# Attachment relationships between Children with Physical Disabilities and Their Caregivers

## Anna Nedelisky The New School University

Past research has empirically linked the experience of raising a disabled child to high levels of parental stress, depression, social isolation, psychological maladjustment, and child maltreatment. Findings from this research indicate that the cumulative influence of these factors may significantly affect the child-caregiver attachment relationship. Likewise, exposure to medical intervention, repeated hospitalizations, onerous care-giving responsibilities, and extensive financial outlays has also been found to constitute a source of stress for the caregivers of a child with a physical disability. A consequence of this stress is that attachment relations may, in some instances, be adversely affected. The effects of childhood physical disability on the child-caregiver attachment relationship will be further explored in this review of the literature.

A series of behaviors used to achieve and maintain proximity to a caregiver in infancy signifies the formation of an attachment relationship (Bowlby, 1969). Yet, the implications of this early relationship experience appear to extend far beyond these first years of life, in that the attachment relationship may also serve to teach the child how to interpret and interact with the world in general (Bowlby, 1969).

The attachment relationship established between a child with a physical disability and his or her caregiver may be impacted by the presence of a disability in a number of meaningful ways. Childhood physical disability has been associated with an increased vulnerability to psychological as well as social maladjustment in both the caregiver(s) and the disabled child (Lavigne et al., 1992; Miller et al., 1992; Patterson et al., 1992, Wallander et al., 1988). This phenomenon appears to have an interactive effect in that the burden of caring for a child with a physical disability seems to be correlated with the increased risk of psychological and/or social maladjustment in the caregiver (Breslau, Staruch & Mortimer, 1982; Wallander & Varni, 1998; Weigner & Donders, 2000), and the experience of being provided for by a caregiver who has a psychological or social maladjustment seems to increase the pre-existing risk that the physically disabled child may develop such a maladjustment as well (Emery & O'Leary, 1984; Orvaschel & Walsh-Allis, 1988; Turner, Beidel, & Costello, 1987). As a result, it appears evident that the presence of a child with a physical disability may have a significant effect on the well being of the individual caregiver and the child, as well as the child-caregiver attachment relationship. This paper is

Correspondence concerning this article should be addressed to Anna Nedelisky. E-mail: anedelis@aol.com.

designed to explore child-caregiver attachment relations in families in which there is a child with a physical disability.

# The Effects of Childhood Physical Disability on the Family & the Disabled Child

Roughly 41 million people in the U.S. have been estimated to have a disability (Kaye, 1998). Ten point seven percent of these disabled individuals are 18 years of age or younger and are considered "limited in their activity" (i.e. functional limitations in adults and limitations in play in children; Kaye, 1998). Children below the age of five account for two to three percent of this number (Wenger et al., 1996). A chronic physical disorder is defined as any disorder which interferes with the daily functioning of the individual for more than three months in a year, causes hospitalization lasting for more than one month in a year, or is predicted to do either at the time of diagnosis (Pless & Pinkerton, 1975). Factors, such as the severity of the physical impairment, the potential for developmental delay, and the financial and social support of the family, play a crucial role in determining how the child and his/her family adjust to the physical disability (Hendricks et al., 2000; Wiegner & Donders, 2000).

Providing the care needed by a child with a physical disability can be a burden on the family (Leonard et al., 1993; Patterson et al., 1992). For some families, providing for a disabled child may consist of care that is needed up to 24 hours a day, seven days a week, for years on end. The chronic burden of caring for a child with a physical disability can lead to a depletion of caregiver time and energy, disruptions to family life due to multiple visits to medical facilities, constant anxiety in relation to financial problems and the future of the disabled child, as well as feelings of guilt and isolation (Breslau, Staruch, & Mortimer, 1982). Studies investigating the relationship between family ad-

justment and the presence of a child with a physical disability have also reported elevated levels of depression in parents of disabled children (Breslau, Staruch, & Mortimer, 1982; Canning, Harris, & Kelleher, 1996; Jessop, Riessman, & Stein, 1988). Likewise, parents of a child with a physical disability experience higher levels of stress than parents of a non-disabled child (Hendricks et al., 2000; Patterson et al., 1992; Leonard et al., 1993). The impact of this stress may be mediated by the methods the family develops for allocating responsibility for care within the home, the parent's pre-morbid psychological adjustment, or current degree of social support (Wiegner & Donders, 2000).

Reviews investigating the adverse effects of childhood physical disability have confirmed that children who have a chronic physical disability are twice as likely to develop a secondary emotional disorder than physically healthy children (Eiser, 1990; Pless & Nolan, 1991). A predictive association between parental depression, anxiety, and marital discord on child maladjustment has been demonstrated in research on physically healthy children (Emery & O'Leary, 1984; Orvaschel & Walsh-Allis, 1988; Turner & Beidel, & Costello, 1987; Varni & Setoguchi, 1993). When the established risk of psychological maladjustment in parents of physically disabled children is taken into account (Breslau, Staruch & Mortimer, 1982; Wallander & Varni, 1998; Weigner & Donders, 2000), it is reasonable to suggest that children with a physical disability may have an even greater risk of becoming maladjusted.

Varni and Setoguchi (1993) found that social support appears to mediate the relationship between psychological maladjustment and healthy adjustment in physically disabled children. Family support and perceived social support (as in the cognitive appraisal that one is cared for and valued and that significant others are available to them if they are needed [Heller, Swindle, Dusenburg, 1986]) from parents, classmates, teachers, and friends were all found to be significant factors in the positive adaptation of children with physical disabilities (Varni & Setoguchi, 1993). Furthermore, Varni and colleagues (1991) recommend that teaching social skills (such as conversation and friendshipmaking skills, as well as teaching how to handle teasing and name-calling) may serve as an intervention against the development of maladjustment in children who are disabled.

### **Attachment Theory**

Attachment behavior, according to Bowlby (1969, p. 371), "refers to any of the various forms of behavior that a child commonly engages in to attain and/or maintain a desired proximity." These behaviors can include smiling, looking, vocalizing, following, or clinging. Ainsworth (1967) suggested that greeting behaviors, gazing, and exploration are also attachment behaviors. Bowlby (1969) viewed the attachment between the child and the caregiver as a reciprocal phenomenon in which both parties must emit and accurately respond to the other's signals and cues. The way in which parents respond to their infant's signals de-

termines to a large degree the quality of the child-caregiver attachment relationship (Isabella & Belsky, 1991). The influence of the attachment relationship is thought to extend beyond infancy and, in essence, acts as a foundation upon which the individual learns to relate to others as well as to the world in general (Bowlby, 1969).

# Implications of a Physical Disability in Child-hood on the Child-Caregiver Attachment Relationship

# Attachment and the Communication/Interpretation of Cues

Disabled children, in many instances, are unable to send unambiguous cues or to respond to the caregiver in a clear manner (Osofsky, 1976). A sense of constant fear or distress, depression and emotional numbing are common reactions to persistent illness and disability (Cox & Lambrenos, 1992). The communication of fear and distress are infant attachment behaviors that precede the emergence of the attachment relationship (Cox & Lambrenos, 1992). In a review of the literature on childhood physical disability and child-caregiver attachment. Cox and Lambrenos (1992) found that social and emotional communication may develop in such a way that the caregiver has a great deal of difficulty in understanding the child's meaning and, therefore, in alleviating the child's distress. As a result of the physical disability, the child's emotions may be expressed in such a way that the caregiver has difficulty registering or interpreting them. "It may be presumed," suggest Cox and Lambrenos (1992, p. 1040), "that the quality of an attachment relationship may be impaired if physical disabilities interfere with child attachment behaviors or with relevant parent-child interactions that precede their appearance."

Just as the caregiver may have difficulty interpreting a disabled child's cues and signals, a child with a physical disability may also have difficulty interpreting the caregiver's actions (Cox & Lambrenos, 1992). The child may subsequently fail or be delayed in learning to associate feelings with certain expressions and may, therefore, be less capable of either regulating or expressing his/her own affective state. The disabled child may also be less physically able to orient him/herself in close proximity to the caregiver, which traditionally facilitates a greater sense of security in the child (Cox & Lambrenos, 1992). A child who feels distant from the caregiver may in turn come to feel abandoned by the caregiver, which could further serve to complicate the attachment process.

#### Attachment and Hospitalization

Young children, regardless of physical disability, require continuous and sensitive care-taking experiences in order to develop a sense of trust in the people around them (Minde, 2000). In a hospital, however, a young child's

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need to be assured of continual and sensitive care is repeatedly violated. A study by Minde and colleagues (1980) reported that infants who were hospitalized for an average of 49 days were cared for by an average of 72 different nurses. The over-stimulation and consistent change evident in the lives of these young, hospitalized children clearly illustrates the difficulty they face in securing any sense of solidarity or trust in their surroundings. The experience of prolonged hospitalization in childhood may subsequently be found to affect a child's capacity to form healthy attachments.

Similar to Bowlby (1959), Douglas (1975) and Quinton and Rutter (1976) found that repeated hospitalizations may be associated with an indefinite separation from the child's caregivers and may be very traumatic and stressful experiences. Unfortunately, some children seem to be given reason to fear that the separation represented by their stay in the hospital may be more extensive than it first appears. Thompson (1985) found that mothers of young infants appeared much more committed to their infants if their infants were allowed to go home for two or more weeks during the first three months of life. These findings support earlier research by Lampe, Trause and Kennell (1977) who matched 30 hospitalized infants by social class and illness and then compared the degrees to which they were visited by their parents. Lampe and colleagues (1977) found that only 16% of infants who had never been home were visited daily by their parents or caretakers, whereas 70% of those who had been home received daily visits. These findings appear to indicate that the attachment relationship is attained, to some degree, through the experience of providing complete care for the infant in the home and that this level of attachment must be achieved before the parents or caregivers can truly commit themselves to the infant (Lampe, Trause, & Kennell, 1977).

#### Attachment & Stress

Parents of disabled children experience a number of stressors (Breslau, Staruch, & Mortimer, 1982; Hendricks et al., 2000: Miller et al., 1992: Patterson et al., 1992: Leonard et al., 1993; Wiegner & Donders, 2000). The infant-mother attachment relationship and the experience of stress were assessed in a sample of 100 economically disadvantaged infants and mothers (Vaughn et al., 1979). Higher stressfulevent scores were found to be associated with a change from secure to anxious attachment at 12 and 18-month assessments (Vaughn et al., 1979). In a study of attachment and life circumstances, Thompson, Lamb, and Estes (1982) found that attachment classifications are prone to modification as conditions change in the family. The studies by Thompson and colleagues (1982) and Vaughn and colleagues (1979) were completed with non-disabled middle and lower class populations. However, given the well established association between stress and the experience of caring for a physically disabled child (Breslau et al., 1982;

Henricks et al., 2000; Leonard et al., 1993; Miller et al., 1992; Patterson et al., 1992), it seems reasonable to generalize from these findings that stress in the context of caring for a physically disabled child may result in a diminished child-caregiver attachment relationship.

This generalization seems to be supported by Crisis Theory, which posits that people who experience a great deal of stress tend to become inner focused and become less capable of attending to cues in their environment (Capuzzi, 1989). When applied to a discussion of the formation of child-caregiver attachment in the context of a childhood disability, it seems likely that the stress involved in having a disabled child may result in a decrease of caregiver sensitivity to the child's cues, which would in turn affect the caregiver's responsiveness to the child.

## The Disabled Child-Caregiver Attachment Relationship

For children with physical disabilities and non-disabled children alike, ratings of maternal sensitivity, accessibility, emotional expressivity, and acceptance during the fourth quarter of the infant's first year of life are all factors that appear to predict whether an infant will subsequently be classified as forming a secure or insecure attachment (Ainsworth et al., 1978). Though a moderate level of attentiveness and stimulation during the last few months of a child's infancy sounds like a reasonable feat to accomplish. research has shown that mothers of disabled children have a great deal more with which to contend. Rogers (1988) found that mothers of children with disabilities tend to be more active and express less positive affect than mothers of non-disabled children. Other researchers have consistently reported that, in comparison with controls, mothers of physically disabled children are more active, controlling and stimulating, and less responsive in their interactions (Tyler & Kogan, 1972; Wasserman et al., 1985). In light of the fact that maternal sensitivity and emotional responsivity have been found to be positively correlated with the formation of secure attachment in normal samples (Ainsworth et al., 1978) and that mothers of disabled children have been found to be less likely to interact with their children in this manner (Rogers, 1988; Tyler & Kogan, 1972; Wasserman et al., 1985), the apparent lack of a difference in attachment security reported by some researchers among disabled infant groups versus non-disabled infants is interesting (Cox & Lambrenos, 1992).

In a study by Wasserman, Lennon, Allen, and Shilansky (1987), the apparent lack of attachment differences between a disabled and non-disabled child population was further explored. Attachment was assessed in 46 non-disabled infants and 36 disabled infants (who were diagnosed with mostly congenital facial or orthopedic malformations). This study reported no difference in attachment security between the non-disabled and the physically disabled samples. Consistent with Ainsworth's findings

(1978), early maternal responsivity (i.e. matching or responding to the infant's bids or cues) and availability (i.e. attention directed towards the infant) were found to be associated with infant attachment security for both groups. Specifically, in both disabled and non-disabled groups, higher levels of maternal responsivity, availability, and agerelated increments of positive maternal affect (i.e. exhibiting warmth or happiness) at nine months were associated with secure infant attachment. Mothers of disabled infants were found to be lower in responsivity at nine months, higher in positive affect at 12 months, and were not found to differ in nine-month availability from the control mothers. In sum, the results of this study's comparison of attachment in disabled versus non-disabled infants found that mothers of disabled infants are no more or less likely to foster secure attachment in their infants than control mothers; they simply seem to use a different strategy for its promotion (Wasserman et al., 1987).

Building on this finding, the results of a study by Capuzzi (1989) showed that there was a significant increase in attachment in a disabled population and their mothers between one and six months and also between one and 12 months. This finding led Capuzzi (1989) to propose that the attachment relationship between the disabled infant and his/her mother is dynamic in that it adapts and develops over time. "Like any other affectional relationship," notes Vaughn and colleagues (1979, p. 975), "infant-mother attachments arise from interaction; they continue to develop even after an affective bond has formed, and they are responsive to changes in the behavior of either partner." This study by Capuzzi (1989) indicated that social support appears to buffer the negative effects of having a disabled infant on the infant-mother attachment relationship. particular, Capuzzi (1989) found that affirmative support appeared to be most important in predicting maternal attachment, though she stressed that more research into this topic is needed.

In a review of the attachment literature pertaining to children with a series of physical as well as mental and developmental disabilities, Blacher & Meyer (1983) reported that the attachment relationship between disabled children and their caregivers may be delayed or even absent. The presence of a disability in childhood, therefore, may have an adverse or detrimental effect on the quality or formation of the child-caregiver attachment relationship. Past research by Holt (1968) appears to stand in support of these findings. In collecting follow up data on a study of 30 eight to 12 year old children who had been hospitalized between two to five years of age for a variety of different illnesses, Holt (1968) found that some children failed to include their mothers in drawings of their families. The exclusion of the mother suggested to Holt (1968) that the children might have felt abandoned by their mothers during their respective hospitalizations. The fact that these drawings were made in later youth appears to indicate that the perceived maternal abandonment in early childhood may have a lasting effect on the child's attachment to his/her mother.

Other research investigating the attachment phenomenon in disabled populations has indicated that childhood disability does not defeat attachment between young disabled children and their caregiver(s), although the extent to which the disability may impair the attachment relationship is still unclear (Blacher & Meyer, 1983; Cox & Lambrenos, 1992; Capuzzi, 1989). Having previously found an apparent association between the physical manifestation of the disability, the performance of the child on intelligence measures, and maternal detachment, Wasserman, Allen and Solomon (1985) next sought to understand if there is a relationship between patterns of mothering and the maladjustments or deficits in children with physical disabilities. Fourteen disabled infants (facial and orthopedic disabilities) and their mothers, 14 premature infants (who share the deviant early experience of extended hospitalization with physically disabled infants, but have no current disabilities) and their mothers, and 14 healthy infants and their mothers were videotaped in free-play, separation, and reunion scenarios at nine, 12, 18, and 24 months. Infants with physical disabilities were found to have consistently less focused elaborated play and scored 24 months behind healthy infants in standardized measures of cognitive-linguistic functioning (Wasserman et al., 1985). Infants with physical disabilities were also found to be less likely to employ social initiatives (such as requesting interaction with his/her mother or the experimenter) and were more passive in respect to separation and exploration at the age of two years. Whereas healthy infants tended to develop increasingly positive affective expression with age (i.e. smiles, laughter, affectionate contact, and positive physical expression), infants with physical disabilities tended to decrease in positive affective expression (Wasserman et al., 1985).

Wasserman and her colleagues (1985) found that mothers of children with physical disabilities generally exerted a greater attempt to respond to the differences in their child's competence by stimulating, focusing, and using other compensatory methods than mothers of either premature or healthy children. A developmental increase in the use of encouragement, one component of which is positive reinforcement, was particularly noted in mothers of children with physical disabilities. The findings of Wasserman and colleagues (1985) suggested, however, that the sustained effort of such compensatory labors might lead to maternal burn out or even the maternal distancing effects observed in the study by Wasserman & Allen (1985).

Another factor, which may act as a potential challenge to the disabled infant-caregiver attachment relationship, is the developmental milestone marked by the age of two. As Wasserman and her colleagues have discussed in the previously reviewed studies (Wasserman & Allen, 1985; Wasserman et al., 1985), the age of two marks a pivotal time in a young child's life when increases in cognitive skill, independence, and exploration occur. Just as this age can be exciting, it can also be an extraordinarily difficult time for caregivers who have yet to recognize the full extent of their child's disability. Wasserman and Allen (1985)

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noted that children born with physical disabilities might be different behaviorally from developmentally normal children as early as their second year. These differences may not be due to their general risk status so much as mediated by the experience of early child-caregiver separation, repeated hospitalizations, or thwarted caregiver hopes (Wasserman & Allen, 1985). Whereas children with physical disabilities may not appear to differ from healthy children in attachment, play, and affective expression at one year, divergences in behavior may become evident by the age of two (Wasserman et al., 1985). Likewise, an increase in maternal ignoring may become apparent as the physically disabled child reaches the age of two (Wasserman et al., 1985). Noting that physically disabled infants, who were not especially delayed or ignored at one year, appear to experience maternal ignoring by the age of two, researchers suggested that mothers of physically disabled children may get their first sense that the child is not as lively or as active as was expected and may subsequently withdraw from the child at this age (Wasserman et al., 1985). The emergence of the physically disabled child's second year, therefore, may have profound implications for the quality of the physically disabled child-caregiver attachment relationship, as well as mark a crucial time for meaningful intervention.

### Rejection versus Attachment

In contrast to the act of forming an attachment, researchers have found that parental rejection and/or a reluctance to attach to the disabled infant may be common (Cox & Lambrenos, 1992). Attachment appears to not only play a significant role in the nurturing and growth of a child, but it may also play a role in the stability of the home and the safety of the disabled child (Blacher & Meyers, 1983). Believing that the existence as well as the quality of the attachment relationship is particularly pertinent to how parents of disabled children mediate the varied crises and agonies they experience, Blacher and Meyers (1983) suggested that attachment plays a significant role in the care of this vulnerable population:

... the quality of attachment could well relate to the early burnout of parents as care-providers, to the early inclination to place children out of the natural home, to abuse or neglect, to family accord or discord, and even to the quality of parent collaboration with service providers and school personnel. (p. 359)

Brooks-Gunn and Lewis (1982) also studied the effects of childhood physical disability on the child-caregiver attachment relationship. They found that the age-related decrease in maternal responsivity to infants' fretting and crying was much more rapid for disabled infants and their mothers than in the comparison group. Based on these findings, Brooks-Gunn and Lewis (1982) suggested that there is a correlation between decreased maternal responsivity and the description of the disabled child as "diffi-

cult." These researchers stressed that disabled infants dubbed "difficult" were not necessarily found to be any less responsive in their behavior than a comparison group, despite the fact that they were perceived as such by their mothers. Brooks-Gunn and Lewis (1982) found that by the end of the first year, mothers of disabled infants vocalized less in response to interaction sequences initiated by their infants' behavior than mothers of non-disabled children. This difference in maternal responsivity to interactions initiated by the behavior of the "difficult" disabled infant was found to persist to the end of the infants' second year (Brooks-Gunn & Lewis, 1982). In a study of ten children with cerebral palsy, Kogan and colleagues (1974) also noted a marked decline in maternal responsivity to their disabled children. Data collected at three one-year intervals (between the ages of one to four) showed a gradual decrease in maternal warmth and acceptance as the disabled child aged in comparison with an age-matched non-disabled group. Kogan and colleagues (1974) noted that a decline in maternal warmth and acceptance in the mothers of disabled children appeared to be related to the child's increasing deficit in gross motor development.

Likewise, preliminary research by Cox and Lambrenos (1992) suggests that many parents seem to "turn off" their responses to their disabled children as they discover that their children are not making the developmental progress that might be reasonably expected of them as they enter their second year of life. Major developmental markers such as a failure or a delay in the child's ability to stand, walk, or talk at certain expected ages are events which parents, who may have previously operated in denial, are now perhaps forced to read and interpret as an indicator of the child's disability (Cox & Lambrenos, 1992). Cox and Lambrenos (1992) warn that parents, who choose to "turn off" their responses to their disabled children and subsequently withdraw from them during their second year of life, could experience a serious impact on the existing childcaregiver attachment relationship (Cox & Lambrenos, 1992).

# The Disabled Child-Caregiver Attachment Relationship: A Risk Factor for Maltreatment

Research by past theorists, such as Helfer (1975), has been in accord with recent reports suggesting that a disruption in the attachment relationship does indeed appear to be a risk factor for maltreatment in a disabled child population (Brooks-Gunn & Lewis, 1982; Cox & Lambrenos, 1992). The Child Abuse Prevention and Maltreatment Act (CAPTA) defines "Maltreatment" as:

at minimum, any recent act or failure to act on the part of a parent or caretaker, which results in death, serious physical or emotional harm, sexual abuse or exploitation, or an act or failure to act which presents an imminent risk of serious harm. (42 U.S.C.A. §510g(2), 1998)

Helfer (1975) proposed that parental maltreatment of disabled children might be due to a disability-related interference affecting the bonding process between the child and the caregiver(s). Schwartz and Schwartz (1977) concurred, suggesting that poor maternal attachment may be a factor in the maltreatment of disabled children. Ainsworth (1980) proposed that influential disruptions in the formation of the infant-caregiver attachment relationship frequently occur when the infant is separated from the caregiver at or immediately after birth. Despite the fact that recent attempts to demonstrate these findings have been contradictory (Rode et al., 1981), it remains plausible that disabled children appear to run a greater risk of such separations and, as a result, attachment relationship disruptions may be more likely in this population (Holt, 1968; Lampe, Trause, & Kennell, 1977; Minde, 2000; Thompson, 1985). Recommendations

Through an extensive review of the literature, this author concludes that a unidirectional causal relationship between childhood physical disability and the quality of the child-caregiver attachment relationship is not possible to establish at this time, though it is apparent that the presence of a physical disability may constitute a risk factor to the well-being of the child-caregiver attachment relationship (Capuzzi, 1989; Cox & Lambrenos, 1992). Like any other relationship, however, the child-caregiver attachment relationship is a dynamic entity that develops over time (Capuzzi, 1989; Vaughn et al., 1979). Initiating appropriate interventions to promote the healthy development of this attachment relationship, as well as greater emphasis in the research community on the longitudinal study of the effect of physical disability on the child-caregiver attachment relationship, represent the next steps in further clarifying our understanding of the attachment phenomenon in a physically disabled child population (Cox & Lambrenos, 1992). By educating caregivers regarding issues, such as the significance of the attachment relationship to the development of the child or the beneficial attributes of social support and improved communication skills, intervention programs could make a significant contribution to the care and well being of the disabled child (Minde, 2000).

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