionally, differences in the child's behavior and appearance as compared to normal children and the reactions of others (i.e., drawing attention to or staring at the child) tend to add to the parent's distress (Flagg-Williams, 1991).

The constant presence of multiple stressors over long periods can result in an environment where the family is placed at risk for developing many unhealthy relational patterns (Failla & Jones, 1991). Indeed, Wallander, Varni, Babani, DeHaan, Wilcox, and Banis (1989) found that certain factors involved in having a child with a disability may increase the likelihood of family dysfunction. Varni et al. (1988) found that among a sample of 23 families with children suffering from JRA, family functioning was significantly related to the child's adaptation to their disease. Furthermore, similar results were discovered using a population of families with children having insulin-dependent diabetes (IDDM) (Varni et al., 1988).

Current research suggests that social support is a mediating factor of stress for adults, reducing the distressing impact of serious life events and ongoing strains (Varni et al., 1988). This can also be viewed as a coping mechanism when dealing with a child

with a disability. Notably, many families with a disabled child are seen as encountering social isolation. Some researchers in this area have found that larger social network size is associated with greater coping success than families with less social support (Kazak, 1986; Kazak, 1987). Interestingly, Kazak and Marvin (as cited in Flagg-Williams, 1991) discovered that the families of children diagnosed with spina bifida had smaller social networks than did comparison families. This study found that it was more beneficial for families to have highly interconnected networks (considerable familiarity among members) than it was to have a large network without interconnectedness. Thus, increasing size of a social support system does not necessarily insure increased benefit of that network.

Interestingly, strong social support can influence many facets of family relations (Dunst et al., 1986). In a study involving 137 parents of mentally retarded, physically impaired and developmentally disabled children, the mediating influences of social support were examined as they related to the family and the disabled child (Dunst et al., 1986). Improved parental attitudes, parent-child interactions, parental expectations, and child behavior were all found to be linked with strong social support (Dunst et al., 1986). Additionally, Dunst et al. (1986) discovered that parents reporting more social support satisfaction evidenced less overprotection of their child, independent of the diagnosis of the child or the severity of the disability. The authors theorized that parents with supportive social networks felt less compelled to overcompensate for their social situation by sheltering their child.

Studies of families of children with disabilities show that two-parent families appear to have a clear advantage over one-parent households in coping with stress,

(McKinney & Peterson, 1987; Trute & Hauch, 1988). McCubbin (1989) found that two-parent families had significantly higher levels of financial well-being, cooperation, and optimism about the disability, and that improved maternal coping related to higher family integration. Mothers of single-parent families showed less coping behavior related to maintaining cooperation, integration, and optimism among family members. Thus, the lack of a significant other with whom to share caregiving concerns, family management, and personal issues seems to undermine the single-parent's ability to cope with their child's situation (McCubbin, 1989).

Burke (1987) compared 30 single-parent families to 30 two-parent families, both having a child with a disability. Results indicated that single-parent mothers evidenced more distress concerning financial issues, housing, and care for the child while the mothers were at work. These findings suggest that single-parent households are more in need of health and social services than those families where spousal support is not an apparent issue. The presence of a spouse may also enhance parents' coping with the social stigma associated with disabilities (Flagg-Williams, 1991). Baxter's study (as cited in Flagg-Williams, 1991) showed that parents experienced increased distress because of noticeable differences in their disabled child's behavior, appearance, and speech. To compound the issue, the staring and attention of others exacerbated this distress. Collectively, it appears that positive parental functioning is related to the presence and strength of the parental relationship in two-parent families (Trute & Hauch, 1988). Moreover, it would appear that having a greater number of adults in the home is a distinct advantage (Boyce et al., 1991). Adults appear to provide support for one another

and distribute caregiving responsibilities in a manner that is impossible in a single-parent home.

Spouses who appear to be successfully coping with their child's disability also evidence strengths in their marital relationships as well. Husbands and wives who openly share their concerns related to the child's condition appear to experience reduced distress over longer periods of time (Donnelly, 1994). According to Friedrich, Cohen, and Wiltner (1987), parents of children with a developmental disability experienced higher levels of marital satisfaction because the dimensions of cohesiveness and expressiveness characterized their marriage. These parents appeared to have captured elements that were needed in order to adapt to the strain of their child's disability. However, there are a number of studies that offer contrasting findings, revealing that overall rates of marital satisfaction are no different between families with and without children with disabilities (Kazak, 1987; Kazak & Simms, 1996). Despite conflicting research, it appears that higher levels of marital satisfaction are associated with lower levels of stress for some parents of children with disabilities. In addition to marital satisfaction, studies show that resources (i.e., financial, community) also impact the level of stress endured by families of a disabled child.

Theories of stress suggest that families with access to certain resources achieve increased resistance to stress, whereas the absence of certain resources can exacerbate the effects of stress (Knussen & Sloper, 1992). Depletion of financial resources occurs when caring for a child with a disability due to the extensive costs of care (special equipment, medical attention, and programs) and the low level of benefit support (Gallagher et al.,

1983; Knussen & Sloper, 1992). Thus, low socioeconomic status certainly adds to the familial pressures of a child with a disability (Gallagher et al., 1983).

The parents' perceived adequacy of medical and social resources also appears to be a mediating factor in parental stress. Knussen & Sloper (1992) reported that levels of unmet parental needs (e.g. financial, medical) were directly related to adaptation, with the areas of the most unmet need being information regarding the child's condition, information about available services, transportation problems, and housing adaptations to accommodate the child's disability. In related research, Bristol and Schloper (1984) conducted a longitudinal study of families of autistic children. They discovered that amount of parent training and social support services were significant differentiating factors between high-stress and low-stress families.

In summary, parents of children developmental disabilities must not only learn to cope with the psychological, emotional, social, and financial strain of a child with developmental disabilities, but must also have means to diminish the stress and strain of their care-giving responsibilities. However, because of the tension parents experience when coping with children with disabilities, the extant research shows that these children are at greater risk for child abuse (Gallagher et al., 1983).

Physical Abuse of Children with Developmental Disabilities

Physical abuse is defined by the National Center on Child Abuse and Neglect as physical injury resulting from an aggressive act, intentional or unintentional, that results in harm to a child (U.S. Department of Health and Human Services, 1992). Alarming, physical abuse statistics show a continuous increase in the amount of confirmed cases in

the United States. The first national survey on child abuse in the United States was conducted by Gil in 1970 (as cited in Zirpoli, 1986). The results indicated that around 6,000 cases of child abuse occurred in 1967. However, in 1973, those numbers increased to 60,000 cases of child abuse in a study by Kempe (1973) and 500,000 cases of abuse as concluded by Light (1973). The U. S. Department of Health and Human Services estimated that 269,700 children were physically abused in 1986 and that this number jumped to 381,700 in 1993 (U. S. Department of Health and Human Services, 1996).

Notably, research has suggested that children with disabilities are at greater risk of becoming victims of child physical abuse (Baladarian, 1994; Kolko, Kazdin, Thomas, & Day, 1993; White, Benedict, Wulff, & Kelley, 1987; Zirpoli, 1986). In a large study involving children with CP, Cohen and Warren (1987) found that of the 2,771 children served by 42 United Cerebral Palsy (UCP) affiliated preschool programs, 33 of these programs reported either known abuse or symptoms often associated with abuse. Approximately 10.9 percent of the children with a disability prior to abuse evidenced either known or possible abuse. However, these abuse rate results stand in contrast to other research. In a study of 86 children with cerebral palsy (CP), Diamond and Jaudes (1983) found that 20% of the children were abused and 14% were considered to have a high potential for abuse. Glaser and Bentovim (as cited in White et al., 1987) surveyed 174 hospitalized children with medical, social, and psychological histories that indicated possible abuse. Of these 174 children, 67 of them (38%) suffered from a disability. Results indicated that 46% of children with a disability suffered from abuse, while 65% of the children without a disability also suffered from abuse. Although the rates of abuse for the disabled children were lower than rates for children without a disability for this

sample, the instances of abuse that included both groups was considerable. These varied results may be a product of contrasting methodology, populations, and definition of abuse, yet, each study emphasizes the substantial risk of abuse or the potential for abuse that children with disabilities face.

Additionally, Cohen and Warren (1987) investigated rates of physical abuse at 14 UCP affiliated respite programs. Among these 14 centers, seven of them noted either previous abuse at the centers or the symptoms often associated with abuse. Of the children with congenital disabilities, 3.2% of the children in these respite programs were abused. Cohen and Warren (1987) suggested that the lower levels of abuse may be due to the possibility that respite care programs prevent abuse, parents may be less likely to abuse before the child receives respite care in order to avoid identification of abuse, or that respite care workers are less likely to recognize the signs of abuse.

Risk factors that influence child abuse potential have become an increasingly researched area. It is apparent that families of children with developmental disabilities encounter an increased level of stress related to the severity of the child's disability and their required level of care (Ammerman et al., 1988). Although level of stress can be influenced by improvements in the child's disability, periods of exacerbation in the child's illness can place parents at risk for abusing their child with a disability (Benedict, Wulff, & White, 1992; Ammerman & Patz, 1996). Research also suggests that the level of family functioning is also closely tied to physical abuse (Milner, 1994). Indicators such as family conflict, cohesion, expression, and independence show a significant relationship with elevated levels of physical abuse within the family (Milner, 1994). Families that have been involved in child physical abuse typically experience stressful

events in addition to exhibiting elevated conflict and decreased cohesiveness (Kolko et al., 1993). Abuse has also been shown to be influenced by punitive parenting and parental distress (Milner, Robertson, & Rogers, 1990). Inadequate parenting skills in conjunction with child-related problems further increases the likelihood for abuse (Milner & Crouch, 1993).

Research has shown that parents' perceptions of their children also play a major role in child abuse potential (Stratton & Swaffer, 1988). Literature indicates that abuse is more likely within families where parents perceive their children as exhibiting increased levels of problem behaviors (Milner, 1994). These parents may view their children with decreased acceptance, which may negatively influence their parenting practices (Kolko et al., 1993). Stratton and Swaffer (1988) found that abusive mothers had a tendency to see their handicapped children's challenging behaviors as intentional and purposeful, and viewed the child as in control twice as often as the mothers themselves. Mothers perceived their children as having a great deal of power to control outcomes of situations at home. The authors concluded that the mothers' pattern of attributing intent to their children's problem behavior lead the mothers to respond to conflict by blaming the child.

Child factors have also been identified as contributors to abuse. Characteristics that have been recognized as influencing the potential for abuse include chronic and pervasive behavioral and emotional problems such as depression, anxiety, impulsivity, and aggression, poor attachments to caregivers, increased need for care and supervision, and physical abnormalities (Ammerman & Patz, 1996; Ammerman et al., 1988; Kolko et al., 1993). However, these factors alone are not sufficient to explain abuse. The conflict and familial distress that these characteristics produce can interfere significantly with the

caregiver's ability to successfully interact with the child and the family and increase the overall likelihood for physical abuse (Ammerman et al., 1988; Kolko et al., 1993).

Thus, studies focusing on physical abuse of children with disabilities indicate that this population is at greater risk for abuse than children without disabilities.

Additionally, factors such as increased stress, negative parental perceptions and poor parenting skills, and challenging child behaviors increase the likelihood that abuse will occur. Due to the substantial influence these factors have on child physical abuse, it can be hypothesized that diminishing the influence of these factors should decrease the likelihood of abuse.

Respite Care

The literature on child physical abuse certainly identifies the significant influence that stress, behavioral and emotional problems, physical constraints, parental perceptions, and family relations have on maltreatment of children with disabilities. These factors relate in a limitless number of ways to produce a complex situation with which the families of disabled children must cope. Notably, there is a lack of research investigating interventions that focus on these problems and reduce their negative impact on the family. However, it would be implausible to consider that simple interventions would alleviate the impact of these substantial and intricately interrelated problems.

Historically, the typical manner in which services have been provided to children with disabilities and their families is through extended hospitalization. In the 1970s, more and more families began to care for their children with developmental disabilities in the home and place increasingly fewer numbers of these children in institutional settings (Short-

DeGraff & Kologinsky, 1988). This change resulted in an increased need for family and community services providing care and support of individuals with disabilities and thus brought about the inception of respite care programs (Halpern, 1985; Short-DeGraff & Kologinsky, 1988). Over the past 15 years, there has been an increased number of respite care providers available that offer a wide variety of services (Botuck & Winsberg, 1991).

Currently, there are four models of respite care available to families in need (Halpern, 1985). The first model, home-based care, involves placing a trained caregiver in the home of the child with a disability and provides daytime or overnight care (Halpern, 1985). A variation of the home-based model involves care that is provided in a home that is owned by an agency, where the caregiver lives with the client for the duration of the respite (Halpern, 1985). In the third model, services are provided in a group day care setting for a few hours every week, and the fourth model involves residential care that can last for one night or up to several weeks (Halpern, 1985). The majority of these residential care programs offer trained staff to meet the specific emotional, social, behavioral, and medical needs of the developmentally disabled.

Traditionally, respite services of the 1970s were provided to families in a crisis due to the disabled member (Short-DeGraff & Kologinsky, 1988). Today, the purpose of respite care is geared more toward preventing a major crisis from happening at all (Short-DeGraff & Kologinsky, 1988). By far, the predominant concern of families who have a member with a developmental disability is the maintenance of the family structure. Folden & Coffman (1993) have noted that the need most frequently expressed by caregivers was relief from caregiving in order to focus on family health.

Although there is relatively little literature available addressing families of children with developmental disabilities, studies do show that parents perceive respite care services to have a positive impact upon their families (Folden & Coffman, 1993; Joyce, Singer, & Isralowitz, 1983). Botuck and Winsberg (1991) reported that respite care reduced the negative effects upon families with a child with disabilities by: “(a) relieving familial stress, (b) improving family functioning, (c) improving parental attitudes towards their child, and (d) reducing social isolation” (p. 43). In a study conducted by Botuck and Winsberg (1991), the mood, well-being and activity of 14 mothers of disabled children were evaluated before, during, and after a preplanned 10-day respite for their children. It was found that while children were in respite care, their caregivers spent more time with personal care, active social contact, and household care while postrespite results indicated a greater sense of well-being and less depression for these same caregivers (Botuck & Winsberg, 1991). However, these conclusions should be interpreted with caution due to the limited sample size, lack of a control group, and rater bias.

In a study focusing on the impact of respite care on parents’ perceptions of quality of life, Joyce et al. (1983) surveyed 32 families with disabled children concerning family relations, social activities, and emotional and physical burdens. The findings suggest that parents perceived the impact of respite care to have a positive effect on the family by diminishing stress, improving family relations, and allowing more personal time for caregivers. Additionally, 91% of the respondents confirmed that respite care programs can offer parents an alternative in order to avoid institutionalization of their children (Joyce et al., 1983). However, the authors suggest that a larger sample size and a stress-

focused intervention might have added much information to the results. Furthermore, other studies have shown that children were also able to benefit from new experiences, a new environment, and the independence from their families provided by out-of-home respite care (Cavanagh & Ashman, 1985). Thus, the respite environment may provide a setting to learn more independent living practices and increase social contact for children who spend almost all of their time at home (Cavanaugh & Ashman, 1985).

Overall, research focusing on families that receive respite services show that parents have reported high satisfaction with respite care programs, particularly parents with children who benefited from extended physical care and behavioral complications (Halpern, 1985). These studies suggest that the impact of respite care on the family could impart positive and far-reaching changes upon the family with a disabled child. Respite services have the potential to alleviate parental stress, improve family relations, and possibly reduce the risk of child physical abuse.

The current research in respite services supports the effectiveness of this type of care for families of children with disabilities. However, the limitations of these studies include the lack of standardized measures, small sample sizes, samples utilizing children with various disabilities, and varied lengths of respite care service to children and their families. Additionally, the respite care literature lacks control for differing types of disabilities, prospective approaches to data gathering, and longitudinal designs. Finally, no studies have been done which compare respite care specifically with short-term hospitalization, which constitutes a form of respite care with the addition of therapy services.

The current study is designed to address these shortcomings and assess the impact of respite care and short-term hospitalization upon abuse potential and family functioning through the use of a pre-, post- and follow-up contacts with the families. In comparison to previous research, standardized measures will be utilized with a larger number of parents of developmentally disabled children to be included in the sample. The children's diagnosed disability will be considered in addition to length of respite care, and the longitudinal design will allow for evaluation of the lasting effects of these services.

CHAPTER III

STATEMENT OF THE PROBLEM

As stated previously, children with developmental disabilities are at increased risk for exhibiting behavioral problems and experiencing emotional complications (Kazak, 1986). Notably, their families also experience adjustment problems due to the stress of caring for the disabled child. Stressors include a number of care-giving demands, reduced social contact, decreased spousal support, financial instability, and lack of community resources (Knussen & Sloper, 1992; Tunali & Power, 1993). The extant literature indicates that these stressors place children with disabilities at greater risk for abuse at the hands of their caregivers (Kolko et al., 1993). Additionally, their families suffer from higher rates of family functioning problems due to the impact of the child's disability (Wallander et al., 1989).

Respite care services have been identified as having a positive impact upon families of children with a disability (Folden & Coffman, 1993). This type of resource has been associated with relief from stress, improvement of family relations, increased personal time for caregivers, and increased social contact (Botuck & Winsberg, 1991; Joyce et al., 1983). Overall, studies have found that respite services appear to promote positive interactions among family members by reducing the stress related to the child's disability. However, there are few studies that assess the impact respite services have upon the potential for abuse that children with disabilities face. There is also a lack of

research focusing on the long-term effects of respite care on the functioning of the family with a disabled child who receives such services.

Thus, the purpose of this study was to determine the relationship of respite care and short-term hospitalization to the potential for abuse and family functioning among parents of children with disabilities. Because of the lack of data in this area, no hypotheses were formally stated. Rather, research questions were stated.

The following research questions were the focus of the current study:

1. *Is the potential for abuse decreased in parents of children with developmental disabilities who are admitted for respite care and short-term hospitalization?*
2. *If it is decreased, do parents maintain decreased levels of abuse potential at 2 months following discharge?*
3. *Does the quality of family functioning improve after admission for respite care and short-term hospitalization?*
4. *If so, is the improved quality of family functioning maintained at 2 months following discharge?*
5. *Does abuse potential decrease as family functioning improves?*

Due to the lack of literature investigating the impact of respite care and short-term hospitalization upon families of children with disabilities, additional measures were included for exploratory purposes. Exploratory questions included:

1. *Is abuse potential related to type of disability?*
2. *Is abuse potential related to the level of the child's functional ability?*
3. *How does parenting stress relate to the potential for abuse?*
4. *How does parents' psychological distress relate to family functioning?*

5. *Is family functioning predictive of parental psychological distress?*

CHAPTER IV

METHODOLOGY

Participants and Procedures

Participants included the parents of developmentally disabled children and adolescents referred for respite care or short-term hospitalization to the J. D. McCarty Center for Developmental Disabilities (JDMCDD) in Norman, Oklahoma. Subjects included 21 parents (20 female and one male) of children admitted for respite care, and 29 parents (28 female and one male) of children admitted for short-term hospitalization. No limitations were placed on the children, adolescents, or their parents regarding sex, race, ethnicity, or functional ability. Foster parents and grandparents were also included in the study with the requirement that the child or adolescent had been in their custody for one year or more. Both fathers and mothers were included in this research whenever possible. Consent was obtained in accordance with the required procedures of the JDMCDD and the OSU Institutional Review Board.

At the time of outpatient intake (Time 1), parents were approached by the designated JDMCDD research assistant, explained the nature of the study, and asked to consent to participate. Approximately 85% to 90% of the parents originally approached agreed to participate in the study. After consent was obtained, participants were taken to a private, secure office and were asked to complete the appropriate paper-and-pencil

measures. Parents who were unable to complete the measures at JDMCDD due to time constraints were given the measures along with a self-addressed, stamped envelope to mail back to the Center. Parents completed study protocols at time of admission (Time 1), time of discharge (Time 2), and two-month follow-up (Time 3). The majority of the measures completed at two-month follow-up were mailed to the family's home and were returned in the self-addressed, stamped envelope provided. Of the 61 families initially recruited for the study, 82% (n = 50) completed protocols at Time 1 and 2; 72% (n = 44) completed protocols at Time 3. Families who did not complete measures for Time 1 and Time 2 were excluded from the study. Families were paid \$10 for each time of assessment.

Measures

Demographics

Parents of the children and adolescents were asked to complete a brief demographics questionnaire including questions related to age, gender, marital status, income, and child's type and duration of disability (see Appendix A).

Child Abuse Potential Inventory (CAPI)

The CAPI (Milner, 1994) is a 160-item self-report measure created to assess factors in parental functioning thought to contribute to physical child abuse. It has also been utilized as an index of abuse risk with both clinical and non-clinical populations. Notably, the CAPI has been used to assess abuse potential in at risk clinical populations such as parents of conduct disordered children (Kolko et al., 1993) and mothers of

children with disabilities (Ammerman et al., 1994). The questionnaire is answered in an agree-disagree format and is written for a third grade reading level (i.e., “I like most people...”). This inventory includes a physical abuse scale and six factor scales: distress, rigidity, unhappiness, problems with child and self, problems with family, and problems with others. Also included are three validity scales: a lie scale, a random response scale, and an inconsistency scale. These validity scales can be used to form three validity indices: the random response index, the faking-good index, and the faking-bad index. The CAPI internal consistency estimates range from .91 to .96, while test-retest reliabilities range from .75 to .90 (Mollerstrom, Patchner, and Milner, 1992).

Several studies have determined that CAPI scores are highly correlated with behavior of maltreating parents, family conflict, psychological dysfunction, family functioning difficulties, and stressful life events (Haskett, Scott, & Fann, 1995; Kolko et al., 1993; Mollerstrom et al., 1992). After determining that the CAPI profile was valid for each subject, the physical abuse summary score was used as an index of abuse potential.

Family Relations Inventory (FRI)

The FRI (Drotar, Pallotta, & Eckerle, 1994) is a 27-item measure derived from the Family Environment Scale (FES). The FES is a 90 item scale that evaluates three constructs: relationship dimensions, personal growth dimensions, and system maintenance dimensions. The FRI measures the quality of family relations based upon the three subscales that comprise the relationship dimension of the FES in a total score. These subscales include cohesion (perceived support of family members), conflict (the

perception of the expression of anger as a characteristic of the family), and expressiveness (the perception that family members express their feelings directly). Items are answered in a true or false format with respondents considering which items do and do not reflect their perceptions of their own family (i.e., There is a feeling of togetherness in our home). Studies have utilized the FRI to identify maladaptive relationships among nonorganic failure-to-thrive (NOFT) children, adjustment among families with children suffering from juvenile rheumatoid arthritis (JRA), and the quality of family relations among families of children with mental retardation (Friedrich et al., 1987; Varni et al., 1988; Drotar et al., 1994). The FRI has demonstrated adequate reliability and validity (Drotar et al., 1994).

Functional Ability Scale (FAS)

The FAS is a 23-item scale that assesses the child's ability to engage in various functional tasks and activities of daily living (e.g., brush teeth, get into bed). It is an adaptation of the Juvenile Arthritis Functional Ability Rating Scale (JAFAR). Two versions of the FAS (parent report and staff report) will be utilized in the current study. These versions are identical with the exception of the instructions, which have been written to address either parents or staff. The parent report form will be included in the packet that is completed by the parent. The staff report form will be filled out at admission and discharge by three members of the team assigned to care for the subject's child while they are in respite. Scores were averaged to focus on summary scores (see Appendix B and C).

Brief Symptom Inventory (BSI)

The BSI (Derogatis, 1993) is a self report inventory consisting of 53 items that is designed to measure the psychological symptom patterns of psychiatric and medical patients, as well as community nonpatient respondents (i.e., Feeling fearful). It was designed to be a brief form of the Symptom Checklist 90-Revised (Derogatis, 1977). Nine clinical subscales associated with psychological distress are produced: somatization (som), obsessive compulsive symptoms (obs), interpersonal sensitivity (ins), depression (dep), anxiety (anx), phobic anxiety (pho), psychoticism (psy), paranoid ideation (par), and hostility (hos). The BSI also provides a composite index, named the Global Symptom Index (GSI), which is a combination of a measure on intensity of perceived distress (PSDI), and the number of symptoms experienced. The clinical significance of score elevations can be assessed through T-scores (i.e., $M=50$, $SD=10$) and via caseness (Derogatis, 1993).

A GSI score or two or more subscale scores equal to or greater than 63 defines caseness. The caseness criterion for maladaptation has been utilized by various authors to assess adaptation to chronic illness (Thompson et al., 1992). The BSI takes an average of 8-10 minutes to complete, has high internal consistency(71-85), has high test-retest reliability(.68-.90), and has separate gender norms and norms for patients.

The Parenting Stress Index (PSI-SF).

The PSI/SF (Abidin, 1990) is essentially the same as earlier, full-length versions of the PSI (e.g. Abidin, 1986), except that it only takes about 10 minutes to complete. The PSI/SF takes its 36 items directly from the earlier scales, and is comprised of the

same domains and yields the same scores. Each item is answered on a 5-point scale ranging from strongly agree to strongly disagree (i.e., I feel trapped by my responsibilities as a parent). Statistical characteristics of the short form were derived from a new norm sample of 800 parents, and confirm the earlier levels of acceptable reliability and validity. Test-retest reliability from a sample of 270 parents yielded a coefficient of .84, while the Alpha coefficient for internal consistency gathered from the original 800 subjects was .91. Validity data were gathered from a sample of 530 parents, and concurrent validity Pearson coefficients for Total, Child, and Parent Domain scores were .94, .87, and .92 respectively. The PSI/SF is assumed to have content validity as the items were derived from a previously validated, full-length version of the PSI.

Overview of Statistical Analyses

Primary Analyses

The following research questions were addressed:

1. *Is the potential for abuse decreased in parents of children with developmental disabilities who are admitted for respite care and short-term hospitalization?*
2. *If it is decreased, do parents maintain decreased levels of abuse potential at 2 months following discharge?*
3. *Does the quality of family functioning improve after admission for respite care and short-term hospitalization?*
4. *If so, is the improved quality of family functioning maintained at 2 months following discharge?*
5. *Does abuse potential decrease as family functioning improves?*

Within-subjects repeated measures MANOVAs were conducted to answer these five questions for each treatment group. Each MANOVA determined the impact of respite care and short-term hospitalization upon the potential for abuse and family functioning over time. These separate analyses included time (admission, discharge, 2-month follow-up) as the independent variable and the CAPI and FRI as the dependent variables.

Exploratory Analyses

The following questions were addressed:

1. *Is abuse potential related to type of disability?*

A one-way ANOVA was conducted to examine the relationship between type of disability and abuse potential scores (CAPI) at admission

2. *Is abuse potential related to the level of the child's functional ability?*

A Pearson product-moment correlation was conducted to investigate the relationship between abuse potential scores (CAPI) at admission and ratings of child's functional ability as assessed by either treatment team members (FAS-T) and parents (FAS-P) at admission.

3. *How does parenting stress relate to the potential for abuse?*

A Pearson product-moment correlation was computed to investigate the relationships between parenting stress (PSI) and abuse potential scores (CAPI) at admission.

4. *How does parents' psychological distress relate to family functioning?*

A Pearson product-moment correlation was conducted to investigate the relationship between parents' psychological distress (GSI) and family functioning (FRI) at admission.

5. *Is family functioning predictive of parental psychological distress?*

Thompson's transactional stress and coping model was used to guide a regression analysis using family functioning to predict parental psychological distress (Thompson & Gustafson, 1996). This model suggests that the relationship between an illness and its effects are a function of biomedical, developmental, and psychosocial factors.

Demographic parameters associated with this model include gender, age, and SES while illness parameters include type of disability and child's functioning (severity of disability). This regression examined whether family functioning predicts parental psychological distress over and above the contributions of demographic variables and child illness parameters

CHAPTER V

RESULTS

Sample Description

All participants were identified as the primary caregiver for the child with mothers accounting for 92% (n = 46) of the total sample; fathers (n = 2; 4.0%) and grandmothers (n = 2; 4.0%) constituted the remainder of the sample. Subjects with children in the respite and short-term hospitalization groups did not differ significantly in terms of age, $M = 37.3$ and 38.5 , respectively ($p > .05$). Frequencies for other demographic variables (child's race, income, marital status) involving both treatment groups are included in Table 1. Children in the respite care and short-term hospitalization groups did not differ in terms of ethnicity, $X^2(5, N = 50) = 1.84, p > .05$. Additionally, the groups did not differ significantly on level of income, ($M = 20,000$) and ($M = 24,000$) respectively, $F(1, 48) = .89, p > .05$. Further, parents did not differ between groups on current marital status, $X^2(4, N = 50) = 1.80, p > .05$. Thus, parents did not vary on primary demographic variables.

Table 1

Frequencies of Demographic Variables for Respite Care and Short-term HospitalizationGroups

Variable	<u>Respite Care</u>		<u>Short-term Hospitalization</u>	
	n	%	n	%
<u>Child's Ethnicity</u>				
Caucasian	12	57.1	16	55.2
Native-American	5	23.8	5	17.2
African-American	3	14.3	5	17.2
Hispanic	1	4.8	1	3.4
Asian	0	0	1	3.4
Other	0	0	1	3.4
<u>Total Family Income</u>				
0-4999			2	6.9
5000-9999	4	19.0	3	10.3
10000-14999	6	28.6	6	20.7
15000-19999	4	19.0	3	10.3
20000-29999	3	14.3	6	20.7
30000-39999	3	14.3	5	17.2
40000-49999	0	0	1	3.4
50000-59999	0	0	0	0
60000 or greater	1	4.8	3	10.3
<u>Marital Status</u>				
Married	9	42.9	15	51.7
Single Parent	7	33.3	10	34.5
Remarried	2	9.5	2	6.9
Never Married	1	4.8	0	0
Other	2	9.5	2	6.9

Although children receiving care did not constitute the participants of interest in this study, further demographic variables for the children admitted for either respite care or short-term hospitalization were examined for differences. Descriptions of diagnostic and treatment variables for both treatment groups are included in Table 2. Children in the respite ($M = 13.0$, $SD = 4.4$ years) and short-term hospitalization ($M = 9.8$, $SD = 4.8$) groups differed significantly in terms of age, $F(1, 48) = 5.61$, $p < .05$. Significant differences were also found between groups for gender, $X^2(1, N = 50) = 5.35$, $p < .05$, with the respite group being comprised of 10 females (48%) and 11 males (52%) while the short-term hospitalization group involved 5 females (17%) and 24 males (83%). Children in the respite and short-term hospitalization groups also differed significantly in terms of years with diagnosis of developmental disability, $M = 11.73$ ($SD = 5.7$) and $M = 8.30$ ($SD = 5.4$), respectively, $F(1, 46) = 4.47$, $p < .05$. As expected, the groups differed significantly on duration of care, with the respite group ($M = 9.19$, $SD = 3.61$) receiving fewer days of inpatient treatment than the short-term hospitalization group ($M = 53.66$, $SD = 37.26$), $F(1, 48) = 29.53$, $p < .001$. Children in the respite and short-term hospitalization groups did not differ significantly regarding any type of past respite care specifically, $X^2(1, N = 49) = 2.87$, $p > .05$. However, significant differences were found between groups regarding previous care at the J. D. McCarty Center, with 76% ($n = 16$) of the respite group and 52% ($n = 15$) of the short-term hospitalization group having received some form of care at the Center previous to the time of this study, $X^2(1, N = 49) = 4.07$, $p < .05$. Additionally, the groups did not differ significantly regarding the child's primary diagnosis, $X^2(1, N = 43) = .053$, $p > .05$.

Table 2.

Description of Diagnostic and Treatment Variables

Variable	<u>Respite Care</u>		<u>Short-term Hospitalization</u>	
	n	%	n	%
Past Respite Care				
yes	11	52.4	8	27.6
no	10	47.6	20	69.0
Previous Care at JDM				
yes	16	76.2	15	51.7
no	4	19.0	14	48.3
Primary Diagnosis				
cerebral palsy	10	47.6	13	44.8
downs syndrome	0	0	2	6.9
mental retardation	1	4.8	0	0
cerebral palsy and other	0	0	1	3.4
mental retardation and other	1	4.8	1	3.4
other	8	38.1	12	41.4

Note: JDM = J. D. McCarty Center for Developmental Disabilities

Further analyses were performed to examine the effects of child's gender and diagnosis on all primary (CAPI, FRI) and exploratory (FAS-P, GSI, PSI) dependent measures for all subjects. A multivariate analysis of variance (MANOVA) revealed no significant main effect for gender on the dependent variables ($F(6, 29) = .680, p > .05$), thus indicating parents' responses to the study protocol did not differ according to the gender of their child. A second MANOVA examining the effects of child's diagnosis on the same dependent and exploratory measures was conducted. Only the "cerebral palsy" and "other" categories were included for this analysis due to the small number of subject's children ($n \leq 2$) in four of the diagnostic categories. The MANOVA revealed no significant main effect for child's diagnosis on the dependent measures, $F(6, 29) = 2.05, p > .05$.

Thus, while parents did not differ on any demographic parameters, children receiving respite services did differ on a number of variables. These findings serve to further describe the children with developmental disabilities receiving inpatient care. However, because parents constitute the population of interest in this study, child parameters were excluded from further analyses.

Screening Analyses

First, data were examined in order to exclude invalid profiles obtained on the CAPI Abuse Scale. Invalid profiles were identified using the validity scales of the CAPI and identification procedures designated by Milner (1986). After correcting for educational background, participants' scores were evaluated for distorted response patterns (faking-good, F+; faking-bad, F-; random response, RR). Three (14%; F+ = 3)

participants in the respite care group and four (14%; $F+ = 3$, $RR = 1$) participants in the short-term hospitalization group were found to have approached the measure using a distorted response style. Consequently, these profiles were omitted from the analyses. A MANOVA examining differences between valid and invalid profiles for participants on demographic variables (age, SES) did not yield a significant main effect, $F(2, 46) = .34$, $p > .05$.

Additionally, CAPI Abuse Scale scores were examined for classification into elevated and nonelevated categories using the conservative cutoff score of 215. Participants with valid profiles and abuse scores exceeding this cutoff have expressed characteristics consistent with known, active physical child abusers (Milner, 1986). The percentage of participants in the respite group exceeding the cutoff criteria decreased from 29% ($n = 6$) at Time 1 to 24% ($n = 5$) at Time 2 and 22% ($n = 4$) at Time 3. A Cochran test, evaluating the differences among these proportions, was nonsignificant, $X^2(2) = 1.00$, $p = .607$. Three participants (15%) exceeded the cutoff criteria at Time 1, 2 and 3; 10 (48%) achieved scores within the normal range across time. A change in abuse potential classification across time was observed for 8 (38%) participants.

For the short-term hospitalization group, participants exceeding the cutoff criteria of 215 changed from 17% ($n = 5$) at Time 1 and Time 2 to 21% ($n = 6$) at Time 3. The differences among these proportions showed no significance, $X^2(2) = 3.00$, $p = .223$. Four participants (14%) exceeded the cutoff score criteria at Time 1, 2, and 3; 22 (76%) achieved scores within the normal range across Time. A change in adjustment levels across time was observed for 3 (10%) participants. Overall, with both groups collapsed, participants exceeding the 215 cutoff criteria remained at 22% across Time 1, 2, and 3.

Seven participants (14%) exceeded the cutoff score criteria at Time 1, 2, and 3; 32 (64%) achieved scores within the normal range across Time. A change in adjustment levels over time was observed for 11 (22%) participants.

To evaluate parents' psychological distress, scores on the Brief Symptom Inventory (BSI) were examined for caseness criteria (Derogatis, 1993). Criteria for caseness is met if either the GSI T score is greater than or equal to 63, or if two or more of the nine clinical subscale T scores are greater than or equal to 63. Individuals meeting this criteria are considered to be within the clinically significant range for psychological distress (Derogatis, 1993). The percentage of participants in the respite group meeting caseness criteria decreased from 67% (n = 14) at Time 1 to 57% (n = 12) at Time 2 and 33% (n = 6) at Time 3. The Cochran test for differences among these proportions was significant, $X^2(2) = 6.22$, $p = .045$. Follow-up pairwise comparisons using the McNemar test were conducted. The proportions did not differ significantly from admission to discharge, $p = .727$, approached significance from admission to 2 month follow-up, $p = .070$, and showed no significance from discharge to 2 month follow-up, $p = .125$. Six participants (29%) met caseness criteria at Time 1, 2 and 3; 5 (24%) demonstrated normal adjustment levels across time. A change in adjustment levels across time was observed for 10 (48%) participants.

For the short-term hospitalization group, participants meeting caseness criteria also decreased from 41% (n = 12) at Time 1 to 38% (n = 11) at Time 2 and 28% (n = 8) at Time 3. No significant differences were found among these proportions, $X^2(2) = .667$, $p = .717$. Five participants (17%) met caseness criteria at Time 1, 2, and 3; 13 (45%)

showed good adjustment levels across time. A change in adjustment levels across time was observed for 11 (38%) participants.

Overall, with both groups collapsed, the percentage of participants meeting caseness criteria decreased from 52% (n = 26) at Time 1 to 46% (n = 23) at Time 2 and 32% (n = 14) at Time 3. Differences between these percentages were approaching significance, $\chi^2(2) = 5.44$, $p = .066$. Eleven participants (22%) met caseness criteria at Time 1, 2 and 3; 18 (36%) demonstrated normal adjustment levels across Time. A change in adjustment levels across time was observed for 21 (42%) participants.

For descriptive purposes, means and standard deviations of the primary (CAPI, FRI) and exploratory dependent measures (FAS-P, FAS-T, GSI, PSI) for respite care and short-term hospitalization are included in Table 3 and Table 4 respectively, and combined in Table 5.

Table 3

Means and Standard Deviations for Respite Care Primary and Exploratory DependentMeasures

Variable	Respite				
	n	Min.	Max.	M	SD
CAPI					
admission	18	31.00	401.00	160.67	106.07
discharge	18	21.00	422.00	155.00	125.30
2 mos. follow-up	15	29.00	417.00	155.73	121.39
FRI					
admission	18	15.00	38.00	22.44	5.92
discharge	18	15.00	40.00	22.50	6.59
2 mos. follow-up	15	15.00	40.00	23.80	6.78
PSI					
admission	18	62.00	150.00	103.56	23.11
discharge	18	37.00	144.00	99.44	25.97
2 mos. follow-up	15	71.00	147.00	102.53	23.33
GSI					
admission	18	39.00	80.00	61.72	9.05
discharge	18	33.00	80.00	59.00	12.50
2 mos. follow-up	15	33.00	80.00	56.87	11.78
FAS-P					
admission	18	26.00	68.00	45.44	14.33
discharge	18	25.00	69.00	45.28	14.76
2 mos. follow-up	15	27.00	69.00	47.33	14.81
FAS-T					
admission	18	23.00	68.00	45.26	17.22
discharge	18	23.00	69.00	44.61	16.92

Note: Measures: CAPI = Child Abuse Potential Inventory
 FRI = Family Relations Inventory
 PSI = Parenting Stress Inventory
 GSI = Global Symptom Index of the Brief Symptom Inventory
 FAS -P = Functional Ability Scale - Parent
 FAS - T = Functional Ability Scale - Team

Table 4

Means and Standard Deviations for Short-term Hospitalization Primary and ExploratoryDependent Measures

Variable	Short-term Hospitalization				
	n	Min.	Max.	M	SD
CAPI					
admission	25	31.00	382.00	142.56	109.98
discharge	24	12.00	364.00	142.33	105.48
2 mos. follow-up	23	26.00	404.00	131.57	101.25
FRI					
admission	25	18.00	48.00	26.52	8.21
discharge	24	15.00	46.00	28.58	8.40
2 mos. follow-up	23	7.00	42.00	22.83	6.08
PSI					
admission	25	55.00	133.00	99.72	24.30
discharge	25	8.00	141.00	94.00	28.06
2 mos. follow-up	23	50.00	140.00	92.87	22.27
GSI					
admission	24	33.00	80.00	58.00	11.05
discharge	25	33.00	71.00	53.64	11.30
2 mos. follow-up	23	36.00	71.00	53.43	8.89
FAS-P					
admission	25	23.00	69.00	47.76	14.22
discharge	25	23.00	69.00	45.76	15.56
2 mos. follow-up	22	23.00	69.00	49.32	16.26
FAS-T					
admission	25	23.67	69.00	43.55	17.50
discharge	25	23.00	69.00	43.31	17.25

Note: Measures: CAPI = Child Abuse Potential Inventory
 FRI = Family Relations Inventory
 PSI = Parenting Stress Inventory
 GSI = Global Symptom Index of the Brief Symptom Inventory
 FAS -P = Functional Ability Scale - Parent
 FAS - T = Functional Ability Scale - Team

Table 5

Means and Standard Deviations for Primary and Exploratory Dependent Measures for
Respite Care and Short-term Hospitalization Combined

Variable	Respite Care and Short-term Hospitalization				
	n	Min.	Max.	M	SD
CAPI					
admission	43	31.00	401.00	150.14	107.46
discharge	42	12.00	422.00	147.76	113.10
2 mos. follow-up	38	26.00	417.00	141.11	108.69
FRI					
admission	43	15.00	48.00	24.81	7.54
discharge	42	15.00	46.00	25.98	8.18
2 mos. follow-up	38	7.00	42.00	23.21	6.30
PSI					
admission	43	55.00	150.00	101.33	23.61
discharge	43	8.00	144.00	96.28	27.02
2 mos. follow-up	38	50.00	147.00	96.68	22.89
GSI					
admission	42	33.00	80.00	59.59	10.29
discharge	43	33.00	80.00	55.88	11.97
2 mos. follow-up	38	33.00	80.00	54.79	10.11
FAS-P					
admission	43	23.00	69.00	46.79	14.14
discharge	43	23.00	69.00	45.56	15.05
2 mos. follow-up	37	23.00	69.00	48.51	15.51
FAS-T					
admission	43	23.00	69.00	44.26	17.20
discharge	43	23.00	69.00	43.85	16.92

Note: Measures: CAPI = Child Abuse Potential Inventory
 FRI = Family Relations Inventory
 PSI = Parenting Stress Inventory
 GSI = Global Symptom Index of the Brief Symptom Inventory
 FAS -P = Functional Ability Scale - Parent
 FAS - T = Functional Ability Scale - Team

Analyses for Research Questions 1 through 5

Repeated measures multivariate analyses of variance (MANOVA) were conducted separately for respite, short-term hospitalization, and with the groups combined (respite and short-term hospitalization). The MANOVAs compared the primary dependent measures (CAPI, FRI) over Time (3 levels; admission, discharge, 2 month follow-up) in order to address the following research questions:

- 1. Is the potential for abuse decreased in parents of children with developmental disabilities who are admitted for respite care and short-term hospitalization?*
- 2. If it is decreased, do parents maintain decreased levels of abuse potential at 2 months following discharge?*
- 3. Does the quality of family functioning improve after admission for respite care and short-term hospitalization?*
- 4. If so, is the improved quality of family functioning maintained at 2 months following discharge?*
- 5. Does abuse potential decrease as family functioning improves?*

For respite, short-term hospitalization, and the groups combined, results yielded no significant main effect between Time (admission, discharge, two month follow-up) and the two dependent measures (CAPI, FRI), respectively, $F(4, 11) = .343, p > .05$, $F(4, 18) = 1.21, p > .05$, and $F(4, 33) = 1.01, p > .05$. These findings indicate that a decrease in the potential for abuse in parents of children with developmental disabilities hospitalized for respite and short-term hospitalization was not found at discharge, and consequently was not maintained at two months following discharge. Similarly, family functioning was not found to have improved as a result of respite care at discharge, nor

was any improvement found at two months follow-up. However, due to apriori hypotheses, univariate tests were examined for possible significant differences. A significant effect was uncovered for time on the FRI for the short-term hospitalization group, $F(1, 21) = 3.21, p \leq .05$. Pairwise comparisons among the means for Time 1, 2, and 3 revealed a significant difference between discharge and 2 month follow-up for FRI scores, $t = 2.33, p < .03$. This finding suggests that family functioning decreased significantly between the time of child discharge and two month follow-up. Further, the MANOVA revealed that, as a function of respite or short-term hospitalization, abuse potential did not decrease as family functioning improves.

Exploratory Analyses

As previously stated, there is a growing emphasis placed upon the importance of services for children with developmental disabilities and their families. However, there remains a need for an increase in literature investigating the impact of services upon this particular population. Because of this need, additional exploratory questions were included in the analyses.

1. *Is abuse potential related to type of disability?*

One-way analyses of variance (ANOVA) were conducted to examine the relationship between type of disability and CAPI scores at admission for respite, short-term hospitalization and both treatment groups combined. The results for respite, $F(1, 14) = .010, p > .05$, short-term hospitalization, $F(1, 19) = .007, p > .05$, and combined groups, $F(1, 35) = .026, p > .05$, revealed a nonsignificant relationship, thus indicating that abuse potential appeared to be independent of type of disability.

2. *Is abuse potential related to the level of the child's functional ability?*

Pearson's product-moment correlations were conducted for subjects in the respite group, the short-term hospitalization group, then both groups combined using abuse potential scores at admission (CAPI-a) and ratings of the child's functional ability as assessed by treatment team members (FAS-T) and parents (FAS-P) at admission. Results indicated a nonsignificant relationship with respite for both FAS-T scores ($r = -.067$, $p = .79$) and FAS-P scores ($r = -.024$, $p = .92$). The same nonsignificant relationship was found with short-term hospitalization for FAS-T scores ($r = .190$, $p = .36$) and FAS-P scores ($r = .243$, $p = .24$) as well as for FAS-T scores ($r = .09$, $p = .57$) and FAS-P scores ($r = .126$, $p = .42$) with groups combined.

3. *Is parenting stress associated with the potential for abuse?*

Pearson's product-moment correlations were also conducted to assess the relationship between parenting stress (PSI) and the potential for abuse (CAPI) for the three groups. Results revealed a significant association for abuse potential and stress for respite, $r = .689$, $p = .01$, short-term hospitalization, $r = .441$, $p = .03$, and combined groups, $r = .542$, $p = .01$. The results indicated that higher potential for abuse is associated with increased levels of parenting stress.

4. *How does parents' psychological distress relate to family functioning?*

Pearson's correlations were conducted to examine the relationship between parent's psychological distress (GSI-a) and family functioning (FRI-a). Results indicated a nonsignificant relationship between caregiver psychological distress and family functioning, for respite, $r = -.118$, $p = .640$, short-term hospitalization, $r = -.092$, $p = .669$, and combined groups, $r = -.185$, $p = .204$.

5. *Is family functioning predictive of parental psychological distress?*

A hierarchical multiple regression was then conducted to examine the contribution of demographic and illness parameters, child's functional ability, and family functioning to parental psychological distress (Table 6). Entry of the variables for the regression was based upon Thompson's (1985) Transactional stress and coping model. Demographic parameters (age of child, SES) were entered simultaneously on Step 1; illness related variables (FAS-T, illness duration) were entered on Step 2, while family functioning (FRI) was entered on Step 3. Forced entry was utilized on each of the three steps.

Table 6.

Hierarchical Multiple Regression of Time 1 Psychological Distress for Parents

Step	Predictor Variable	b	R ²	R ² Change	F-change
Criterion Variable: GSI (Time 1)					
1	Child's Age	-.125	.104	.104	1.67
	Gender	.122			
	SES	-.262			
2	Illness Duration	.090	.111	.007	.160
	FAS-T (Time 1)	.088			
3	FRI (Time 1)	-.174	.139	.028	1.29

Note: Measures: GSI = Global Symptom Index of the Brief Symptom Inventory
 FAS – T = Functional Ability Scale – Team
 FRI = Family Relations Inventory

Demographic variables were not significant predictors of parental psychological distress, R^2 change = .104, $p > .050$. Additionally, the variables of illness duration and FAS-T were not significant, R^2 change = .007, $p > .05$. Further, family functioning failed to significantly contribute to the prediction of parental psychological distress at Time 1, R^2 change = .028, $p > .05$.

Additional Post Hoc Analyses

An exploratory repeated measures analysis of variance (MANOVA) was conducted to determine the effect of time on the exploratory dependent measures (GSI, PSI, FAS-P) for respite, short-term hospitalization, and combined groups. Results yielded a significant interaction for Time on these measures for short-term hospitalization, $F(6, 15) = 3.18$, $p < .05$, and combined groups, $F(6, 30) = 4.93$, $p < .01$. Results approached significance for respite care, $F(6, 9) = 2.56$, $p = .09$. Examination of univariate F tests revealed a significant main effect of Time on the GSI for respite, $F(2, 28) = 5.73$, $p < .05$, short-term hospitalization, $F(2, 40) = 6.12$, $p < .01$, and combined groups, $F(1, 35) = 10.33$, $p < .01$. Means comparisons revealed significant differences between GSI scores for respite at Time 1 and Time 3, $t(14) = 4.23$, $p = .001$, for short-term hospitalization at Time 1 and Time 2, $t(23) = 2.21$, $p = .04$, and at Time 1 and Time 3, $t(21) = 2.86$, $p = .009$, and for combined groups at Time 1 and Time 2, $t(41) = 2.81$, $p = .007$, and at Time 1 and Time 3, $t(36) = 4.30$, $p = .000$. These findings suggest that respite care and short-term hospitalization may alleviate parents' psychological distress at discharge and up to two months following those services, despite the fact that CAPI scores did not change.

Further, an additional hierarchical multiple regression was conducted to examine the contribution of demographic and illness parameters, child's functional ability, and family functioning to the potential for child abuse (see Table 7). CAPI scores at Time 1 were utilized for this analysis. Entry of the variables for the regression was again based upon Thompson's (1985) Transactional stress and coping model. Demographic parameters (age of child, SES) were entered simultaneously on Step 1; illness related variables (FAS-T, illness duration) were entered on Step 2, while family functioning (FRI at Time 1) was entered on Step 3. Forced entry was utilized on each of the three steps.

Table 7.

Hierarchical Multiple Regression of Time 1 Child Abuse Potential

Step	Predictor Variable	b	R ²	R ² Change	F-change
Criterion Variable: CAPI (Time 1)					
1	Child's Age	.034	.038	.038	.518
	Gender	-.034			
	SES	-.180			
2	Illness Duration	-.104	.059	.021	.409
	FAS-T (Time 1)	.098			
3	FRI (Time 1)	-.460	.259	.200	9.72

Note: Measures: CAPI = Child Abuse Potential Inventory
 FAS – T = Functional Ability Scale – Team
 FRI = Family Relations Inventory.

Demographic variables were not significant predictors of abuse potential (R^2 change = .038, $p > .050$). Additionally, the variables of illness duration and FAS-T were not significant (R^2 change = .021, $p > .05$). However, family functioning did significantly contribute to the prediction of the potential for child abuse (R^2 change = .200, $p < .01$) at Time 1. Examination of the beta weights showed that improved family functioning was associated with decreased levels of abuse potential by caregivers.

CHAPTER VI

DISCUSSION

The current study sought to examine the effects of two forms of respite services for families of children with developmental disabilities on the potential for abuse and family functioning. More specifically, this study focused on determining whether: 1) the potential for abuse is decreased in parents of children with developmental disabilities who are admitted for respite care and short-term hospitalization, 2) if abuse potential is decreased, whether parents maintain decreased levels of abuse potential at 2 months following discharge, 3) whether family functioning improves after admission for respite care or short-term hospitalization, 4) if family functioning does improve, whether parents maintain improved family functioning at 2 months following discharge, and 5) whether abuse potential decreases as family functioning improves.

Further, exploratory questions sought to examine 1) the relationship between abuse potential and type of disability, 2) the relationship between abuse potential and child's level of functional ability, 3) the relationship between abuse potential and parenting stress; 4) the relationship between family functioning and psychological distress; and 5) the influence of family functioning on psychological distress.

The effects of respite care and short-term hospitalization on the potential for abuse and on family functioning were examined over time in order to investigate whether treatment effectively decreased abuse potential and increased family functioning.

Significant reductions in abuse potential were not found as a result of either respite care or short-term hospitalization. However, although not significant, the data did show small trends toward the reduction of abuse potential for both respite care and short-term hospitalization. Although the literature is consistent in showing that reductions in stress can translate into reductions in child abuse, there are far fewer studies showing that the effects of respite services on the reduction of parental stress translates into a reduction of abuse potential (Larkin & Hopcroft, 1993; Rimmerman, 1989; Subramanian, 1985). Such findings may be explained by the amount of relief experienced by parents as a result of respite services. Although respite may account for a reduction of parental stress in several areas, not all sources of stress may be influenced (Subramanian, 1985). Thus, parents receiving respite services may continue to experience a level of stress that maintains a heightened level of abuse potential.

The absence of a decrease in abuse potential may also be the result of the influence of previous respite care. Approximately three-quarters of the respite care group, and approximately half of the short-term hospitalization group, reported previous care at the J. D. McCarty Center. As literature has shown that respite care can indeed diminish the likelihood of child abuse, and with the majority of the study sample having received past respite care, the cumulative effects may have served as a preventative measure for the potential abuse of the child (Subramanian, 1985).

Further, overall improvements in family functioning were not found for either respite care or short-term hospitalization groups. No identifiable trends were noted within the data. Notably, some studies have indeed found respite services to have a “maintenance” effect upon family functioning. This suggests that respite services may

not only play a role in sustaining family functioning but also possibly prevent deterioration of functioning. The literature also suggests that families with lower levels of conflict and higher levels of organization can agree on the use of respite services, reduce family tensions, promote family development, and enhance the likelihood of future respite use, thus maintaining the level of family functioning (Halpern, 1985). However, other studies indicate that families utilizing respite services experience alleviation of family stress and improvement of family functioning (Bruns & Burchard, 2000; Cavanagh & Ashman, 1985; Folden & Coffman, 1993; Halpern, 1985). Thus, further research is necessary to clarify the relationship of respite to family functioning.

Interestingly, a significant decrease in family functioning was found for the short-term hospitalization group between discharge and two-month follow-up. This decrease in family functioning for the short-term hospitalization group, and not for the respite group, may be related to the length of inpatient care and factors that precipitated hospitalization. Indeed, the average duration of short-term hospitalization in this study was 54 days, six times longer than the average nine-day service for respite care. Thus, the admission into short-term hospitalization and length of care may be indicative of the child's greater need for services during inpatient care. Once placed back in the home, these needs may increase family stress, stretch resources, and thus may have a negative impact on family functioning after discharge.

Interestingly, Bruns and Burchard (2000) found that an increase in the number of hours of respite services was associated with a decrease in parental stress, enhanced family functioning, and an overall improvement in family outcome. Such results suggest that lengthening services provided through respite care and short-term hospitalization and

increasing parents' personal time may be beneficial in the significant reduction of abuse potential and other indicators of family stress. Families caring for a child with developmental disabilities may also experience multiple levels or areas of stress. These stressors may only be marginally addressed with the current level of respite services, while extensions of these services may more adequately capture the true needs of families.

To further examine the possible predictors of parental psychological distress, a hierarchical regression analysis was conducted to examine the relative contribution of demographic variables, illness parameters, and family functioning to a measure of psychological distress. The model was constructed to determine the parents' psychological distress variance accounted for by family functioning over and above the contribution of demographic variables and illness parameters.

Using parents' self-reported levels of general psychological distress as the criterion measure, family functioning was not found to be a significant predictor of psychological distress. These findings are consistent with previous research suggesting that parental psychological distress may be more related to concerns with caretaking and negative views of the child's limitations rather than family functioning per se (Dyson, 1991). Results support the idea that families with a child with developmental disabilities may respond with resilience and adaptive coping in spite of high levels of distress. Failla and Jones (1991) suggest that adaptive coping despite increased distress may be attributable to family hardiness, a constellation of beliefs characterized by control, commitment, and challenge, that allows family members a higher perception of efficacy over life events rather than feeling controlled by them. Further studies show that

psychological effects on parents of a child diagnosed with a chronic illness tend to diminish over time while the effects on family functioning tend to remain more stable (Northam, Anderson, Adler, Werther, & Warne, 1996). This stable family functioning, regardless of the impact of stress due to the child's functioning, suggests high adaptability and a style of approaching the child's limitations as a challenge rather than a hardship (Sawyer, 1992). Thus, further research is needed to clarify the resilience of family functioning in the presence of familial stressors.

As mentioned previously, a significant decrease in parental psychological distress was found over time as a result of both respite care and short-term hospitalization. These findings indicate that services for children with developmental disabilities indeed have a positive effect upon parents' psychological distress and significantly decrease these reported symptoms up to two months after services are terminated. One study suggested that the utilization of respite services is an indicator of psychological distress of the caregiver and that this distress is directly related to the child's disability (Hoare, Harris, Jackson, & Kerley, 1998). This indicates that the use of respite services suggests the presence of elevated parental psychological distress before treatment and that such distress may drive the need for respite. Other research supports these findings, with consistent reports of respite services significantly reducing parental psychological distress (Bruns & Burchard, 2000; Caradoc-Davies & Harvey, 1995; Larkin & Hopcroft, 1993). Such findings are underscored by the finding that reductions in the number of participants meeting caseness criteria, a measure of clinically significant psychological distress, was noted for respite care. Interestingly, the reduction in parents meeting caseness criteria approached significance when comparing psychological distress at

admission to distress at 2month follow-up. Collectively, these results gives further support to the effectiveness of respite services.

To examine the possible predictors of child abuse potential, an exploratory hierarchical regression analysis was conducted to examine the relative contribution of demographic variables, illness parameters, and family functioning to abuse potential. The model was constructed to determine the parental risk for child abuse variance accounted for by family functioning over and above the contribution of demographic variables and illness parameters.

Using parents' self-reported levels of abuse potential as the criterion measure, family functioning was found to be a significant predictor of abuse potential. These findings are consistent with studies showing that current levels of family functioning are associated with the potential for child abuse (Milner, 1994). Moos and Moos (1986) determined that family conflict, a dimension of family functioning, has the strongest positive relationship with CAPI abuse scores while family cohesion and expressiveness have the strongest inverse relationship. Notably, studies have also showed that families at increased risk for abuse tend to score lower on cohesion and expressiveness and higher on family conflict (Mollerstrom et al., 1992). Additional research suggests that when cognitive deficits and inadequate communication skills by the child are paired with parenting stress and psychopathology, family conflict is higher than for normal families and the potential for child abuse increases (Ammerman & Patz, 1996). Thus, the prediction of abuse potential by family functioning may be influenced by many factors and deserves further investigation.

Notably, significant relationships were not found between abuse potential and type of child's disability. Further, abuse potential was not significantly related to level of child's functional ability as perceived by either the parents or treatment team members. These findings are in accord with literature that suggests abuse potential is more closely related to other risk factors besides type of disability, including child aggressiveness, externalized child behavior problems, psychological dysfunction among parents and children, family conflict, lack of social support, and substance use (Ammerman, Kolko, Kirisci, Blackson, & Dawes, 1999; Kolko et al., 1993; Milner, 1994). Further, studies have shown that the presence of a disability is not a significant predictor of child abuse once parent and child factors are taken into account (Ammerman & Patz, 1996). However, the number of studies focusing on developmental disabilities and the risk for child abuse remain few. Previous research supports the connection between disabilities in general and abuse, with disabled children representing a disproportionately high number of victims of abuse. Such data highlights the need for further investigation in this area.

Consistent with other research, the potential for child abuse and parenting stress were found to be significantly related for both respite care and short-term hospitalization groups (Subramanian, 1985). A number of studies have broken these two factors down into component elements in order to identify more specific contributors to parenting stress and child abuse. These contributors include low socioeconomic status, lack of social support, single-parent household, inappropriate parenting strategies, and psychological distress (Ammerman et al., 1998, Burrell, Thompson, & Sexton, 1994; & Milner, 1994). Other child characteristics that contribute to parenting stress and the

potential for child abuse include impulsivity, poor attachment history, developmental disabilities, and both behavioral and emotional problems (Kolko et al., 1993). The relationship between parent and child factors is particularly relevant for families with a child with a developmental disability due to their disproportionate representation among the population of abused children. Further investigation is needed to identify precursors to abuse, including parent-child interaction processes, marital dysfunction, and deficits in social and community resources (Kolko et al., 1993).

Although the present study supports further investigation into the impact of respite services upon families with a child with developmental disabilities, several limitations must be considered. First, the current sample size was relatively small and included two specified types of respite care. In order to minimize the possibility of Type II errors and the threat to the external validity, an increased sample size would be preferred. Further, the study of these services was restricted to one center for developmental disabilities in a Midwestern city. Consequently, the extent to which these results are applicable to the general population is uncertain.

A second limitation of this study was that a healthy control group was not included. Acquiring information on families with healthy children having similar demographics (gender, SES) may either broaden or limit the applicability of the results found in the current study. The information provided from matched control families may help to identify whether family functioning, resilience, and adaptation to stressors is generalizable to the population as a whole or a characteristic of families coping with a disability.

A third limitation of this study was the use of data gathered from only one family member. Results may have been biased by the primary caregiver's expectation of a positive impact of respite care or personal characteristics that color responses to research measures (Botuck & Winsberg, 1991). Additional insight into family functioning may be gained by measuring responses from several family members. This strategy may also give further information as to the pervasiveness and extent of the effects of respite care and short-term hospitalization.

A final limitation of this study is the use of self-report methodology. Self-report measures can introduce recall bias and other methodological problems. In order to decrease the possibility of these problems, future studies would benefit from including contrasting measurement methods (e.g., structured interviews with parents, children, or staff, behavioral observations, and follow-up phone interviews).

Several other suggestions can be made for future research regarding the effectiveness of respite services. Further efforts should be made to examine the impact of respite services upon the utilization of alternate services (ie., child care, day-care services, support programs, mental health services, financial assistance) (Bruns & Burchard, 2000; Rimmerman et al., 1989). Investigations showing the cost-offset utility of respite services may increase the utilization of such programs, enhance incentives for the development of more comprehensive services, increase the availability of services for families in need, and reduce the usage of alternative services that may not adequately address the needs of families. Future research may also seek to examine or control the availability and usage of additional health related services while utilizing respite services. This approach may minimize threats to internal validity and help clarify the role of

respite services for families of children with developmental disabilities. Alternate services may impact the results of respite by either magnifying or altering its effects, thus creating difficulties with the interpretation and generalizability of results.

Additionally, investigations should examine the components of respite programs that are deemed most beneficial by families using these programs. With the multitude of treatment modalities and services that can be included in these programs, efforts should be made to incorporate and increase the aspects that provide the greatest relief. Studies indicate that increases in access, scheduling flexibility, financial assistance and mental health services are some of the components of respite that families frequently request (Rimmerman et al., 1989). Enhancing these aspects of respite programs may provide caregivers with an increased sense of support and may positively impact parental stress due to availability and access to such resources.

Lastly, more longitudinal investigations of the effects of respite services are clearly needed. As stated previously, there is a paucity of research examining the impact of respite programs upon families caring for children with a developmental disability over time. Longitudinal studies should be conducted in order to identify the extended effects of these services upon child and family functioning, stress, and abuse potential as well as additional, yet to be identified factors that may be effectively changed by respite care. Additionally, research should investigate the possibilities of specific stress interventions for parents while their children receive respite services. Furthermore, a longitudinal design is required to identify the possibilities of an optimal duration of care in order to maximize the benefits of services without creating excessive utilization of these services.

In summary, although this research provided practical information about the impact of respite care and short-term hospitalization on families caring for a child with developmental disabilities, it is clear that research on respite services is sparse and requires more methodologically sound, longitudinal studies. Despite the expansion of respite programs, there remains a lack of methodologically sound research focusing on the outcome of respite services and the variables that might influence its efficacy (Bruns & Burchard, 2000). Although information has been gathered regarding respite and stress, distress, and social isolation, further research is needed to investigate additional factors associated with the enhancement of positive outcomes or that promote negative results, especially as it concerns child abuse potential.

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APPENDIXES

APPENDIX A

DEMOGRAPHICS

Background Information

Today's Date _____

Subject No. _____

1. Child's Name: _____ Age: _____ DOB: _____ SS#: _____

2. Mother's Name: _____ Age: _____ DOB: _____ SS#: _____

3. Father's Name: _____ Age: _____ DOB: _____ SS#: _____

4. Name of person filling out this form and relationship to child (e.g., mother):

5. Who currently lives in the household with you and your child? Please note their relationship to the child and age (e.g., brother-15 months, stepparent - 36 yrs old).

Name	Relation to child	Age
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

6. Telephone number: _____

7. Child's Gender: Male Female
 1 2

8. Child's Race: Caucasian African-American Hispanic Native American
 1 2 3 4

 Asian American Other
 5 _____

9. Child's Grade _____

10. Is your child in Special Education Yes _____ No _____

If yes, what type of placement? _____

11. Parents' Marital Status: Married 1 Single Parent 2 Remarried 3 Never Married 4 Other 5

12. Parents' Occupations: Father _____ Mother _____

13. Parents' Highest Level of Education: Father _____
Mother _____

14. Please indicate your total family income for this last year:

(This information will be held strictly confidential).

_____ 0-4,999	_____ 30,000-39,999
_____ 5,000-9,999	_____ 40,000-49,999
_____ 10,000-14,999	_____ 50,000-59,000
_____ 15,000-19,999	_____ 60,000 or more
_____ 20,000-29,999	

15. Has your child received previous respite care?: Yes _____ No _____

16. Has your child been previously evaluated at the J. D. McCarty Center?:
Yes _____ No _____

17. How long has your child had their chronic illness? _____

18. At what age was your child diagnosed with their illness? _____

19. What is your child's primary diagnosis? _____
(For example, cerebral palsy)

20. Please indicate the type of insurance you currently have for your child:

_____ Private Insurance
_____ HMO/PDD
_____ Medicaid
_____ Self Pay
_____ Other (please indicate) _____

APPENDIX B

FUNCTIONAL ABILITIES SCALE - PARENT

Child's Name _____

Date _____

Your Name _____

Subject # _____

Your Occupation _____

FAS-P

We would like to ask you some questions about your child's ability to perform certain activities, such as eating, dressing, and going to school (if applicable). We want to know how well he/she has been able to do things by him/herself during the past week.

	All the Time	Sometimes	Almost Never
1. Take his/her shirt off	_____	_____	_____
2. Button his/her shirt	_____	_____	_____
3. Pull on a shirt/sweater over his/her head	_____	_____	_____
4. Turn on a water faucet	_____	_____	_____
5. Sit on the floor, then stand up	_____	_____	_____
6. Dry his/her back with a towel	_____	_____	_____
7. Wash his/her face with a washcloth	_____	_____	_____
8. Tie his/her shoelaces	_____	_____	_____
9. Pull on his/her socks	_____	_____	_____
10. Brush his/her teeth	_____	_____	_____
11. Stand up from a chair without using his/her arms	_____	_____	_____
12. Get into bed	_____	_____	_____
13. Cut his/her food with a knife and fork	_____	_____	_____

	All the Time	Sometimes	Almost Never
14. Lift an empty glass to his/her mouth	_____	_____	_____
15. Reopen a previously opened food jar	_____	_____	_____
16. Walk 50 feet without help	_____	_____	_____
17. Walk up 5 steps	_____	_____	_____
18. Stand up on his/her tiptoes	_____	_____	_____
19. Reach above his/her head	_____	_____	_____
20. Get out of bed	_____	_____	_____
21. Pick up something off the floor from a standing position	_____	_____	_____
22. Push open a door after turning the knob	_____	_____	_____
23. Turn his/her head and look over his/her shoulder	_____	_____	_____

APPENDIX C

FUNCTIONAL ABILITY SCALE – TEAM

Child's Name _____

Date _____

Your Name _____

Subject # _____

Your Occupation _____

ADM / DISCH

FAS-T

We would like to ask you some questions about the above named child's ability to perform certain activities, such as eating, dressing, and going to school (if applicable). We want to know how well he/she has been able to do things by him/herself during the past week.

	All the Time	Sometimes	Almost Never
1. Take his/her shirt off	_____	_____	_____
2. Button his/her shirt	_____	_____	_____
3. Pull on a shirt/sweater over his/her head	_____	_____	_____
4. Turn on a water faucet	_____	_____	_____
5. Sit on the floor, then stand up	_____	_____	_____
6. Dry his/her back with a towel	_____	_____	_____
7. Wash his/her face with a washcloth	_____	_____	_____
8. Tie his/her shoelaces	_____	_____	_____
9. Pull on his/her socks	_____	_____	_____
10. Brush his/her teeth	_____	_____	_____
11. Stand up from a chair without using his/her arms	_____	_____	_____
12. Get into bed	_____	_____	_____
13. Cut his/her food with a knife and fork	_____	_____	_____
14. Lift an empty glass to his/her mouth	_____	_____	_____

- | | | | |
|---|-------|-------|-------|
| 15. Reopen a previously opened food jar | _____ | _____ | _____ |
| 16. Walk 50 feet without help | _____ | _____ | _____ |
| 17. Walk up 5 steps | _____ | _____ | _____ |
| 18. Stand up on his/her tiptoes | _____ | _____ | _____ |
| 19. Reach above his/her head | _____ | _____ | _____ |
| 20. Get out of bed | _____ | _____ | _____ |
| 21. Pick up something off the floor from
a standing position | _____ | _____ | _____ |
| 22. Push open a door after turning the knob | _____ | _____ | _____ |
| 23. Turn his/her head and look over
his/her shoulder | _____ | _____ | _____ |

APPENDIX D

IRB APPROVAL FORM

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD

DATE: 04-23-97

IRB #: AS-97-063

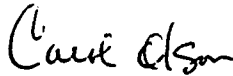
Proposal Title: THE INFLUENCE OF HOSPITALIZATION OF CHILDREN
WITH CEREBRAL PALSY ON PARENTAL STRESS, ADJUSTMENT AND
HEALTH CARE UTILIZATION-A PROSPECTIVE STUDY

Principal Investigator(s): Larry L. Mullins, Karen M. Aniol

Reviewed and Processed as: Continuation

Approval Status Recommended by Reviewer(s): Approved

Signature:



Date: November 12, 1998

Carol Olson, Director of University Research Compliance
cc: Karen Aniol

Approvals are valid for one calendar year, after which time a request for continuation must be submitted. Any modification to the research project approved by the IRB must be submitted for approval. Approved projects are subject to monitoring by the IRB. Expedited and exempt projects may be reviewed by the full Institutional Review Board.

VITA 

Karen M. Aniol

Candidate for the Degree of

Doctor of Philosophy

Dissertation: EFFECTS OF RESPITE CARE ON THE POTENTIAL FOR ABUSE
AND FAMILY FUNCTIONING

Major Field: Psychology

Biographical:

Personal Data: Born in Columbia, Missouri on March 22, 1972, the daughter of Larry and Jo Ann Aniol.

Education: Received Bachelor of Arts degree in Psychology from Baylor University, Waco, Texas in August 1994. Received Master of Science degree with a major in Clinical Psychology at Oklahoma State University in May, 1998. Completed the requirements for the Doctor of Philosophy degree at Oklahoma State University in July, 2000.

Experience: Completing internship at the University of California, San Diego.

Professional Memberships: American Psychological Association, Association for the Advancement of Behavior Therapy.