

**RAISING CHILDREN WHO HAVE SPINA BIFIDA OR CEREBRAL PALSY:
A COMPARISON OF MOTHERS' ACCOUNTS OF STIGMA**

by

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**A thesis submitted in conformity with the requirements
for the degree of Master of Science,
Graduate Department of Nursing Science,
University of Toronto**

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ABSTRACT

Raising Children who have Spina Bifida or Cerebral Palsy:

A Comparison of Mothers' Accounts of Stigma

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A secondary analysis of a larger study (McKeever, 1993) was undertaken to compare experiences of *stigma* described by mothers whose children had cerebral palsy ($n = 8$) or spina bifida ($n = 10$). Mothers' accounts were analyzed using Goffman's (1963) conceptualization of stigma.

Mothers described children with cerebral palsy as deviating markedly from expectations of *normal* children and those with spina bifida as less deviant. However, children with spina bifida (80%) attracted more unsolicited attention than did children with cerebral palsy (50%). Mothers used strategies such as avoidance and minimization to *cover up* discrediting attributes.

Mothers of children with cerebral palsy experienced more *courtesy stigma* in the form of devaluing and insensitive comments about themselves. They managed courtesy stigma by using humour, seeking affiliation with *considerate* individuals, dissociating from *inconsiderate* individuals and portraying a conventional family life.

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CHAPTER I

THE RESEARCH PROBLEM

Background

In Canada, the responsibility for care of children with disabilities resides within families. In most cases, mothers assume the primary responsibility for both caregiving and childrearing. Hence, they simultaneously are affected by long-term care policies and normative expectations of motherhood (Anderson, 1990; Anderson & Elfert, 1989; Folden & Coffman, 1993; McKeever, 1992; McKeever, Angus, Spalding, & Thaha 1998; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1996).

Although raising children with disabilities has many rewards (McKeever, 1992), children with severe disabilities require care that is complex, labour-intensive, and both physically and psychologically stressful (Abel & Nelson, 1990; Blum, Resnick, Nelson, & St. Germaine, 1991; Havermans & Eiser, 1991; McKeever, 1992; Ray & Ritchie, 1993). Responsibilities can include the physical care requirements of feeding, toileting, bathing, and lifting; the highly skilled care requirements of physical assessment, therapeutic interventions, clinical decision making, and care coordination; and the emotional care requirements of play and comfort (Anderson & Elfert, 1989; Brust, Leonard, & Sielaff, 1992; Deatrick, Knafl, & Walsh, 1988; Ray & Ritchie, 1993).

Mothers find devaluing judgments expressed by others, including those of health care professionals toward their children with disabilities, particularly distressing and stressful (Baxter, 1989; Leyser & Dekel, 1991; McKeever, Angus, Spalding, & Thala, 1998; Stewart et al., 1996). The negative relationships that can ensue between health care

professionals and parents represent barriers to receiving and accessing appropriate health care (Baxter, 1989a; Knafl, Breitmayer, Gallo, & Zoeller, 1992; Stewart et al., 1996).

McKeever (1993) explored the daily activities, subjective experiences, and life circumstances of mothers of children with severe disabilities. Many of the findings of this study reflected society's deep ambivalence toward these children. This ambivalence may have reflected the contemporary Western belief that the primary purpose of mothering is to raise healthy, well-adjusted children to be productive adult citizens. Ambivalence was reflected in the words and deeds of relatives, friends, professionals, and strangers. Ambivalence was also inherent in the policies and programs affecting these mothers and their children (McKeever, Angus, Spalding, Thaha, 1997).

According to many sociologists, discriminating attitudes and behaviours toward adults and children with disabilities are embedded in social values and expectations, which serve as schema through which meanings of disability are constructed (Goffman, 1963; Phillips, 1990; Stone, 1995; Susman, 1994; Zola, 1993). A dominant ideology of the *wrongness* of the disabled body underlies models of care and linguistic diagnostic labels that indicate devalued social status (Goldin, 1990; Phillips, 1990; Zola, 1993). This view is not surprising considering the current cultural emphasis placed on bodily perfection, beauty, and self-sufficiency (Phillips, 1990; Stone, 1995; Strauss & Broder, 1991), which implies that *normal* people should strive to meet these attributes (Davis, 1997b). Individuals who do not possess normative attributes are considered deviants or as analogous to *damaged goods* (Davis, 1997b; Phillips, 1990). Discriminatory social attitudes are held toward people not only in relation to the norm, but also in relation to how far they deviate from the norm (Davis, 1997b). Most images of people with disabilities in the media include only physically attractive, strong-willed, and cognitively

normal individuals (Phillips, 1990; Stone, 1995). Phillips (1990) indicates that although ideology homogenizes people with disabilities, there are hierarchies within and among these populations. More recently, the portrayal of individuals with physical disabilities and the absence of individuals with cognitive disabilities reflect hierarchical discrimination within and among populations with disabilities. Those individuals with cognitive disabilities deviate further from the ideal citizen than do other groups of people with disabilities; as a result, this group is not found in public images portraying people with disabilities. These differences between and among populations with disabilities and the hierarchical social attitudes and actions conveyed toward these groups perpetuate the ideology that *some goods are more damaged than others* (Phillips, 1990).

Gething (1992) argues that health professionals participate in the construction of normative assumptions about motherhood and disability against which mothers of children with disabilities are judged and their social positions are determined. Although anecdotal evidence reveals a hierarchical relationship in the degree of social stigma experienced by different groups of individuals with disabilities, no research has been conducted that addresses the issue as it pertains to children with only physical disabilities and to children with both physical and cognitive disabilities. Moreover, only a few investigators have explored the social position held by mothers of children with disabilities (Birenbaum, 1970; McKeever, Angus, Spalding, & Thaha, 1998; Turner-Henson, Holaday, Corser, Ogletree, & Swan, 1994).

In order to explore whether children with cognitive and physical disabilities are more stigmatized than children with only physical disabilities, I reanalyzed and compared mothers' descriptions of raising children who have cerebral palsy (cognitive and physical

disabilities) and those who have spina bifida (physical disabilities only) drawn from a larger study by McKeever (1993).

Cerebral palsy and spina bifida are common causes of severe chronic disabilities of childhood (Behram, 1996, Davis, 1997a). Cerebral palsy is a group of syndromes with prevalence rates reported between 1.4 and 2.7 per 1,000 live births (Davis, 1997a). Although cerebral palsy predominantly results in motor system dysfunction, other problems have been identified in children with cerebral palsy. These problems include impaired cognition, sensory deficits, seizure disorders, feeding problems, behavioural dysfunction, and emotional problems (Davis, 1997). Children with cerebral palsy have muscle contractures, uncoordinated movement, and impaired speech, which make their disability immediately apparent. Consequently, most have difficulty sitting upright, moving fluidly, speaking clearly, or swallowing rhythmically. Many drool and require assistance to eat. Although cognitive deficits are reported in 50–66% of these children (Davis, 1997a), all children with cerebral palsy in the present study had cognitive impairment. These children are unable to engage in developmentally appropriate activities as a result of their physical and cognitive disabilities.

Spina bifida is a congenital defect of the spinal cord seen in 10–30% of the general population (Whaley & Wong, 1999). This condition results in problems associated with motor function, reflexes, and bladder and bowel function. Upper motor neuron disturbance may also be caused by conditions associated with spina bifida. These conditions include Chiari malformation, hydrocephalus, and other dysgenic central nervous system (CNS) malformations (Oi & Matsumoto, 1992). Children with spina bifida, although they also have severe physical disabilities, appear normal in their facial expressions, speech, upper body movement, and ability to eat. Seventy percent of

survivors have normal intelligence (Behram, 1996). The children with spina bifida in the present study had no cognitive impairment.

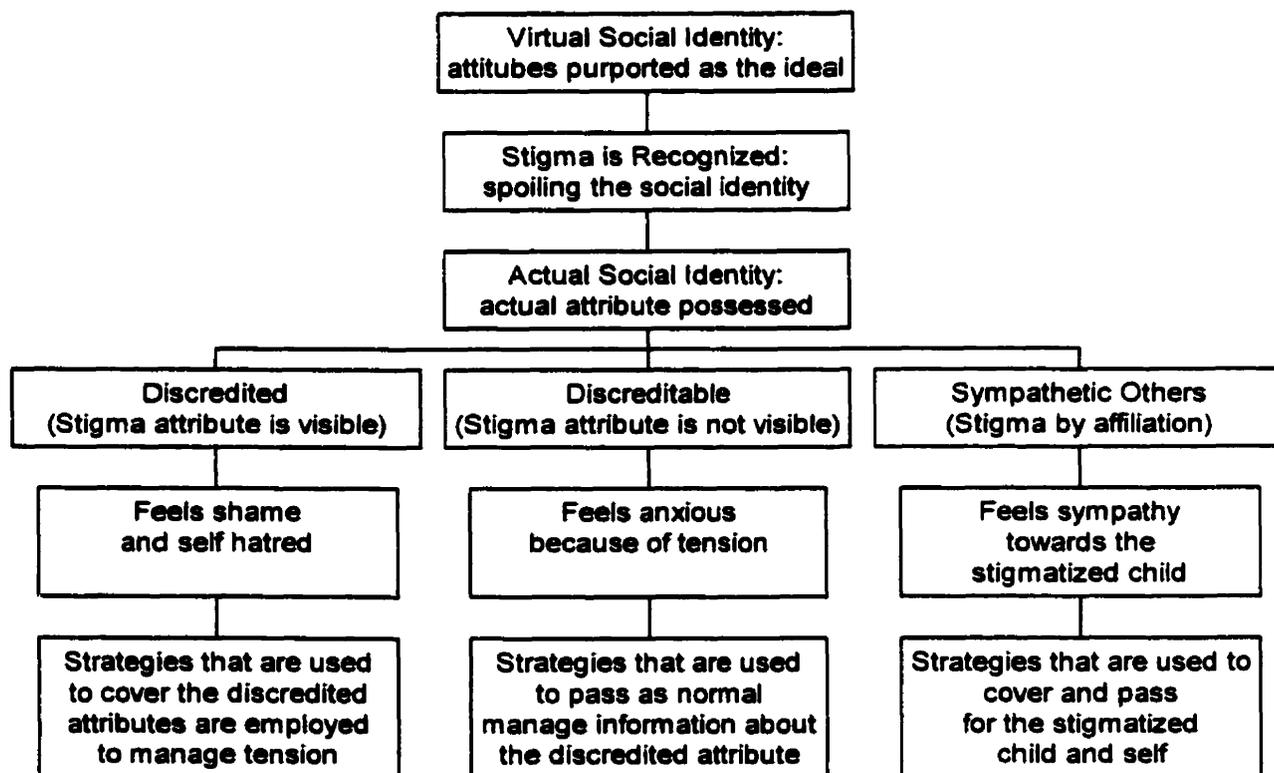
Children with cerebral palsy have disabilities that are more obtrusive in nature than those of children with spina bifida. Children with spina bifida appear physically and cognitively closer to the normative stereotype of the ideal child than do children with cerebral palsy.

I postulated that children with cerebral palsy are more stigmatized than those with spina bifida and that this hierarchical discrimination is also experienced by mothers. This study contributes to the body of knowledge related to the experience of mothering children with severe disabilities. This knowledge will be useful for improving nursing care by increasing nurses' awareness of the social experiences of these mothers and children and of how their own behaviours can contribute to or mitigate these experiences.

Theoretical Perspective

Goffman's (1963) conceptualization of stigma provided the framework for the secondary analysis of the data (Diagram 1). His ideas about stigma are grounded within the symbolic interactionist theoretical perspective. Goffman (1963) described stigma symbols and their meanings within the context of face-to-face social interactions between individuals who are considered *conventionally normal* and individuals who possess a visible mark or sign that is judged to be *stigmatizing*. In addition, he delineated a variety of strategies that individuals use to manage information about the stigma and to manage tension that is created during social interactions as a result of the stigmatizing attribute.

Diagram 1

Adaptation of Goffman's Stigma Framework

(Goffman, 1963)

According to Goffman (1963), *stigma* refers to a visible mark or sign that makes an individual different from the normative stereotypical individual. Societal norms govern social roles that are played out in everyday social interactions. People are stigmatized when they fail to conform to society's normative expectations. As a result, they are unable to gain full social acceptance and experience suffering (Goffman, 1963).

Goffman (1963) describes how stereotypes are used as frameworks against which individuals are judged. He refers to such stereotypes as *virtual social identities*. Examples of virtual social identities are stereotypes that describe the normal child and the good or normal mother. An individual's *social identity* is constituted by his or her structural characteristics (e.g., child's scholastic level, developmental stage, age) and personal attributes (e.g., honest, shy, outgoing). In social situations where a stigmatizing attribute is recognized, a discrepancy is noted between the virtual social identity, against which judgments are made, and the person's *actual social identity*. Recognition of this discrepancy results in the person's social identity being *discredited* or *spoiled* (Goffman, 1963).

Goffman (1963) describes people with three types of social identities: *normals*, *stigmatized*, and *sympathetic others*. He used the term *normals* to define individuals who conform to societal expectations, the term *stigmatized* to define those who possess undesirable attributes that depart from normative expectations, and the term *sympathetic others* to define those who accept, try to understand, and collude with the stigmatized.

Stigmatized individuals are either *discredited*, when their disability is apparent to others (e.g., wheelchair users or children whose muscles are spastic), or *discreditable*, when their disability is not apparent and can be hidden from others (e.g., babies with disabilities in strollers or children with well controlled epilepsy who appear normal).

Issues for the discredited and the discreditable individual differ. The discredited person is concerned with managing tension that is generated during social contacts, whereas the discreditable person is concerned with concealing information that would reveal a stigmatizing attribute.

Parents, siblings, friends, spouses, and professionals who seek to understand the situation of discredited and discreditable persons and affiliate with them experience what Goffman (1963) refers to as a *courtesy stigma*. Most mothers of children with disabilities pass as normal because they can carry out many conventional social roles, yet they deviate from the stereotypical norm when associated with their stigmatized children. Because their identity is spoiled not as a result of their own physical attributes but by their affiliation with their stigmatized children, mothers can present an image of normality by managing information about themselves in many contexts. Hence, the experience of courtesy stigma is situational.

The visibility or awareness of a person's stigmatizing attributes can result in acts of kindness, but they more often create social boundaries, negative attitudes, and discriminatory actions. These devaluing processes ultimately affect the psychological integrity of stigmatized individuals. Goffman (1963) posits that stigmatized individuals accept and internalize the social norms that discredit them and, as a result, they can experience feelings of shame and self-hatred. These feelings can trigger a variety of responses that range from attempts to correct, repair, or hide the discredited attribute (e.g., surgery to alter the facial features that characterize a syndrome; use of a chair instead of a wheelchair); to master activities that are difficult for the individual (e.g., child who is blind learns to ski; child with spina bifida learns to skate); to use their stigmatized attribute for secondary gains (e.g., individuals who draw attention to

themselves because of their disability); to seek a “deeper meaning” from suffering; or to understand the limitations of people who do not have disabilities. During interactions with normals, stigmatized individuals experience uncertainty about how they will be received. This results in self-conscious and calculating conduct. When attention is drawn to discredited individuals’ attributes through staring or starting up conversations, anxiety is created for the stigmatized individual. In anticipating tension during interactions, stigmatized individuals may respond defensively with *cowardice* or *hostile bravado*. Alternative techniques to manage tension constitute what Goffman (1963) referred to as *covering*. Covering involves efforts to keep the stigma from being the focus of attention (e.g., a girl with a missing leg uses a lifelike artificial limb in public; a person with cancer wears a wig to cover baldness). To cover successfully, the stigmatized individual must learn the rules of social interaction, so that his or her stigma becomes as unobtrusive as possible (Goffman, 1963).

Stigmatized individuals with discreditable social identities also manage information about themselves carefully in order to conceal their stigmatizing attribute. They must decide whether to “display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where” (Goffman, 1963, p. 42). Successfully managing information by hiding the discrediting attribute is referred to as *passing*. Passing as a normal is much more difficult when the person’s stigma is visible, widely known about by others (known-about-ness), immediately perceivable because it interferes with the flow of interaction (*obtrusive* in nature), and the focus of attention (*perceived focus*) in relation to specific aspects of life (e.g., job, social interactions). Techniques used to pass as a normal include concealing or obliterating information conveyed through stigma symbols (e.g., walkers or wheelchairs).

presenting signs of the stigmatizing attribute as a less offensive attribute (e.g., a person who is deaf may strive to give others the impression that he/she is absentminded), selectively disclosing facts about the discrediting attribute to a trustworthy individual, recruiting intimate others to assist with passing, and maintaining distance in order to avoid the obligation to disclose information. This last disclosure technique creates a considerable degree of anxiety, as the individual's situation is transformed from that of being discreditable to that of being discredited (Goffman, 1963).

Most people with disabilities know sympathetic others who accept them as normal in spite of their stigmatizing attributes. Sympathetic others include individuals, who share the same stigma, as well as, some parents, friends, neighbours, relatives, and professionals. Goffman (1963) refers to sympathetic others as the *wise*. Their insider status makes them privy to the secrets and strategies used by the stigmatized person. Sympathetic others play a role in assisting stigmatized individuals to manage their social situations and to use passing and covering tactics. When sympathetic others collude to cover and pass for the stigmatized, they risk spoiling their own personal identities. This risk taking does not necessarily lead to a spoiled identity if information about the others is managed successfully. Alternatively, if the sympathetic others' collusion with the stigmatized individual becomes visible, the public-at-large would treat both the sympathetic others and the stigmatized individual as one. In this way, the sympathetic others share the devaluing experience of the stigmatized person (Goffman, 1963). In response, the wise manage their stigma by attempting to balance their commitment to those with spoiled identities with their commitment to appear normal, embracing the stigmatized individual regardless of the consequences, or dissociating themselves from

the stigmatized individual in an attempt to remain a member of the conventional social order.

In summary, Goffman's (1963) elaborations on the concept of stigma provided a comprehensive framework from which the social processes of stigma and courtesy stigma could be examined. He purports that stigmatized individuals are judged according to society's normative expectations. As a result, they are assigned a devalued position in society. In order to improve their social positions, stigmatized individuals employ strategies to normalize their particular situation.

Goffman's portrayal of stigma led me to question differences in the stigma assigned to children with both cognitive and physical disabilities and those with only physical disabilities and the corresponding courtesy stigma assigned to their mothers. I postulated that evidence of such stigmas would be embedded within mothers' narrative accounts of raising their children who had severe disabilities. Goffman's theoretical perspective provided a framework to guide the review of the literature, the design of the study, and the secondary analysis of data.

Review of the Literature

No investigations have been conducted to compare the discrimination or negative social attitudes experienced by mothers of children with physical disabilities and those experienced by mothers of children with cognitive disabilities. However, related research pertinent to this study will be reviewed under the following headings: effects of discrimination on children with disabilities, effects of discrimination on parents and siblings, and parents' relationships with health care professionals.

Effects of Discrimination on Children with Disabilities

The findings of numerous studies indicate that children with disabilities are at higher risk for psychological and social adjustment problems than are their peers, as a result of societal attitudes towards their differences. These children have been found to be at greater risk than children in the general population for psychiatric, social, behavioural, and school adjustment problems (Cadman, Boyle, Szatmari, & Offord, 1987; Varni, Rubinfeld, Talbot, & Setoguchi, 1989; Wallander & Varni, 1989; Wallander, Varni, Babani, Banis, & Wilcox, 1988).

Studies examining the social acceptance of these children by peers have reported conflicting findings. Siperstein and Leffert (1997) surveyed 764 healthy students to elicit their perception of accepted and rejected classmates with cognitive disabilities. Findings revealed that accepted children were judged to possess higher social behaviour skills than socially rejected children but differed from rejected children in the social cognitive strategies generated. Evans, Salisbury, Palombaro, Berryman, and Hollowood (1992) examined the social acceptance and social competence of eight children with severe physical disabilities and eight healthy peers. No significant relationship was found between peer acceptance and the number of times peers played with these children. No significant relationship was found between social competence and acceptance for children with disabilities and that for children without disabilities. Moreover, no correlation was found between social acceptance and social competence. Tobiasen (1987) examined the influence of age and gender on judgments of facial deformities. Three hundred and seventeen participants were shown slides of children with facial clefts, with corrected facial clefts, and without facial clefts. Uncorrected pictures were rated consistently negatively, as less friendly, less popular, less likely choices as friends, less smart, and less

good-looking than corrected pictures. No significant relationships were found between the uncorrected pictures and the age and gender of the subject.

Data measured in two of the studies did not meet the criteria for measuring analysis of variance using ANOVA. This test assumes that data are measured on an interval or ratio scale and not a nominal scale. This test also assumes that there is a random assignment of subjects. Although subjects were drawn from a number of school systems in both studies, randomization was not described. Both studies had large sample sizes (Siperstein & Leffert, 1997; Tobiasen, 1987). Evans, Salisbury, Palombaro, Berryman, and Hollowood (1992) randomly selected a comparison group matched for gender, which strengthened the study design; however, findings should be interpreted cautiously in this study because of the small sample size ($n = 8$).

Many children with disabilities experience teasing or rejection from other children (Tackett, Kerr, & Helmstadter, 1990; Turner, Thomas, Dowel, Rumsey, & Sandy, 1997; Turner-Henson et al., 1994), negative responses from strangers (Tackett et al., 1990) and suffer from low self-esteem and self-confidence (Blum et al., 1991; Turner et al., 1997; Westbrook, Bauman, & Shinnar, 1992). Two investigators have examined a number of variables that have been found to be related to physical appearance and self-esteem of children with congenital or acquired limb deficiencies (Varni, Rubenfield, et al., 1989; Varni & Setoguchi, 1991).

Varni, Rubenfield, Talbot, and Setoguchi (1989) interviewed 41 children with congenital ($n = 34$) or acquired limb deficiencies ($n = 7$). Findings revealed that peer social support, self-perception of physical appearance, and conflict and organization within the family were significant predictors of self-esteem, revealing moderate to strong relationships. Microstressors were weak but significant predictors of self-esteem. These

variables accounted for 66% of the variance in general self-esteem (Varni, Rubinfeld, et al., 1989). In a more recent study, 51 children with congenital ($n = 43$) or acquired ($n = 8$) limb loss were interviewed. Findings showed that social support, peer acceptance, and scholastic and athletic competence revealed moderate relationships predictive of higher perceived physical appearance, whereas higher stress and marital discord were statistically predictive of lower self-perceived physical appearance. Lower depressive symptoms, trait anxiety, and higher self-esteem revealed moderate to strong relationships predictive of higher self-perceived physical appearance. These variables were found to account for 78% of the variance in perceived physical appearance (Varni & Setoguchi, 1991).

Investigators of both studies concluded that there might be potentially modifiable psychological and social factors of perceived physical appearance and self-esteem in children with limb deficiencies. They suggested that interventions such as social skills training designed to empower the child could address issues such as teasing and name-calling. These, along with stress management, cognitive problem solving and behavioural family therapy to address stress, might modify the negative impact on children with congenital or acquired limb deficiencies.

It is important to note that these investigators examined perceived physical appearance and self-esteem in children with limb deficiencies. Although the results establish a relationship between psychological and social factors attributed to physical appearance and self-esteem, these findings may not be generalizable to other populations.

Westbrook, Bauman, and Shinnar (1992) tested a theoretical model that posited that stigma was associated with low self-esteem among adolescents with idiopathic epilepsy. Sixty-three adolescents who were receiving drug therapy and had experienced

one seizure in the preceding two years participated in the study. Most adolescents did not feel stigmatized by their epilepsy. However, more than half (53%) reported that they kept their diagnosis a secret, and, of the 47% who had disclosed their diagnosis, the majority (78%) had disclosed to only one friend. Voluntary disclosure was reported by 65%, and 19% reported that they disclosed only because they had had a seizure in public. Twenty-three percent had low levels of self-esteem, 56% had average levels of self-esteem, and 20% had high levels of self-esteem. Only two hypotheses were supported in this study. Low self-esteem was significantly correlated with seizure type, seizure frequency, and perceived stigma, while perceived stigma and disclosure management strategies had no statistically significant relationship to the type of seizure, frequency of seizures, and duration of epilepsy. These researchers concluded that the measures used to determine perceived stigma and disclosure management might not have accurately reflected these constructs (Westbrook et al., 1992). The investigators also suggested that stigma theory does not incorporate personal characteristics of the subjects, which may be an important modifier of the hypothesized relationships.

Although the study design was appropriate in testing a theoretical model, findings were limited by the theory itself. The strategy to manage stigma—passing—was not incorporated in the model tested. Passing may have been an important variable to study because the majority of participants had good seizure control. Unless an individual disclosed that he or she had epilepsy or had a seizure in a public place, he or she may have passed as normal and not experienced stigma at all. In addition, a qualitative approach would have been helpful to employ in order to elicit further information regarding disclosure management. This would have further delineated an understanding of this concept.

In summary, these studies inform us about the negative effects of discrimination on children with disabilities. Social problems, stress, and low self-esteem are experienced by children with various disabilities as a result of social discrimination. The importance of physical appearance, as well as social behaviour skills, in determining social attitudes towards children with disabilities has also been illuminated.

Many of the studies reviewed used survey and descriptive correlational designs. Although these designs were appropriate to use, a qualitative approach could have elicited information about the effects of discrimination experienced by children with disabilities. Although some studies reported large sample sizes, randomization was not described. Others reported using stratified sampling techniques that included children diagnosed with a wide spectrum of diseases. Findings from these studies should be interpreted cautiously. In a number of studies, inappropriate statistical tests were employed for the measurement scale identified.

Effects of Discrimination on Parents and Siblings

Numerous investigators have examined the impact of stigma and discrimination toward children on their parents, and one investigator has examined the effects on siblings. Birenbaum (1970) interviewed 103 mothers of children with developmental delay to examine their adaptations to the stigma experienced. Mothers' relationships with friends remained unchanged when "consideration" of their plight was recognized and awkwardness and embarrassment were avoided. Relationships with those friends who responded to the child in ways that mothers considered inappropriate were terminated. Few relationships were established with other mothers of children with developmental delay. Mothers were reluctant to form alliances with these mothers, as these threatened

the normal conventional identity they chose to establish for themselves. As a result, selective relationships were elicited to maintain a normal-appearing life.

To ascertain the mothers' commitment to their children, six possible social dilemmas were presented to mothers, and the mothers were asked to choose between two outcomes, one of which favoured the child. Fifty-six percent of mothers said that they would intervene on the behalf of their child who was being teased. However, 30% said they would do nothing in such a situation, and over 15% said they would comfort the child or instruct him or her to stop playing with the person doing the teasing. Eighty-five percent of mothers said they would send their child to a program recommended by a professional but administered by a religious organization not of the family's faith. Eighty-five percent of mothers felt that their husbands should hire an individual with developmental delay, and 15% suggested that these individuals were more reliable than those persons without a disability were. The majority of mothers (60%) said they would keep a dinner engagement when their child became ill, but most identified that they would only do so if they had a capable babysitter. Only seven mothers said they would send their husband and stay with the child. Over half of the mothers felt that the family should consider moving house in order to improve their economic position only if a full-time day program existed for the child. Fifteen percent suggested that the family should move because mothers could start a program wherever they relocated. Thirty percent said that the family should move because the family's economic needs were greater than individual needs. Over 60% of mothers of those children who were not disabled wanted to support them in college, and 55% said that they would send the child who was not disabled to college rather than sending the child with developmental delay to a recommended program.

Birenbaum (1970) concluded that mothers of children with developmental delay experienced discrimination. Recognizing the situational variability of discrimination and altering the meanings of relationships with family, friends, and other parents of similar children, as well as limiting participation in related organizations, made it possible for mothers to maintain a normal-appearing life. Recognizing and upholding the primacy of conventional family life provided other ways of portraying an image of normality. Patterns of adaptation resulted in cycles of affiliation and dissociation from the community and those similarly situated. This study was conducted 30 years ago, hence these findings may have been influenced by the social attitudes prevalent at the time, which upheld structural-functional norms of conventional family life and preceded social-political activism regarding disability issues.

Gallo, Breitmayer, Knafl, and Zoeller (1991) interviewed 27 siblings (between 6 and 14 years of age) of children with a variety of chronic illnesses to ascertain their perceptions of stigma. Three major categories emerged: how siblings reveal chronic illness to others, sibling responses to the ill child, and impact of the illness on daily living. Fifty-eight percent of the siblings had revealed the chronic illness to others, but the majority of these siblings had done so selectively because they feared that the ill child would be teased or ridiculed. The age of the siblings was significantly related to differences in revealing or not revealing the illness ($p = .004$, 2 tailed). Younger siblings (≤ 10 years) were more reluctant to reveal the illness and were more secretive about the illness than older siblings. Forty-one percent were worried about the ill child, and 20% responded that they were sorry or sad that the child had an illness. Reasons for worrying were related to the response of others—teasing and rejection—and the negative impact of the illness on the child. Nine siblings reported that the ill child was a “normal” or

“regular” child. Fifty-two percent played and enjoyed time with the ill child. Seventy-four percent reported routine tasks they performed in relation to their sibling’s illness including reminding the ill child about medications and diet restrictions; watching the ill child play; assisting with chores and other tasks; and encouraging, speaking out for, and protecting the ill child. Seventy-eight percent reported that the others did not treat the ill child and him- or herself differently because of the illness.

These investigators concluded that the decision to reveal or not reveal the child’s illness related to the sibling’s understanding of the negative consequences of the illness and the impact of discrimination (Gallo et al., 1991). Siblings used coping strategies to conceal the illness when they were aware of the consequences of discrimination. This strategy of concealment is consistent with Goffman’s (1963) ideas of covering.

Van Riper, Pridham, and Ryff (1992) examined the impact of initial and ongoing interactions between parents of a child with Down syndrome and others. The sample consisted of 90 parents of children with Down syndrome whose ages ranged from 3 months to 18 years. Parents experienced both positive and negative interactions with health care professionals and others. Parents described the negative impact of having a child who did not meet societal expectations, the impact of being told the diagnosis, the impact of clinicians’ negative responses, and the changes that occurred as the parents redefined their situation by becoming acquainted with the child. Discrimination experienced by family members influenced how they defined their situation and responded to their child. The process by which a thematic analysis was performed was not described. Although narrative text displayed supported major themes, the categories were not well delineated.

Turner-Henson and colleagues (1994) surveyed 365 parents to determine the types of discrimination experienced by children with chronic illnesses. Children in the sample were between 10 and 12 years of age and had a wide range of illnesses. Thirty-five percent of parents reported that discrimination was experienced by themselves or their children. Discrimination originated from the children's peer groups, school settings, community agencies, and government agencies. Difficulties taking the child to public places (15%) resulted from structural, legal, and attitudinal barriers. Over half (55%) of these problems were experienced in or related to the child's school and were associated with physical education classes, exclusion from activities, personnel unwilling to provide care or meals, and exclusion from school trips. Parents also reported problems related to ridicule by peers, exclusion from sleepovers with friends, and discrimination from social groups. Parents also reported limited access to public places (23%) and an inability to avoid allergens (25%). Other barriers cited by parents were related to limited mobility as a result of inaccessible seating and the child's illness (physical demands or difficulty in managing treatments in public). Demographic and child factors significantly predicted mothers' perceptions of discrimination. Mothers of white children were more likely to report discrimination than those of black children ($p < .01$). Home ownership was predictive of mothers' perceptions of discrimination ($p < .05$). Mothers who did not own their own home reported more discrimination, and those with higher levels of education were less likely to report discrimination ($p < .01$). The visibility of the disability ($p < .05$) and the severity of illness ($p < .01$) had a positive relationship to discrimination. However, for children with asthma, there were fewer reports of discrimination ($p < .01$).

Thirty-five percent of the parents perceived that they and their children experienced discrimination as a result of human-made barriers (Turner-Henson et al.,

1994). These investigators suggested that more structured activities in school settings are necessary to promote integration. Although parents reported that they as well as their children experienced discrimination, perceptions about the impact of this discrimination on their experience as mothers were not elicited.

Baxter (1989a) examined the relationship between parental stress attributed to social attitudes and two sets of potentially stress-inducing and stigmatizing conditions: deviating characteristics of the child and distressing reactions of others. One hundred and thirty-one mother–father dyads with children with developmental delay were interviewed separately.

The most frequently cited characteristics influencing a child's noticeability were abnormal speech (65.9%, $n = 63$), appearance (51.9%, $n = 67$), and behaviour (48.8%, $n = 63$). The child's unusual behaviour ($r = .28, p < .001$) and speech ($r = .21, p < .01$) were significantly associated with parental stress. Stress was significantly associated with behavioural problems ($r = .31, p < .001$) and with worry about the child's behaviour in public ($r = .29, p < .001$). Parents' responses to open-ended questions indicated that the capacity of the behaviour to draw the attention of others to the disability and the parent's ability to cope in the situation were stress-inducing.

The extent to which the reactions of others were observed and perceived to be distressing to parents was measured on a 3-point Likert-type ordinal scale. Parents most frequently observed others treating the child as though he or she was younger (81.3%, $n = 104$) and treating him or her differently from siblings (72.9%, $n = 89$). Although others ignored the child infrequently (39.4%, $n = 50$), parents were very distressed by this reaction (78.9%, $n = 30$). Fifty-seven percent of parents who observed reactions of

ignoring, staring, being uncomfortable, or drawing attention to the child found these distressing.

Parental stress was significantly associated with the distressing reactions of others: staring at the children ($r = 0.50, p < 0.001$), treating the children differently from siblings ($r = 0.50, p < 0.001$), drawing the attention of others to the children ($r = 0.29, p < 0.001$), changing tone of voice ($r = 0.40, p < 0.001$), treating the children as though they were much younger ($r = 0.29, p < 0.001$), displaying discomfort ($r = 0.55, p < 0.001$), ignoring the children ($r = 0.35, p < 0.001$), or being overly sympathetic ($r = 0.47, p < 0.001$). Correlational findings revealed weak to moderate relationships. Stressor characteristics of the child and stressor reactions of others explained 57% of the variance in parental stress ($R_2 = .57767$). Social attitudes were related to the visibility of the child's deviating characteristics. Although abnormal speech and appearance were more frequently cited as influencing the child's noticeability, unusual behaviour was the most stress inducing for parents. This investigator concluded that discriminating attitudes toward the child with a disability were stressful to parents.

Leyser and Dekel (1991) examined stressors, coping strategies, and social supports for 82 Jewish parents of school-aged children with a variety of disabilities. A semi-structured interview questionnaire (Leyser, Margalit, & Avraham, 1988) measured the impact of the child on family life and siblings, areas of stress, and availability of personal and professional support systems. Thirty-eight percent of parents felt that the child's disability affected the family "much" or "very much," 17% felt there was "some effect," and 45% felt that there was "little" or "no effect." The most stressful aspects for these families included their financial status (75%) and the lack of community support (75%). Twenty percent of parents felt they were greatly stigmatized, and 40% felt they

were stigmatized to some extent. Parents who experienced the most stress experienced more daily hardships, such as financial constraints, lack of support, lack of time, and feelings of stigma; were found to have a boy ($R_2 = .336$) or mothers who were older ($R_2 = .384$); and had fewer children in the family ($R_2 = .464$).

The majority of parents sought out support for themselves from health care professionals (75%), religious leaders (78%), and their own parents (25%). Forty-five percent of parents sought support from neighbours and friends, and more than half reported that they had no discussions. Although no parents were involved with a community support group, 40% expressed interest in meeting other parents with similar problems. Most parents (95%) were satisfied with the services available in the special school ($M = 4.38$, $SD = 0.623$ on a 5-point scale). The relationship between the child with the disability and his or her siblings was perceived to be normal (75%). The child's future was not a concern for many of the parents. These investigators concluded that these parents experienced great stress and many family problems.

In summary, investigators have determined the impact that stigma and discrimination have on parents and siblings of the child with a disability. They have delineated the types of discrimination experienced by parents, as well as the influence that stigma has on parenting, the stress experienced by parents, and the coping strategies employed by siblings. Many of the studies reviewed used qualitative methods, which were appropriate to explore parent's perceptions of discrimination. For one of the qualitative studies, the data analysis procedures used were not described (Van Riper et al., 1992). Although narrative text supported major themes, the categories were not well delineated. Some investigators used descriptive survey designs. Although some of these studies examined specific diagnostic categories, others reported using stratified sampling

techniques that included children diagnosed with a wide spectrum of diseases. Findings from these studies should be interpreted cautiously. Birenbaum's (1970) study of mothers of children with developmental delay specifically examined courtesy stigma, which is relevant to the secondary data analysis undertaken in the present study. However, it is important to note that findings may have been influenced by the social attitudes prevalent in publications at the time the study was undertaken, which upheld structural-functional norms of conventional family life and preceded social-political activism regarding disability issues.

Parents' Relationships with Health Care Professionals

A number of investigators have examined the relationship between health care professionals and parents of children with disabilities. Stewart and colleagues (1996) described stressful and supportive interactions that 90 mothers of chronically ill children aged 1 to 17 years experienced with health care professionals. Although mothers described health care professionals as key members of their social support network, they perceived gaps in the support provided. The support provided by health care professionals was of four types: practical (34.4%), emotional (25%), informational (23.3%), and affirmational (10%). The support provided in relation to physical care was informational (31%), including explanations about the child's condition, treatment, and management and suggestions of alternative approaches; and affirmational (21%), which encompassed feedback about maternal caregiving. Mothers found that informational (14%), instrumental (13%), and affirmational (12%) support from health care professionals was absent or inappropriate.

Baxter (1989b) examined parents' perceptions of the attitudes of health care professionals toward their children. A stratified sample of children who were moderately

to severely developmentally delayed in three age categories was recruited from six schools for children with intellectual disabilities. Sixty-one mother–father dyads and nine mothers ($n = 61$ parents) were interviewed separately in their homes.

Parents perceived professionals as showing a helpful attitude (32.1%, $n = 42$) when they demonstrated professional interest in the child (15.3%, $n = 20$) and treated parents with consideration and respect (9.9%, $n = 13$). When professionals were not being helpful (20.6%, $n = 27$), they failed to show interest in the child or in the parents (6.1%, $n = 8$), they lacked consideration and respect (6.1%, $n = 8$), and they lacked commitment (5.3%, $n = 7$). These negative attitudes were found to be distressing to parents. Parents expected professionals to provide helpful information and practical assistance and to treat them with consideration and respect.

Knafl and colleagues (1992) explored the behaviours of health care professionals who promoted and sustained a positive working relationship with parents. A purposive sample of 102 parents (51 couples) whose children aged 7 to 14 years of age had a chronic illness were interviewed. Although most couples (34) reported positive encounters with health care professionals, 17 were dissatisfied. One or both partners in nine couples had questioned a physician's competence. Fourteen parents reporting negative reactions described difficult interactions between the child and physician (4) or between the parent and physician (14). Parents reported the following to be important in establishing positive relationships: (a) an exchange of information that reflected accurate and complete accounts of the child's illness and management (14 mothers and 20 fathers), (b) an interaction style that communicated empathy and genuine concern (24 mothers and 17 fathers), (c) a relationship with the child based on respect (18 mothers and 12 fathers), and (d) acknowledgment of parental competence (9 mothers and 6 fathers). Most parents

were satisfied with the care that health care professionals provided. Parents preferred health care providers who interacted effectively with the children and themselves and who fostered confidence in their caregiving abilities.

Patterson, Jernell, Leonard, and Titus (1994) also examined parent–professional relationships. The parents of 48 “medically fragile” children between the ages of 3 and 19 years who were cared for at home participated in this study. Survey data were collected by interview and self-report questionnaires. Factors influencing positive aspects of the relationship included (a) support provided to parents and family (73% mothers, 22% fathers); (b) genuine caring for the child (39% mothers, 34% fathers); (c) competence and skill of the staff (29% mothers, 34% fathers); and (d) demonstrated respect toward and collaboration with the family (24% mothers, 20% fathers). Factors influencing negative aspects of the relationship included (a) invasion of privacy (61% mothers, 20% fathers); (b) unprofessional and inadequately trained staff (55% mothers, 54% fathers); (c) lack of respect demonstrated toward the family (37% mothers, 20% fathers); and (d) scheduling hassles, including cancellations and staff turnover (33% mothers, 27% fathers). A high level of strain for mothers was significantly associated with more home care hours provided by health aides ($r = .34, p < .05$), whereas a high level of strain for fathers was significantly associated with more personal strain ($r = .42, p < .01$). These correlation coefficients revealed weak to moderate relationships. The professionals’ skill and competence, as well as their attitudes toward the child and family, were critical factors in establishing a supportive parent–professional relationship.

In summary, the qualitative study designs employed were appropriate in exploring parents’ perceptions of supportive and nonsupportive interactions with health care professionals. Negative interactions with health care professionals have been found to be

stressful and devaluing experiences for parents. Findings from these studies reveal the importance of health care professionals' skill and competence, as well as of their attitudes toward the child and the parents, in establishing a positive relationship with parents. The qualitative designs employed were appropriate in exploring parents' perceptions of health care interactions.

Conclusions

Only one research study specifically explored the concept of stigma experienced by mothers of children with disabilities. Birenbaum's (1970) study was conducted at a time when structural-functional norms of traditional nuclear families were upheld, and it preceded social-political activism regarding disability issues. Although other investigators have found evidence of stigma and discrimination toward children with disabilities and their mothers, most of these studies were not designed with this focus, with the exception of three studies (Gallo et al., 1991; Turner-Henson et al., 1994; Westbrook et al., 1992). Gallo and colleagues (1991) examined the courtesy stigma of siblings of children with a variety of chronic illnesses. The data for this study were derived from a larger study. This is a limitation of the study design. Westbrook and colleagues (1992) tested a theoretical model that addressed the concept of stigma. Although the study design was appropriate in testing a theoretical model, findings were limited by the theory itself. The strategy of passing as normal was not incorporated into the model tested, but would have been an important variable to study since study participants had good seizure control. Turner-Henson and colleagues (1994) delineated the types of discrimination experienced by both mothers and children with various chronic illnesses; however, the subjective experiences of mothers were not elicited. The data for this study were limited because they were derived from a larger study. Furthermore, no research had been conducted that compared

discrimination against groups of children with different disabilities, and no research focused on how mothers responded to such discrimination.

Many of the studies reviewed used survey and descriptive correlational designs and stratified sampling techniques. Few studies supported strong correlational relationships. In a number of studies, inappropriate statistical tests were employed for the measurement scale identified. These studies have examined the differences in stigma that children with severe physical and cognitive disabilities experience. To begin to address these issues, the present study was designed to explore differences in mothers' accounts of children with cognitive and physical disabilities.

CHAPTER II

DESIGN AND METHODS

The Original Study

This thesis is a secondary analysis of a subset of data drawn from a larger study designed to elicit the daily activities, subjective experiences, and life circumstances of biological and foster mothers of children who had severe disabilities (McKeever, 1993). The larger study will be described briefly to provide the context for the secondary data analysis.

A descriptive exploratory design was used to portray the experiences of mothers of children with severe disabilities. The proposal underwent ethical review. After giving informed consent, each mother participated in a two-part home interview. First, an unstructured narrative account of daily life elicited information about mothers' activities, experiences, and concerns. Interviews lasted approximately 2 hours and were audiotaped. Immediately following each interview, field notes of observations made during the interviews were completed. Second, a structured interview format elicited descriptive information about the children and a list of his or her daily care requirements.

A random sample of 33 biological mothers and a convenience sample of 29 foster mothers were recruited. For the purposes of this thesis, I will only describe information pertaining to biological mothers, as the data I analyzed were drawn from this sampling strata. The biological mothers were selected from the outpatient population of a pediatric rehabilitation centre in Ontario, Canada.

The following inclusion criteria were used to determine eligibility:

1. all mothers spoke English,
2. all mothers had cared for at least one child with a disability at home for the preceding 6 months, and
3. all mothers lived within a 60-mile radius of a large Canadian city.

The Present Study

Statement of Purpose

The aim of this study was to describe similarities and differences in the stigma experienced by two subgroups of mothers of children with disabilities. The rationale for selecting two subgroups was to compare mothers' descriptions of stigma assigned to children whose disabilities were physical and cognitive (cerebral palsy) versus those assigned to children whose disabilities were only physical (spina bifida).

I postulated that mothers' accounts of raising children who had cerebral palsy would reflect more stigma than would those of mothers whose children had spina bifida because of society's hierarchical discrimination against people with cognitive disabilities. The knowledge gained through this inquiry should contribute to our understanding of dominant values and expectations, against which mothers of children with disabilities are judged and their social positions are determined. This knowledge would be useful for improving the quality of nursing care by increasing nurses' awareness of the social experiences of these mothers and children and of how their own behaviours can contribute to or mitigate these experiences.

Research Questions

The following research questions were derived from the literature, from my clinical experience, and were formulated according to Goffman's conceptualization of stigma (1963).

1. How do mothers of children with (a) cerebral palsy or (b) spina bifida describe their children's actual social identity?
2. How do mothers of children with (a) cerebral palsy or (b) spina bifida describe the courtesy stigma assigned to them?
3. How do mothers of children with (a) cerebral palsy or (b) spina bifida describe the strategies they employ to manage courtesy stigma?
4. How do mothers of children with (a) cerebral palsy or (b) spina bifida describe the strategies they employ to manage their children's stigma?

Design

A theoretically deductive approach was used to identify descriptions of stigma embedded within mothers' accounts of raising children with disabilities. Detailed descriptive data had been collected as part of the original study through interviews, field notes, and observations of mothers.

Sample

Two subgroups of mothers of children with disabilities were drawn from the sample of 33 biological mothers who participated in the original study to constitute a purposive sample for this study ($N = 18$). It consisted of mothers whose children were diagnosed with cerebral palsy ($n = 8$) and mothers whose children were diagnosed with spina bifida ($n = 10$). One case was excluded because of inadequate data. Fourteen other cases did not meet the inclusion criteria. Some children ($n = 11$) had a diagnosis other

than cerebral palsy or spina bifida. Other children who had cerebral palsy were of normal cognition ($n = 3$). The following inclusion criteria were used to determine the sample for this thesis.

Inclusion criteria. The two subgroups consisted of mothers of children with cerebral palsy and mothers of children with spina bifida. All children with cerebral palsy had both physical and cognitive disabilities. All children with spina bifida had physical disabilities only. Cognitive disabilities were determined by assessing data about the child's communication skills, school status, and self-care ability in relation to their peers.

Data Analysis Procedures

The data in the form of typed accounts were analyzed according to the steps outlined by Miles and Huberman (1994).

1. Unmarked copies of transcribed audiotaped accounts, field notes, and observational data from the original study, with room on both the right and left margins for codes and comments, were transferred to a computer as separate files for each mother.
2. Transcripts were read in random order several times to obtain a sense of the scope of the data and to gain a sense of each mother-child dyad.
3. Handwritten summaries were created for each case. These summaries were organized to illustrate how the theory related to the data and to identify segments of text that elaborated the mother's views of stigma toward her child and herself. In addition, memos and theoretical ideas about codes and their relationships were written to link data together into clusters. These handwritten memos were kept in a separate file labeled according to the concepts they described.

4. A preliminary list of codes was generated from the conceptual framework, research questions, hypotheses, and emerging concepts that had been described by participants. These codes were operationally defined and filed in a “code book,” which was used as a reference during the coding process.
5. Summaries were also used to suggest emic codes, which were as close as possible to the participants’ descriptive terms, and later to reorient me to each case when I returned to the transcribed data during data analysis and final write-up.
6. The transcribed texts were coded to answer the research questions. During and following analysis, data were copied and filed according to clustered themes for easy retrieval of data sets. Segments of texts were highlighted with coloured markers reflecting the research questions. This process enhanced the efficiency of data management and storage.
7. Data were grouped according to the child’s diagnostic group (cerebral palsy or spina bifida), age, and developmental stage.
8. Data were coded using the preliminary list of codes. In addition, new and more differentiated codes were placed in the margins. These emerging codes were subsequently used to review and code all cases. Remarks representing my reactions to the meaning of the content and potentially new interpretations, leads, and connections with other parts of data were recorded in the right margins of the transcripts.
9. For each of the research questions, data were clustered into categories and/or themes.

10. To move from coding to interpretation, I used a number of strategies that allowed me to draw conclusions while avoiding bias: counting, comparing cases, and noting relationships within and between the two groups. Conclusions and interpretations were drawn. Supporting evidence was found for preliminary explanations. This process included generating meaning from a particular configuration of data, noting regularities and themes as well as contrasts, paradoxes, and irregularities.
11. Finally, an interim summary was created to present the main findings. This summary was presented to my thesis committee for further feedback. Discussion with committee members regarding how the research findings related to the conceptual framework used in the study illuminated further interpretation of the data.

Methodological Rigor

An audit trail was kept to facilitate replicability of the study. The audit trail was established first by developing a codebook with operational definitions of codes. These codes were shared with an external reviewer, who is a Clinical Nurse Specialist with expertise in qualitative research methods and clinical pediatric disability issues, to determine definitional clarity, validity, and reliability. Subsequently, emerging categories and theoretical ideas about coded data were recorded in memos.

I used strategies suggested by Miles and Huberman (1994) to enhance the validity of the findings. Eight cases that contained coded data were shared with the external reviewer to determine if first-level coding reflected pre-established codes that were operationally defined. Second-level codes were also shared with the external reviewer to determine if the data were represented by the assigned codes and to verify conclusions

drawn. Differences in coding related to additional examples of virtual identity noted, one example of hope noted, coding of a seizure as a physical vs. cognitive discrediting attribute, and coding of data that related to the father and not to the mother. Other comments were related to examples of some coded phrases that were stronger than others and to further coding required for courtesy stigma. All transcripts were examined for additional examples of virtual identity and for further coding of courtesy stigma and were again reviewed with the external reviewer. No differences were identified at this time.

I used the process of triangulation, which involved comparing and contrasting data from multiple sources (field notes, observations, transcript data, descriptive information from the structured interview format about the child and about his or her daily requirements) to detect similarities and differences. Triangulation supported findings by demonstrating that multiple sources agreed with the finding or at least did not contradict the finding. The external reviewer established the content validity of coded data and categories created. In addition, I checked each category for its accuracy and inclusiveness. All of these tactics enhanced the creditability of the study findings.

Strengths and Limitations

The theoretical deductive approach employed in this study was appropriate to analyze descriptions of stigma from mothers of children with disabilities. However, the data had been drawn from a larger study and were reanalyzed. Therefore, the findings were limited because the original study was not designed to examine descriptions of stigma.

The sample size was small ($n = 18$). However, the goal was not to generalize findings, but to determine descriptions of stigma as described by mothers of two subgroups of children with disabilities (cerebral palsy and spina bifida). Examining two

subgroups of children was a strength of the sampling procedures employed. This was done to reduce sampling bias found in other studies that used stratified sampling techniques to examine a variety of chronic illnesses. The problem with the stratified sampling approach is that the sample is not representative of the population of children with disabilities, since functional abilities and limitations vary so widely with these ranges of conditions.

The unstructured interview format of the original study allowed mothers to describe their activities, experiences, and concerns about raising children with disabilities. Because the interview questions were not designed to permit further exploration of the concept of stigma being studied research findings from this study are limited. The fact that I did not interview the mothers was a limitation that was reduced by reading the transcripts, field notes, and recorded observations several times in order to gain insight into the interviews that occurred. Not participating in the interviews may have reduced bias, because I had no influence over participant responses. The credibility of the study findings are further limited by the fact that only mothers were interviewed and the data collected reflected only mothers perceived stigma. I used the process of triangulation, which involved comparing and contrasting data from field notes, observations, transcript data, and descriptive information from the structured interview format about the child and about his or her daily requirements. This process ensured that multiple sources agreed with findings and that bias was minimized.

Goffman's conceptualization of stigma was an appropriate framework because it provided a comprehensive understanding of the concept of stigma. Although, many authors have acknowledged the important contributions that Goffman (1963) made, they have also critiqued his ideas because he viewed individuals with a disability as deviant.

Within his framework, an imbalance of power exists, because the discredited individual is considered to be less than human as portrayed by more powerful groups. Moreover, the categorization of the stigmatized is broadly inclusive, without boundaries and specificity. Not only is the individual with a disability stigmatized, according to Goffman (1963), but so are other marginal groups. For example, criminals, homosexuals, ethnic minorities and others are stigmatized (Ainlay, Coleman, & Becker, 1986; Alonzo & Reynolds, 1995; Fine & Asch, 1988; Gardner, 1991; Murphy, Scheer, Murphy, & Mack, 1988). In order to address this limitation, the sample was defined within the context of particular disabilities. Ainlay and colleagues (1986) argue that Goffman does not acknowledge how stigma is qualified within the context of a particular culture, period of history, or economic, political, or social situation. In the present study, stigma is defined within the context of mothers' perceived experiences of raising children with disabilities in contemporary Canadian society. I believe that although the framework is comprehensive, it fails to explicitly delineate details relevant to the child with disabilities and to the mothers' experiences of courtesy stigma.

CHAPTER III

THE FINDINGS

Characteristics of the Mothers and Their Children

In this study, a secondary analysis of a subset of data from a larger study was undertaken to describe similarities and differences in stigma described by mothers of two subgroups of children with disabilities. Eighteen of the original 33 mothers met the inclusion criteria.

Characteristics of the Mothers

The majority of families were comprised of married, two-parent households, and the mothers provided most of the extraordinary care that their children required. However, one father was reported to provide care for his child throughout the day while the mother was employed outside the home. The median age of mothers of children with cerebral palsy was 49 and the median age for mothers of children with spina bifida was 40. Six of these families had other children under the age of 5 years. The majority of these mothers (72%) were employed outside the home on a part- or full-time basis (33% part-time; 39% full-time). The total income reported for ten households was below that of the average total income for individuals living in Canada \$65,561 (Statistics Canada, 1996).

Forty-seven percent of the mothers had completed or partially completed secondary school, and half had completed or partially completed post secondary school. Half of the mothers were immigrants to Canada, and their ethnicity was diverse. They had immigrated from the following regions: Europe ($n = 4$), the West Indies ($n = 1$), the

Middle East ($n = 1$), North America ($n = 1$), Central America ($n = 1$), and South America ($n = 1$). The cultural heritage of the remaining women reported in this sample was Northern European. No differences were noted between the two groups with regards to marital status, employment status, education or heritage. More detailed characteristics of the sample are reported in the tables. To compare groups, the Fisher Exact test was used. The probability value of the observed association between the two subgroups is reported in the Tables 1 through 5.

Table 1

Marital Status ($n = 18$)

	CP	SB	Total
	$n = 8$	$n = 10$	
Married	6	8	14
Divorced	2	2	4
Total	8	9	18

Note. The proportion of observed frequencies is not significantly different from that expected from random occurrence ($P = 1.000$). CP = child with cerebral palsy; SB = child with spina bifida.

Table 2

Employment Status ($n = 18$)

	CP	SB	Total
	$n = 8$	$n = 10$	
Employed	5	8	13
Unemployed	3	2	5
Total	8	10	18

Note. The proportion of observed frequencies is not significantly different from that expected from random occurrence ($P = .6078$).

Table 3

Level of Education ($n = 17$)*

	CP	SB	Total
	$n = 8$	$n = 10$	
Secondary school	4	4	8
Post Secondary school	4	5	9
Total	8	9	17

Note. The proportion of observed frequencies is not significantly different from that expected from random occurrence ($P = 1.0$).

*For one family data were missing.

Table 4

Heritage (n = 18)

	CP	SB	Total
	n = 8	n = 10	
Canadian	2	7	9
Immigrant	6	3	9
Total	8	10	18

Note. The proportion of observed frequencies is not significantly different from that expected from random occurrence ($P = .153$).

Table 5

Maternal Age (n = 18)

	CP	SB
	n = 8	n = 10
Age range	37–43	21–46
Median	49	40

Note. Statistical comparisons were not undertaken due to the small numbers in each subcategory.

Characteristics of the Children

The children with disabilities ranged in age from 2 to 13 years, and the median age was 9 years in both groups. Five of the children were under the age of 5 years (3 children with cerebral palsy; 2 children with spina bifida). With the exception of one

mother who had twins with cerebral palsy, mothers had one child with either spina bifida or cerebral palsy. Many of the children were profoundly disabled and had multiple diagnoses. In addition to having either cerebral palsy or spina bifida, these children experienced respiratory problems (e.g., asthma, pneumonia), neurological problems (e.g., epilepsy, hydrocephalus), skeletal problems (e.g., scoliosis, clubbed feet, dislocated hips), genital urinary problems (e.g., bladder extrophy), and severe growth retardation. Associated functional impairments included paralysis (hemiparesis or quadriplegia), visual problems, hearing impairment, aspiration, feeding and digestive problems, and bladder and bowel incontinence. All children in both groups had significant mobility impairments, and none could ambulate independently. As a result of these problems, 97% of the children required at least one assistive device. All children with cerebral palsy had cognitive impairments and all children with spina bifida were cognitively normal. More detailed characteristics of the sample of children are reported in Tables 6 and 7.

Table 6

Children's Ages ($n = 18$)

	CP	SB
	$n = 8$	$n = 10$
Age		
Age range	2–11 years	2–13 years
Median age	9 years	9 years

Note. Statistical comparisons were not undertaken due to the small numbers in each subcategory.

Table 7

Children's Impairments* (n = 18)

	CP	SB
	n = 8	n = 10
Impairments		
Neurologic	5	9
Cognitive	8	0
Sensory	5	0
Feeding	2	0
Bladder/bowel	0	8
Orthopedic	0	5
Mobility	8	10

*Statistical comparisons were not undertaken due to the small numbers in each subcategory.

Results

The research questions guided the analysis of the transcribed interview data and provided a framework to organize the findings. Each example used to illustrate a theme includes the corresponding case number.

Research Question 1

How do mothers of children with (a) cerebral palsy and
(b) spina bifida describe their child's actual social identity?

Mothers' accounts contained many examples of how their children were different from other children. The differences mothers described were drawn from comparisons to

the normative stereotype, that is to the virtual social identity of the ideal child. The themes that were identified reflected the mothers' descriptions of their child's actual social identity and the obtrusiveness of cerebral palsy and spina bifida.

Actual social identity of children with cerebral palsy. All mothers spontaneously compared their children's actual social identity to the normative stereotype of the ideal child (virtual social identity). This comparison illuminated the children's differentness or actual social identity.

The mother of a 2-year-old child described how she searched to understand her child's differences. In the context of the account, she recalled when she first recognized his differences and the subsequent medical examinations and tests that were done to explore his limitations. She explained that his "chromosomes were perfect, all the other tests were normal, so there is a blank." When her son was about 6 months of age, this mother had recognized that there was something different about him because "he wouldn't kick like a normal baby." She recalled thinking that "he looks like a normal baby." At 6 months of age, the doctor noted his arm was spastic and diagnosed him with cerebral palsy. At the time of the interview he was a toddler, and she continued to compare him to a developmentally normal child, saying,

A major worry is if he wouldn't walk in the future and with the talking because he's two and he's still not talking. . . . he's just finished commando crawling, so now he's doing the proper crawling now and pulling himself up and that's it. [06]

The comparisons that this mother made were based on the concept of "normalcy." She compared her child's progress in his motor and cognitive development to that of the ideal child. She recognized that he wasn't meeting normative developmental milestones. In

addition, she revealed that she was worried about his potential inability to ever meet these and other expectations.

Another mother described how she compared her child to his sibling (S.) and other children she encountered. She said, "I was comparing him to S., who was an excellent baby." Emphasizing some normal aspects of her child, this mother stated, "He had his CAT scan done, everything turned out normal. He had all this medical testing, everything turned out normal; his fatty tissue and fatty acids and all that, everything was normal." She elaborated,

To look at E. he looks normal. But when he was a baby or even up to maybe a year and a half old, to look at him you'd never think anything was wrong with him. . . . The hardest used to be watching other babies. You know, his age or younger, sitting up, clapping their hands and waving. Knowing he'll never do it.

[36]

This mother compared her child with cerebral palsy to his sibling, who was described as "an excellent baby." Being an "excellent baby" meant that the sibling fit or exceeded expectations based on stereotypes. Up to about 1 year of age, the child with cerebral palsy had appeared normal; however, after this point in time, his differences were apparent and the mother recognized that they would become progressively more evident over time. In an attempt to emphasize something normal, she recalled the medical testing that her child had undergone. All of these test results were "normal."

In depicting their children's actual social identity, mothers used adjectives to describe children with cerebral palsy. One mother spoke about her sister-in-law, who had had a miscarriage. She recalled how she told her sister-in-law, "Later it'll be a bad memory but you know like me, I've got a living memory every day" [01]. This comment

implies that this mother lived with a “bad” or negative image of her child, and that perhaps her sister-in-law, whose infant had died, was more fortunate.

Another mother described her state of shock when she first learned about her child’s disabilities. This mother delivered twins, but one died at birth. She said, “I went to the hospital thinking I’m gonna come out with two healthy babies, and I came out with one baby who was physically damaged. It was very traumatic.” This mother elaborated on what it was like to have an infant with disabilities: “And to have this happen! I mean, it disrupted my life. I’m a perfectionist at heart. And to have a non-perfect baby, mmm” [04]. She described her child as being “damaged” and “non-perfect” in an attempt to illuminate how her child was different in negative ways from the normal child that she had expected. This mother’s description of her child was similar to those from other mothers of children with cerebral palsy.

Another mother recalled that her husband had commented that “the average family has 2.5 children, ours has 1.5” [36]. This mother viewed her family as different, and the reference to having “1.5 children” illustrated that her husband perceived that something was imperfect about their child and that the child was less than whole. She explained that although others think that this comment is cruel, she and her husband felt that laughing about their situation helped them to survive.

Obtrusiveness of children with cerebral palsy. The following comments reflect how mothers perceived attention people paid to the child’s disability during interactions: “I think most people just focus on the disability” [07]; “They focus on that sometimes because they’re not used to it, and you know, like they’ve never been around any children with a disability” [11]; as a result, “there doesn’t seem to be an acceptance” [18]. These comments reveal how people directed their attention toward the child’s disability, which

made mothers feel uncomfortable during social interactions. Such undesired attention toward the children included expressions of pity, stares, starting up conversations about the disability, treating the child as a “non-person,” and teasing.

The following examples illustrate the undesired attention that people paid to children with cerebral palsy. The mother of a 10-year-old boy described family, friends, and others interacted with her child, who had severe physical and cognitive disabilities:

They all feel sorry for him, every single one of them and they treat him like he's a baby. Because he crawls he seems smaller than what he really is and they talk to him, like they talk down to him, and he doesn't really like that. He likes people to talk to him normally and he does have a very good vocabulary so I don't understand why people do talk down to him. [01]

This same mother elaborated further,

A lot of people have gone up to him, even if he's in a wheelchair and start saying (exaggerated speech), “Oh, hi N! How are you?,” you know and he goes. in a matter-of-fact manner tone of voice, “I'm fine, how are you?” . . . Like a lot of people will talk about someone in front of them as if they weren't there . . . and you know, like I've had people coming to me in the stores and say, “Is he handicapped or something, what is his problem?” [01]

These comments illustrate this mother's perception of how people focused on the child's disabilities. She described how the exaggerated speech and the inappropriate comments and actions of others were directed toward the child and highlighted his differences. In one scenario, people did not even acknowledge the child's presence as they talked about him, treating him as a non-person. During the interactions with others, the obtrusiveness and visibility of the disability became apparent, making the situation uncomfortable for

both the mother and child. This mother was sympathetic to her son's situation and was distressed by these unpleasant interactions.

Another mother described the unusual attention paid by strangers that she passed in the mall and her response to people who stared at her 9-year-old child:

I used to go shopping a lot with E., you know people would stare. This first year. I guess it really bothered me where I'd stare back or look at them like, What's your problem?" [36]

This mother described how stares from strangers illuminated the child's disability and differentness and made her feel uncomfortable. She described how she responded by staring back, in an attempt to make the strangers feel as uncomfortable as she and her child felt.

In summary, mothers compared their children's actual identity to the virtual social identity of normal children of comparable ages. They recognized that children with cerebral palsy were unable to meet expectations of the stereotypical norm. This difference was a result of their severe physical and cognitive disabilities. Furthermore, although mothers of children with cerebral palsy described positive comments about their children's attributes, they also used negative adjectives to describe their children.

Sixty-seven percent of mothers described situations in which people directed attention towards the child's discrediting attributes during interactions with him or her, which increased the obtrusiveness of the child's disability and, thereby, the visibility of the child's disability to others. These interactions occurred with family members, strangers, and other children.

Actual social identity of children with spina bifida. The following examples illustrate the comparisons that mothers drew between their children's actual social identities and the virtual social identity of the normal child.

A mother compared her 3-year-old child with spina bifida to a child who met the stereotypical ideal of the normal child in most respects. She stated,

She's like a normal, everyday child to me. There's nothing different to me except for the catheterizations. I can look past that. She's no different to me; she's an average, everyday child. To me she's more gifted than disabled. . . . But it's concerning whether she's an average 3-year-old, she has temper tantrums. I don't know how to explain her; she's just a typical everyday child. . . . She's normal in every other way except for her legs . . . a little bit different than other kids. she can't walk the same way as other kids do, can't get around as fast as they do occasionally. [09]

Despite the comparisons that this mother made of her daughter to "a normal everyday child," she still described being worried about the impact of her disabilities. As she described this impact, she concluded by excusing her child's differences, when she stated, "she's just a typical everyday child." This mother's last thought about her daughter's not being able to walk minimized her daughter's differences and stressed that her daughter was "normal" despite this limitation. As she described her daughter's need for catheterizations, she minimized this difference, acknowledging that she could look past her daughter's differences.

Similarly, another mother emphasized her son's normality in the following statement:

Life with N. is pretty much the way it would be having any 9-year-old boy in your house. . . . He's fortunate that he is very functional, very mobile . . . we look on N. as a normal little boy. . . . I guess the biggest difference is fitting his clinic and doctors' appointments in . . . he's really just like any other nine-year-old. . . . They've learned at school, in gym class, if there's running involved then they will modify the rules to give N. a little bit of extra time. But he doesn't sit out. You know he's a very physical kid and loves to be, you know, he's a typical nine-year-old boy. I can't stress that enough. . . . Just like every other kid on the street. . . . he doesn't have a two-wheel bicycle like his friends, but he does have a chain-driven trike with hand brakes." [10]

This mother described her son as "typical," "normal," "functional," and "able bodied," despite his discrediting attributes. She described how her son couldn't run the way the other kids do, therefore he required modified rules so that he could play baseball with them. This mother emphasized his normality by describing how he would not sit out of the game, calling him "very physical," and "a typical 9-year-old boy . . . just like every other kid on the street." She described his ability to master developmentally appropriate tasks not only through activities such as baseball but also through his ability to ride a bicycle like his friends. Despite her attempt to minimize her son's disability and emphasize his accomplishments, her description in fact highlighted his differences, because 9-year-old boys do not typically ride tricycles that require foot restraints. Regardless of these discrediting attributes, this mother reemphasized her son's normality by stating, "he fits in just like everybody else . . . he's able-bodied enough and he's very clever; he's very bright. . . . I don't think his degree of disability will get in the way." Throughout this mother's account, a comparison was drawn between her son and his

peers, who were able-bodied children. Attempts to minimize his disabilities were made so that he could meet some stereotypical expectations of the ideal child.

The following examples illustrate the adjectives that were used to describe children with spina bifida. One mother stated, “He’s different than the other kids. . . . The thing with U. is he doesn’t walk, but he’s not like a sick kid” [07]. “Different,” a common term used to describe disabled people, was used to point out how the child was unlike his peers. Yet, despite being “different,” his disability was minimized, as he was described as being otherwise healthy.

Another mother said that she had a “disabled child” and later referred to the child as a “special needs child . . . that was a little bit different than other kids” [40]. Once again, being “different” referred to the child’s disability and was equated with being deviant from the norm. *Special needs child* is a term used in some contexts in contemporary Canadian society to describe children with disabilities. This term refers to the particular discrediting attributes of the child, once again deviant from the norm.

Obtrusiveness of children with spina bifida. The following examples illustrate the undesired attention that people paid to children with spina bifida. The mother of a 10-year-old child stated,

Like if you go out into the public, you know people stare at her, you know they say, “Oh my God,” because she doesn’t look like there’s anything wrong with her. I get a lot of “Why is she in a wheelchair?” You know like, “What’s wrong with her?” Like her legs are perfectly fine and everything right, so they ask me. I say, “She can’t walk or else she wouldn’t be in one, she’d be up walking around like you.” [11]

This description of an interaction with strangers illustrates how this child was treated as a non-person when her presence was not acknowledged but her disability was discussed openly with her mother. The focus of this unsolicited dialogue was about her inability to walk, highlighting her disability. Again, these interactions with others highlighted the obtrusiveness and visibility of the child's disability, making the situation uncomfortable for both the mother and child.

Another mother described how peers at school teased her child. She recalled, "The first year in regular school was hard. E. had several flat tires in her wheelchair because the kids would pester her and poke pins in her tires" [30]. These interactions with peers drew attention to the child's disability and made it impossible to "cover up" her disability. The mother acknowledged how difficult this was for the child and herself. Other reminders of the child's differences were apparent in interactions with family members. This mother recalled how her "sister used to feel sorry" for her child. She said that family members "used to cry every time they saw her" [30]. This response once again drew attention to the child's disability, spoiling the child's social identity.

In summary, mothers of children with spina bifida compared their children's actual social identities to the normative stereotype of the ideal child (virtual social identity). They emphasized the children's many positive attributes when their children met these stereotypical ideals. Children with spina bifida were described in a way that was a closer fit to the stereotypical norm when efforts employed to normalize the children's differences were successful.

All mothers of children with spina bifida used adjectives to denote that their children differed from the normal child. I found that the adjectives employed by mothers were more commonly found in everyday language to describe children or people with

disabilities. Examples of these adjectives are “handicapped,” “different,” “special needs,” “wrong,” and “problem.”

Sixty-one percent of mothers described how people directed attention toward their child’s disability during interactions with them, which increased the obtrusiveness of the child’s disability and thereby the visibility of the child’s disability to others. These interactions occurred with family members and health care professionals.

Summary comparing children with cerebral palsy and spina bifida. All the mothers’ descriptions of their children’s actual identities included comparisons to the normative stereotype of the ideal child. Descriptors used by mothers of the ideal child included “normal,” “average,” “able-bodied,” “functioning,” “healthy,” “perfect,” “in good condition,” “excellent,” “fully independent,” “beautiful,” and “typical.” Mothers explained that to be “normal” or “average” meant that the child was “intelligent”: could “see,” “walk,” “run,” “stand up,” and “ride a bike”; “attend[ed] regular school”; and “look[ed] normal.”

Mothers described the importance of their children’s appearance and of the developmental milestones they had mastered. Developmental milestones were used as a gauge to measure their children’s progress. “Normal” medical test results served as another way to assess a child’s normality. Mothers took every opportunity to describe those crediting attributes that their children possessed so that they could be compared to the virtual social identity of the normal child. These efforts were made in order to minimize their children’s discrediting attributes.

Differences were also apparent in mothers’ accounts. Although children with spina bifida were at times discredited, more often they were described in a way that was a closer fit to the stereotypical norm when efforts to normalize the child’s differences were

successful. Mothers of children with spina bifida were also able to describe many more crediting attributes than were mothers of children with cerebral palsy. While mothers of children with cerebral palsy acknowledged their children's disabilities and their discredited social position, they also pointed out ways in which their children were normal. Despite mothers' efforts to normalize their children's experiences, children with cerebral palsy were unable to meet most expectations of the stereotypical norm (virtual social identity). The difference between the two subgroups may be related to the degree of disparity that existed between the types of disabilities. Children with spina bifida were physically disabled and dependent on devices for mobility, but appeared otherwise normal. Children with cerebral palsy were physical and cognitively disabled and required the use of wheelchairs. These children were unable to sit upright, control their behaviour, or communicate in a manner that portrayed a normal appearance.

All mothers used adjectives that are commonly used in society to describe people with disabilities. These were used in an attempt to explain how different their children were from others. They included adjectives such as "special," "handicapped," "disabled," "different," "damaged," "bad," and "imperfect." All mothers of children with cerebral palsy used more negative adjectives. These adjectives are more commonly used to describe damaged goods. All children with cerebral palsy required the use of wheelchairs and were cognitively impaired.

Eighty percent of mothers of children with spina bifida described unsolicited attention and remarks that increased the visibility and obtrusiveness of the child's disability, compared with 50% of mothers of children with cerebral palsy. Such attention to the child's visible differences served to stigmatize the child. This unexpected finding may be related to the social isolation experienced by mothers and their children with

cerebral palsy. These mothers had more equipment to carry and their children required more supervision. Therefore, these mothers were unable to participate easily in social activities with other parents, and the children were unable to participate in the normal activities of childhood.

Research Question 2

How do mothers of children with (a) cerebral palsy and
(b) spina bifida describe their own experiences of courtesy stigma?

All mothers described how their children's visible differences created social barriers for the mothers themselves. These social barriers included stigmatizing attitudes and actions that were directed to mothers during social interactions. Mothers described responding to the discourse they experienced by expressing feelings of inadequacy about having produced a child with disabilities and anxiety about anticipating devaluing interactions with others.

Discrediting behaviours directed toward mothers of children with cerebral palsy. The following are mothers' perceptions of discrediting comments or actions that were directed toward them. One mother described devaluing comments that were made about her efforts to care for her son at home. She recalled a conversation she had with her mother-in-law:

You know it's even said to me by my mother-in-law at one point of time before the marriage ended that I should just let B. go because he wasn't a worthy investment of my time. He was never, he was never gonna pay-off. [32]

Later, this same story was retold by the mother to describe her husband's feelings about her desire to care for the child at home: "He really felt that I was kinda off the mark and really deluded and that he felt that the professionals were right, that B. just wasn't gonna

amount to anything and he does want even now B. to be institutionalized.” These comments inferred that the child was not going to develop normally, regardless of the mothering that he would receive, so she should not bother to exert effort to nurture her child, but instead should institutionalize him. This mother perceived these comments to be very disturbing. As a result, she felt alienated by those family members who, despite being aware of her situation, she perceived were uncompassionate towards her.

Another mother recalled her perceptions of negative interactions with health care professionals. She said,

You know when you’ve got these professionals telling you something that you know is wrong and then insisting on it. . . . They ordered the wrong walker. totally unsuitable, it was a waste of money, like as soon as I saw it I said, “This is not for N.” The idea of him having a walker was for him to be upright and he was like practically bent halfway, you know, leaned over, and I said, “This is totally wrong,” and one day the therapist ordered another walker, which I don’t think is suitable for him either because again he has to be bent over, they don’t let him have wheels, and with the steps he’s scared to walk with them and he doesn’t balance right and so he’s constantly falling . . . I think they have to be more open than what they really are. As soon as I started dealing with professionals, I felt that they think they know everything. You know. And they consider the parents, just dumb parents, who don’t know anything, you know, and that’s how they talk to them, that’s how they treat them. And the parents know the child a lot better and if parents do something it should be taken quite seriously you know. [01]

This mother perceived that health care professionals did not support her efforts to advocate for her son. In fact, she felt devalued by the insensitivity of those professionals

who she perceived did not listen to her suggestions about her son's care and who openly discredited her with their demeaning manner. As a result, she perceived interactions with professionals to be disturbing.

Emotional responses to the courtesy stigma experienced by mothers of children with cerebral palsy. Mothers described experiencing feelings of inadequacy and anxiety in their accounts.

Mothers' feelings of inadequacy. Mothers responded to their courtesy stigma with feelings of inadequacy about giving birth to a child with cerebral palsy. The following examples illustrate this inadequacy as described by the mothers. A mother of a 10-year-old boy spoke about how she felt:

It was really hard at first, it made me feel, very inadequate knowing that N. had a handicap and that was really hard to take. Then of course the family members blamed me, you know, nobody else, so I took it pretty hard. [01]

This mother described feeling inadequate at a time shortly after her child was born. This sentiment did not change, as she reported later in the interview: "Yes I still feel that I'm to blame" [01]. This mother perceived that family members overtly blamed her for her child's disability, which subsequently contributed to her feelings of inadequacy.

A mother of a 2-year-old child described how she felt at the time that her child was diagnosed with cerebral palsy:

It was a shock. Because I thought a preemie was bad, you know. Because he was a preemie, I thought that was bad. And when the doctor came out with everything else, saying, you know, I thought, well what else could there be? And that was it. [06]

This mother described feeling unprepared for the news that she received about her child's diagnosis and long-term prognosis. She described how she thought having a premature infant was "bad." This child had cerebral palsy, epilepsy, feeding problems, asthma, growth retardation, and cognitive and motor impairment. The mother later described how she anticipated interactions with others and covered by concealing information from them because she perceived that she was to blame for her child's disability. She described her perceptions of what others thought of her:

I guess they blame the parents for it, you know. Like probably saying maybe I used drugs or something like that. But I don't drink, I don't smoke, I didn't use any tablets; as soon as I found out that I was pregnant, I never—I don't take Tylenol, no coffee, no tea, no Coke, you know, no sugar. So, no dancing, no jumping, no nothing, you know, I did everything. . . . But you never know what they're thinking, so that's why I don't tell people, because that's the first thing they'll say. You know, it's the mother, the mother did this, the mother did that, and that's it. . . . A lot of people, and a lot of people who are family say things about it. You know, like they don't say it in your face sometimes, somebody would overhear it, but they do talk about it behind your back. [06]

This mother described feeling inadequate because she perceived that she was to blame for her child's disability. This feeling was reinforced by family members and friends who she perceived overtly blamed her and contributed to the stigma that she experienced. As a result, she described anticipating the responses of others and presented information in a way that would protect herself and her child.

Mothers' descriptions of anxiety. Mothers of children with cerebral palsy described how they felt anxious in relation to anticipated interactions with others. One

mother of a 2-year-old boy described how she was anxious about what others thought of her, because she had produced a child with disabilities. She revealed,

You can't tell them everything (friends and family). Because you know they're gonna say, "Oh she has a handicapped child and this and that." Not everybody is ahm concerned and you know would take that in a good way; they'll think of it in a bad way. [06]

This mother described how she anticipated a negative response from those she told about her child's disability. In order to protect herself and her child from the stigma that would ensue as a result of disclosing information about the child's disability, she described how she chose to conceal this information from others.

A mother of a 15-year-old boy described how she felt about negative interactions with family members. She said,

I took it pretty hard. But I didn't really let anybody notice it because, you know I didn't want anybody to tell me the wrong thing and everybody I know seemed to say the wrong thing at the wrong time and so I kept to myself. [01]

This mother described how she was worried about negative comments from family members. In order to deal with this, she described withdrawing from those people who made her feel uncomfortable.

Summary. In summary, mothers of children with cerebral palsy described discrediting comments that were directed towards themselves. Mothers' efforts to provide the best for their children were devalued by some family members and some health care professionals who mothers perceived felt that the children were not worthy of the care and attention they received. These mothers responded emotionally to the courtesy stigma that they experienced. As a result, mothers described feeling inadequate because they had

given birth to a child with cerebral palsy and anxious about anticipated interactions with others.

Discrediting behaviours directed toward mothers of children with spina bifida. The following are examples of discrediting comments or actions that mothers of children with spina bifida described.

The mother of a 10-year-old child criticized the care delivered by health care staff, stating,

The staff there treat handicapped children differently. They always delayed getting to them and meeting their needs. One day, I went to visit my daughter there, and found her placed in the play room ungroomed, diapers showing and braces not on. This really bothers me, because I try to make sure she looks her best not her worst. We spend a lot of money on nice clothes and things so she can feel good about herself when she is in public, and they go and treat her like that! They always say, "I'll come, I'll come," and they just put her off. They just send her into the playroom and leave her there. [30]

This mother perceived that her child was being treated differently by health care staff because of her disability. It was of utmost importance to this mother that her daughter look her best. This effort ensured that the child's disability was not visible. In the example cited, this mother described how the staff failed to ensure that the child's braces were on and that her diaper was not showing. This mother perceived that the staff did not value the importance of assisting her to cover up the child's disability. The dismissive actions of the staff, "putting her off" and "delay[ing] getting to them and meeting their needs," were found to be humiliating to this mother. These actions seemed to anger this mother.

Another mother described her interactions with health care professionals during her child's hospitalization. Her daughter had been transferred to a new unit, and the mother was unfamiliar with the staff she met. She said,

I don't know the nurses and I'm nervous, and I don't know how they're gonna react the first couple times, I met a couple of those, I go, she's such a witch, I don't like them because of the attitudes that they hold at first. . . . Then they get more sensitive as time goes on—well I'm the nurse, I know more than you, ahm. . . . So at least some nurses that well you know, just blow you off like as if. "What you asking that for? It's none of your business anyway." [09]

At another point in the interview, she revealed her perceptions of a particularly negative interaction that she had had with a health care professional during her child's hospitalization. She said,

There was one nurse that I had . . . she was very abrupt in the way she came into the room, did her job and left. . . . And then the one day I came and I has an allergy to the solution that they used on her. So I went up to the nurse and said, "Well, why did you do it?" She says, "Well because it's for catheterization, that's the only way you can clean somebody." I said, "Well, it says on the chart that she's allergic to it and you should see the rash she has because of it." And all I said to her was that "I was thinking I'd write an incident report." And she just sort of looked at me and she went, "Go ahead, they won't fire me anyways." Like that was the kind of vanity she had like, I'm better than you, and no matter what you say you can't hurt me. . . . I was so upset. [09]

This mother described the negative interactions that she experienced when her child was hospitalized. She perceived that the nurse's interactions were disrespectful. The more this

mother advocated for her child, the more she perceived resistance from the health care professional. This interaction seemed to anger this mother.

Emotional responses to the courtesy stigma mothers of children with spina bifida experienced.

Mothers' feelings of inadequacy. The following examples illustrate how mothers of children with spina bifida described their responses to the social stigma they felt.

The mother of a 3-year-old girl described how she felt her child's disability was her fault:

Another thing I noticed is that when I. was first born I was really upset, I was blaming myself all the time, and a nurse said to me "It's not your fault. don't worry she'll be fine." And I looked at her and I said, "How do you know it's not my fault, you don't know anything about me." And I kept on going on and on and on about how I was no good. And she said, "You can be anything you wanna be just like I. will be anything she wants to be." So that gave me hope. . . . I blamed myself constantly for the disability. I blamed myself for everything I. had to go through. And then when I got home I stopped taking care of myself and her all the time. And then I went to the doctor and he told me I looked terrible. set me straight, told me if I didn't smarten up I was gonna end up in the hospital. So I realized heck, "I'll take care of myself so that I can take care of I." So I went through a lot of hard times before I finally got a grip on reality and realized that she's no different than anybody else. [09]

This mother described how she initially blamed herself for her child's disability and the suffering that ensued as a result. She described a health care professional wise to her situation that gave her "hope." Despite this support, she described how she still felt

inadequate and how she stopped caring for herself. However, she recognized that she needed to be well in order to provide care for her daughter. As a result, she “got a grip on reality and realized that she’s [her daughter] no different than anybody else.” This latter comment normalizes the child’s differences and the mother’s role in caring for her child, negating the child’s dependency on the mother.

Another mother of a 9-year-old girl described how she felt that she was to blame for her child’s disability. She stated,

I thought it was because of me. . . . Like because I was drinking or I was smoking or because I took vitamins at an early stage. Like I don’t know I thought it was me, you know. . . . Well, I figured out now that after that it happened there was spina bifida on my husband’s side, somewhere, and I thought that, “It figures!” and they never said it, or mentioned it. You know, I think that it’s hereditary, but on his side. And, I guess the thing that made me feel good is that I remarried. had a baby, and did the test and she came out perfect. [35]

This mother described how she initially felt that she was to blame for the child’s disability. It wasn’t until she recognized that the hereditary factor for her child’s disability was on the father’s side of the family that she was able to absolve herself from feeling guilty.

Mothers’ descriptions of anxiety. A mother of a 3-year-old child described feeling “nervous” when interacting with or anticipating interactions with health care providers who used medical terminology to describe her child’s condition. “I know I was very nervous at first, I was very quiet, very nervous. . . .” This mother contrasted her early interactions with health care professionals to her current interactions with the same professionals. She said,

Now I read everything through twice, if I don't like what they're doing, I tell them; if I don't understand the doctor, I'll look at him and I'll say, "In proper English, please," and they'll laugh at me and then they'll explain it to me. But I've become more controlling, more in control. [09]

This mother described how she felt intimidated and angered by the medical terminology that professionals used. This power difference made her anxious when she anticipated future interactions with professionals. However, she recalled that, more recently, she had been able to assert herself and, as a result, felt "more in control." The humour that she employed was useful in breaking the tension experienced during the interaction.

Another mother of a 10-year-old child described feeling anxious. She said, "You know, like you worry, worry, and then when it comes it's nothing. You wasted all that energy worrying, and even if it is something, that's not going to help . . . It just doesn't help. It just makes me nervous and I'm not the way I should be. So why should I worry. [11]"

This mother described feeling "worried" and "nervous." She went on to discuss her perceptions of the impact of "worrying" for so long, as well as her realization that she is somehow different from other mothers.

Summary. In summary, mothers of children with spina bifida described discrediting comments that were directed toward themselves by family members, school personnel, and health care professionals. These comments were perceived to demonstrate a lack of respect toward the mothers.

Mothers also described their response to the courtesy stigma that they experienced. Mothers described feeling responsible for their child's disability. In addition, mothers expressed a number of emotions, including anxiety in relation to

anticipated interactions with others. These mothers were anxious not only about how they would be received by others during that particular interaction, but also about the potential of being discredited.

Summary comparing mothers of children with cerebral palsy and spina bifida. Seventy-two percent of all mothers described experiences in which individuals made insensitive and devaluing comments directed to themselves; 100% of mothers of children with cerebral palsy and 60% of mothers of children with spina bifida described devaluing comments.

Sixty-seven percent of all mothers described feeling inadequate about giving birth to a child with disabilities at some point since their child's birth. Some of these mothers described how they had rationalized their feelings. Feelings of inadequacy were described by 100% of mothers of children with cerebral palsy and by 40% of mothers of children with spina bifida.

Forty-four percent of all mothers described ongoing anxiety in relation to anticipated interactions with others (40% of mothers of children with spina bifida; 38% of mothers with cerebral palsy). This anxiety was labeled by mothers as "nervousness" and "worry" and was related to the stigma they experienced. The content of their dialogue focused on critical events that related to their child's developmental milestones. Once again, the importance of their child measuring up to the normal child's virtual identity was described. When children were unable to do so, the mothers had the potential of being assigned a courtesy stigma. As a result, they described feeling anxious about this potential.

Research Question 3

How do mothers of children with (a) cerebral palsy and (b) spina bifida describe the strategies they employed to manage their child's stigma?

All mothers described employing strategies to manage the children's stigma and to enhance aspects of their children as individuals. These strategies were employed to *cover* the children's differences and to master activities difficult for the children to accomplish as a result of their disabilities.

Covering the discrediting attributes of cerebral palsy.

Correcting the child's differences. To cover the children's stigmatizing attributes, preventing them from being the focus of attention, mothers described how they used assimilative and avoidance strategies. The following are examples of assimilative strategies that were employed.

The mother of a 15-year-old described the importance of her son's computer and walker in covering his differences. This teenager had both motor and cognitive deficits. Although he could speak, his vocabulary was extremely limited. This mother said,

You know that's why we got him the computer speech, to learn how to read and write with the computer because he's got a problem with mobility. We were hoping that'll help. . . . We work with him with the computer, you know, we get him to know where the buttons are and press one button at a time and know how to do the spacing of the chart and we've been trying to teach him the alphabet, he does know it verbally but he doesn't know it by sight. He knows his name by sight but if you write his name he will recognize it, but he doesn't really know of letters. He has written a few like "m," "w," "I," "o," and "p" he knows how to write. We read quite a bit with him, that's why we buy computer software

specifically for him and we get a lot of movies for him that he would like, I have found that watching certain programs has really helped him to understand good and bad. Other people's emotions and things like that. We help him with the walker, you know to get him to walk and that. We try to come up with different ways of doing things. [01]

This mother described stigma symbols, which Goffman (1963) postulated make visible the person's disability. In this case, the computer and walker were stigma symbols.

Although the stigma symbols made visible the boy's disability, they were employed to assist her son to cover his differences. Computers are highly valued socially and often used to enhance abilities. Both were therefore instrumental in correcting the boy's differences. Goffman (1963) would consider this mother "wise" to her son's situation. She described how she fostered his independence by vigilantly working with him, using multiple means to assist him to compensate for the obtrusive nature of his disabilities.

Another mother of a 9-year-old child described how the wheelchair that she had selected for her child would be more functional. She said,

And the chair we had picked out would have given us a lot of freedom because it's got the little wheels—I had a picture of it—anyway, we thought, oh, this is going to be so great! I'll be able to push him to the garden. I couldn't even take him down to the garden (in the other chair). You know, we could go for a walk into town. [16]

This mother referred to the new wheelchair she selected as a "chair." Furthermore, she discussed being able to take her child out "for a walk" when they were able to get the chair. Both of these references served to normalize the symbol of the wheelchair to themselves and the interviewer.

The obtrusive nature of the children's differences caused mothers to want to stop unusual behaviour or to use strategies to avoid it from becoming visible to others. The following examples exemplify how avoidance was used to normalize situations.

The mother of a 10-year-old child described typical behaviours that she perceived as highlighting the obtrusiveness of his disability:

He already broke our V.C.R. He broke our vacuum cleaner, you know, because he tries, keeps trying to get things working more, taking things apart and he ends up breaking them. And it's hard to get him to stop doing that. Yeah, you have to get his mind on something else which he'd rather do, you know, but once he's got his mind set he's pretty stubborn. [01]

This mother described the child's activities, which in this situation highlighted the obtrusiveness of his disabilities. In order to cover his obtrusiveness and prevent it from becoming visible to others, this mother attempted to stop her son from doing the activity.

Normalizing the child's discrediting attributes. In some cases, the child's differences were judged in comparison to those of other people with disabilities, who were depicted as more discredited. The following examples illustrate mothers' descriptions of comparisons that were used to *normalize* the children's disabilities. These normalization efforts serve to present the children as ordinary.

A mother described how she compared her child to other children with disabilities. She stated, it "doesn't bother me any more now because you see so many kids, that you know, look even worse than E. does, you know, facially wise or whatever" [36]. Previously this mother had stressed that, despite E.'s profound physical and cognitive disabilities, his appearance was "normal." This was the attribute that this mother used to compare her child to others with more discredited attributes in an attempt

to normalize his differences. This case was different from the others in that “normalcy” could not be generalized in relation to the child but was specific in relation to one attribute, his appearance.

Another mother described how she compared her 9-year-old child to a child with an amputated limb. In her attempt to raise funds for her child’s equipment, she approached a service club. Subsequently, she was told, “Did you try War Amps?” She responded, “Well, he’s not an amputee. I felt like saying he’s not even circumcised.” The mother perceived the comment from the service club representative to be thoughtless and inconsiderate. This comment would be characterized as being made by individuals who were not wise to the mother’s or child’s situation. The mother’s satirical response highlighted the fact that there was a difference between her child with a physical and cognitive disability and a child with an amputation. In this case, the mother recognized that her child’s needs were greater than those of a child with an amputated limb. As she explained, “there is no respite anymore because there’s nowhere that can provide enough care to accommodate him because he is such extreme care and such complex care.” She elaborated by saying, “If S falls through the cracks, what have they got under their crack? A big coffin to catch them because they cost more than the other kids?”

Not only was this mother stating that her child’s care was more intensive, but also that it was more expensive than that for other children with disabilities. This mother also used numerous examples to illustrate her child’s vulnerability. In recalling one such example, this mother compared her child’s state of health following a recent hospitalization to that of a 90-year-old man. The mother felt that the quality of care that her child received during this hospitalization resulted in his present state. She said,

If I picked him up without his diaper on and turned him around the skin hung off his backside like a 90-year-old man. His legs were that big around. He had no skin on his face and he was pale. Bald spot on his head that I'm just getting rid of. [16]

This comparison highlighted the severity and vulnerability of the child's condition. This case is somewhat different from the other cases in that this mother used the comparison between the two different disabilities not to normalize the child's differences but to illuminate the severity of her child's disability.

Mastering developmental milestones. Mothers described how they assisted their children to master activities.

The following example details one mother's account of the activities her son with cerebral palsy attempted to master within his first year of life. She stated,

When N. sort of grew he, he was pretty active, I mean I worked with him for three months before anybody got involved with us and I got him crawling, pulling himself up, taking toys to him like reaching for toys, and bringing them to him. getting the bottle and drinking it on his own, I got him saying the one word which in Portuguese means "give" and it's an amazing word it's: "duh." Right. [01]

This anecdote revealed how developmental milestones such as crawling and speaking were important goals for her child to master at an early age. She vigilantly assisted him to acquire these milestones.

Another mother described her child's ability to master activities. She recalled, "He goes to camp. Now he's a star. He went, you know to camp for horse back riding for disabled children" [41]. This child was described earlier in the account as a child with severe disabilities who required continual supervision. In order to have him enrolled into

camp; she had to advocate on her son's behalf, because of the considerably long waiting lists. She described his new abilities with pride.

Summary. In summary, mothers described strategies to cover up the differentness of children with cerebral palsy. They described efforts to use aids that would ordinarily be considered stigmatizing symbols of differences to compensate for the child's disability. Avoidance strategies were also used to ensure that the obtrusiveness of the child's disability was not visible to others. Mothers minimized disabilities by contrasting their child with others who were more disabled. Helping the child to master basic developmental milestones was also a strategy used to overcome differences.

Covering the child with spina bifida's differences.

Correcting the child's differences. Mothers also described assimilative strategies that they used to correct the child's differences.

A mother of an 8-year-old boy described how she viewed the child's wheelchair: I don't even think about the wheelchair now. Like it's just . . . it's his feet so you have to go with the wheelchair, you go with the wheelchair or we walk to this place or we take Wheel Transit [wheelchair transportation] . . . you just get used to it and I don't even—sometimes I don't even think about the wheelchair. . . . I try to treat him as normal as the other two kids, so that I kind of try to forget about the wheelchair, not so much that I want to forget about it, but I just don't want it always there as a burden to me. I just want to get going and as I said, it's his legs. I just treat him like the other kids. When the other one asks me to put his shoes on, it's just U.'s got to get into his wheelchair. So it's just one of those everyday habits that you have to live with. [07]

This mother described how she no longer even thinks about her son's wheelchair. She equated the use of the wheelchair to his feet and identified that getting him into his wheelchair was just like putting on his shoes. It was an "everyday habit." This analogy normalized the use of the wheelchair. She went on to say that when he was in the wheelchair, "we walk." Both of these references served to normalize the symbol of the wheelchair and assisted the mother to cover his differences. The child was so fluid in moving around in the wheelchair that others ignored its obtrusiveness. The ease of his movement was evident in the following statement: "He's always bragging that he can speed around the track because they have to do laps around the track. So he can get around the laps faster than the other kids" [07]. Despite this, his mother explained that to compensate, "he's really having to push a lot harder, which I don't mind, it's good for him to push a little bit harder to keep up with the rest of the kids" [07]. This mother acknowledged that encouraging her son to work hard was in effect fostering his independence. This mother's assistance was an important aspect of covering his differences.

A mother of a 3-year-old girl normalized the use of her child's walker in the following statement:

Right now it's not a big problem at the day care all the kids think it's neat having to crawl around. I. is the ring leader, she crawls, and they crawl behind her. If she walks with the walker they all want a turn. [09]

This mother described the walker as a novel device that other children wanted to use. The walker was seen as an assimilative device assisting the child to walk and promoting the acceptance of peers in play.

The obtrusiveness of the children's differences caused mothers to want to stop the children's unusual behaviour or to use strategies to avoid it from becoming visible to others. The following examples exemplify this.

A mother of an 8-year-old boy stated the following:

What we always have to do is try to work our way around it and things. So we were talking about visiting, well my mother, for one thing. When we go for our visits or whatever, her house is easy enough because most of the visiting level is on one floor. But she does have steps to get up. So if he wants to go out, say with the rest of the kids, then he'll also say, "Can you help me get out?" [07]

This mother described how she searched for houses that did not have stairs. This was important because the stairs increased the obtrusiveness of the child's disability.

Avoiding stairs was the strategy that this mother used to cover.

Another mother described how she assisted her 9-year-old child to cover his incontinence. She said,

He'll come home or he'll come upstairs or whatever and say, "Mom! I'm wet." And ah, but no, I'll—I'll jog his memory and, you know, I'll call him up from downstairs. Or if he's going to a friend's house to play, I will make sure that he is clean and dry just before he goes out the door and that I know he's got three or four hours to play where he doesn't have to worry about anything. [10]

This mother described how she tried to anticipate the need to change her son so that he could remain dry when he was out playing. She was sensitive to the fact that his incontinence was visible to others when he was not changed frequently. As a result, she assisted him to avoid the visibility of his incontinence.

Normalizing differences. The following examples illustrate mother's descriptions of comparisons that were used to normalize the child's stigmatizing attributes. The child's disability was contrasted to what mothers considered were more severe disabilities in an attempt to explain how their children were in fact ordinary.

The mother of a child discussed the problems her 9-year-old child experienced: I just try to view him like a regular little kid that can't walk, you know. That's about it, you know. That's all he is. . . . The thing with U. is he doesn't walk but he's not like a sick kid. He is healthy other than that. Like you take him for a doctor's appointment and maintenance appointments and then they'll say. "Oh, this doesn't look right, so we have to, you know check on this kind of thing." And his bladder needs checking or his kidney needs checking, but knock on wood he's never been sick. . . . If he could walk then he would just be, you know. a regular little kid. . . . So, I mean, I think that helps a lot too, because if he was one of these types of children that were, you know, regularly sick and always—like he doesn't have medication. . . . I mean no matter what you have wrong with you: there's always somebody that's much worse than you are. [07]

This mother described how she compared her child to a "sick" child and to a child with a disability "worse" than his. Her comments about her child's ongoing medical assessments served to normalize his disabilities and to emphasize his healthy state. The last comment inferred that her child was better off than others with more severe disabilities were.

Another mother described being "nervous" when she learned how to catheterize her daughter with spina bifida. She said,

Like with I.'s catheterizations, when I first found out I had to do it I was like, "Well, no way, I can't do it, I can't." I was so nervous and so frightened. . . .

Never even seen it done before, never even heard of a catheter. . . . I saw some of the other kids (on the neurosurgical unit) that had growths on their head, or you know missing an eye or missing arms and legs. . . . and I. is mild compared to these other kids. [09]

This mother recalled how she was overwhelmed to learn that her child required catheterizations. She described how she compared her daughter to other children that she saw on the neurosurgical unit of the hospital whose disabilities she perceived were more severe. Comparing her child to others with more severe disabilities allowed her to normalize her child's difference. This relayed a message that her child was not that bad compared to others.

Again, another mother stated, "It's not the end of the world, like it's just she can't walk. Like I don't know what I'd do if my child was like totally disabled, mentally and everything" [11]. This mother concluded that it was better to have a child with a physical disability than a child with a cognitive disability. In contrasting the two disabilities, she was able to normalize her child's disability. She perceived that not being able to walk meant that her daughter was not "totally disabled," as was the case for a child with a cognitive disability. These comments and those of other mothers inferred that mothers thought children with physical disabilities were more socially acceptable than children with cognitive disabilities.

Another mother discussed the difference between her child and a friend's child who had both a cognitive and physical disability. She said,

There seems to be a distinction between mental disability and physical. Mental seems to be more disturbing to people that have to deal with it and how they're

going to accept this person in the community . . . when you know it's been a birth defect and it's not contagious at all. [18]

She went on to explain that despite her child's differences, she perceived that her child was accepted by her family and others. Once again, a comparison was drawn between a physical disability and a cognitive disability. The latter was depicted as more severe. This comparison was used in an attempt to minimize this child's disability.

Mastering of activities that are limited to the child with spina bifida because of his or her differences. Mothers also recalled activities that their children attempted to master.

One mother of a 9-year-old described her child's ability to master activities that were difficult for him because of his disability:

When he plays baseball, ahm, with the other kids in the summer, he knows he can't run the way the other kids do. Ahm, the only adjustment there is a mental one, knowing that even if he hits the ball, which he does very well, ahm. chances are he's not going to make it to first base. But there's no way anybody else is gonna run for it. That was discussed and it was a flat, no, he'll do it himself thank you very much. . . . He does everything else. We have not attempted skating.

Skiing yes. Again with a few modifications. My husband was a ski instructor and a number of years ago was involved in what they called a Track Three Programme which is a skiing programme I believe at the ski hill for disabled kiddies—blind, cerebral palsy, muscular dystrophy, spina bifida—and he was able to use that experience and knowledge. N. was only three or four when he started skiing. You just have special things that are on the market, to attach the skis together at the toes, at the tips so that they stay together. And when he was little there's a special harness, called Wee-is, wee, which again able-bodied normal kids their parents

have for them too, and it's just so this kid can ski in front of you and you hang on to them and they don't get away from you going down the hill; we used that when he was younger. Swims like a fish, he doesn't have a two-wheel bicycle like his friends, but he does have a chain-driven trike with hand brakes. . . . Other than that, N. downhill skis, N. swims like a fish, N. rides his bicycle, N. plays baseball. Ahm. there's very little N. can't do. [10]

This mother recounted proudly how her child was very active in a number of sports—baseball, skiing, and swimming. In an attempt to deal with the limitations he faced, a number of adjustments or modifications were required for him to master these activities. The adjustments described were both physical and psychological. Physical modifications included ski attachments to keep the ski tips together and a harness. Psychological modifications included lower expectations on the part of both the child and the parents. Assistance to succeed in these activities was provided by both his mother and his father. Assistance provided was based on both knowledge of this child's limitations and an awareness of programs for children with disabilities.

A mother of a 10-year-old girl discussed the importance of wrestling in her family. She said,

We wrestle in our family, and even though L. has splints and casts and bags that come off if she wrestles too much, it was important to get her in there wrestling. And she did. And to encourage her to not say "be careful" too many times during the day. They say it often enough, but they have to be able to explore and try things. And she has broken her leg three times by accident and that hasn't been nice; but I wouldn't trade that for a timid child. [18]

Despite the fact that this child had broken her leg three times and wore splints and casts, participating in wrestling was described as an important activity in this family. In particular, it was important that this child was not treated differently by asking her to “be careful.” The mother encouraged the child to master this activity so that the child was not perceived to be timid or different in any way.

Summary. In summary, mothers of children with spina bifida used strategies to cover their child’s physical differences. These mothers described efforts to use aids that would ordinarily be considered stigmatizing symbols of the child’s differences to assimilate the child into social situations. Avoidance strategies were also employed to ensure that the child’s disability was not visible to others. Mothers normalized the child’s disability by contrasting their child with others who were more severely disabled. Mastery was also used as a strategy to overcome differences and to assist the child to be more independent.

Summary comparing children with cerebral palsy and spina bifida. All mothers described using strategies that involved both assimilative and avoidance techniques. Assimilative techniques involved using symbols that usually signified stigma to assist the child to assimilate into mainstream society. Wheelchairs were referred to as “chairs” by mothers in both groups. This use of the term *chair* was a folk term familiar to this group of mothers. Analogies that normalized the child’s situation could also be drawn from the wheelchair symbol. For example, wheelchairs were described as “shoes” or other means of mobilization, and the child’s difference was thereby covered. Fifty percent of mothers in both groups also avoided situations that made the obtrusiveness of the child’s disability visible. This strategy ensured that the mechanics of interactions were fluid, thereby covering up the obtrusiveness of the child’s disability. Sixty percent of mothers of

children with spina bifida and 38% of mothers of children with cerebral palsy used avoidance strategies.

All mothers described how they recognized that their children were different from the stereotypical norm. This was apparent in mothers' descriptions of their children. The child's disability was compared to what mothers considered were more severe disabilities. One-third of the comparisons drawn contrasted physical attributes with cognitive ones. These comparisons reflected hierarchical differences within and among the disabled.

Forty percent of the mothers of children with spina bifida described using comparisons that contrasted discrediting attributes, compared with 25% of mothers with cerebral palsy. Mothers of children with spina bifida used these comparisons to minimize the child's actual identity, whereas mothers of children with cerebral palsy experienced more difficulty in being able to minimize the child's actual identity. Two outliers were noted; one of the mothers used comparisons to highlight the severity of her child's disability, and another compared only one of her child's attributes.

Seventy-eight percent of mothers described how their children strived to correct their condition indirectly by trying to perform activities that they were unable to master as a result of their disabilities. These activities included crawling, walking, talking, developing independence, riding a bike, skiing, and running. Mothers, wise to their children's needs, often ensured that modifications were employed to assist the children to successfully master these activities. In addition, they fostered their children's development by vigilantly assisting them to master activities.

Eighty percent of mothers of children with spina bifida and 75% of mothers of children with cerebral palsy described how they helped their children to master activities.

Differences that were noted between the two groups related to the types of activities in which they were able to engage. Children with cerebral palsy were found to be more limited in activities that they could perform as a result of their functional abilities. These children were unable to sit upright, control their behaviour, or communicate. Activities that mothers assisted them to master included walking and communication. Activities that mothers assisted children with spina bifida to master focused on developing independence and included activities of daily living (catheterizations, enemas, dressing themselves) and play activities.

Research Question 4

How do mothers of children with (a) cerebral palsy and (b) spina bifida describe strategies employed to manage their courtesy stigma?

All mothers described using strategies to manage their own courtesy stigma and portray normality. These included strategies to cover and to seek affiliation and dissociation in order to maintain normalcy.

Covering courtesy stigma of mothers of children with cerebral palsy.

Use of humour. Mothers employed humour when they discussed their personal situations. For example, the mother of a 4-year-old child who had severe brain damage described how she dealt with her situation:

I'm a Type A personality. It was very difficult for me . . . like my pregnancy up to the point of delivery was perfect. Early, I knew I was having twins, I'd eat all the right foods, I try and eat all the foods to make sure I was having adequate amount of each food group, I mean, I was like that. And to have this happen! I mean. it disrupted my life. I'm a perfectionist at heart. And to have a non-perfect baby.

mmm. But I handled it, I coped. Well, I got this child, you know, I can't send her back. [04]

This mother first identified that she coped with the fact that she had a child with disabilities. This was an interesting comment, since earlier in the account she revealed that during the first year of her child's life, her disabilities were not apparent and she could treat her as a "normal baby," allowing her to pass as normal. However, after the child's first year, passing as normal was no longer possible. She remarked humorously, "Well I got this child, you know, I can't send her back." Although she expected a normal child, she did not have a normal child. This latter remark was delivered with an ironic undertone and revealed the lack of control that she felt she had over her personal situation.

A mother who was attempting to raise money for her son's equipment remarked, "They said, did you try War Amps? I said, 'Well he's not an amputee.' I felt like saying he's not even been circumcised [laugh]. You know, you just get like this. I'm going crazy" [16]. This mother used humour to express her frustration in this situation. This mother perceived not only having to raise money but also the service providers comments as frustrating and demeaning. The comment "You just get like this, I'm going crazy" illustrated her level of frustration. This mother contrasted her son's cognitive differences with other children's physical differences in her comments "Well he's not an amputee" and "he's not even been circumcised." She made light of her child's differences during the interview in order to release the tension that she felt.

Another mother of an 11-year-old child who was severely disabled used humour to release the stress she was experiencing. This was apparent in the following comment: "Well God only gives you what you can endure and you must be very strong, you know,

so strong. I'm getting brittle! I'm gonna crack, you know" [32]. Later she commented, "Well good Lord if I grow any more I'm gonna explode! You know [laughs] I don't really need all this!" [32]. This mother identified how difficult her situation was, yet relayed expectations that she must endure the difficulties she was experiencing. The comments "I'm getting brittle," "I'm gonna crack," and "if I grow any more I'm gonna explode" were juxtaposed with comments that she made indicating that she required strength to endure her situation. Humour was used as an emotional release for this mother.

Establishing relationships with the considerate. Mothers spoke of the consideration that others extended to them and their child. Goffman (1963) suggests that these individuals would be considered the wise. These individuals were considerate in that they recognized the mother's plight while they respected the awkwardness of her situation. Mothers found some health care professionals, family members, and neighbours to be considerate.

Mothers of children with cerebral palsy described the following about the considerate. The mother of an 11-year-old boy discussed a health care professional who cared for her child as follows:

Oh I don't care, it's probably just a stupid thing to say, I think the finest quality in professionals or anyone is respect. To respect that everyone brings something to the situation that is valuable and to honour where that person is at and try and help them get to a healthy place, but Q. was very, he had that sensitivity and that respectfulness, and with B. he came in, which is non condescending, you know, not needing to put yourself on a pedestal or think you know best, you know or everything or whatever . . . and he came in to check on B. and said, "B. how are you doing, does it hurt?" and many things were said, and he said, "Does it hurt?"

and he said, “does it hurt a lot, or does it hurt a little?” and B. right away, put his, and I mean he’s very young, you know, and he puts up his hand, and they’ve never done this before, and he goes like this . . . kinda thing, “well it hurts a little.” [32]

This mother described a health care professional with whom she had established a positive relationship. One of the reasons that she felt he was *considerate* was the respectful manner in which he interacted with her child. This health care professional addressed the child directly in his interaction; as a result, the child responded to him in a way that the mother felt he had never done before.

Another mother of a 9-year-old child described a health care professional she encountered. She said,

One hospital might be able to care for S. when they open their new wing in January. Might be able to. . . . Yes. I’m going down to check it out. One of the things in favor of that particular hospital is that S.’s grandparents and my ex-husband’s side of the family live there, not far from that hospital so he would have visitors and that. . . . And also, the head nurse there that I was speaking with knows S. from another hospital, so that’s a plus. So now it’s—although they don’t have a constant care facility where there’s a nurse right in the room, they have like two rooms with the station in the middle with the glass windows, and there would be a nurse at the desk. [16]

This mother described how a professional was considered helpful. Although this mother identified many health care professionals who were not helpful, she was able to identify this one who was helpful because the health care professional “knew” S. Knowing S. in a way that attuned the health care professional to his particular needs made her wise to his

situation. As a result, the mother described how this influenced her to consider the facility for respite.

Limiting relationships with others. While relationships were maintained with considerate others, relationships with those individuals who were perceived as not being helpful were limited. Mothers of children with cerebral palsy identified the following about those individuals with whom they limited their relationship.

One mother of a child recalled her interactions with health care professionals. She began by describing how one nursing agency and a home care agency would send two nurses because they felt that one nurse was not sufficient to care for her son. Unfortunately, the mother did not have full nursing coverage, so she had to cope for 48 or 60 hours alone without nursing care. She said,

But you're his mother. So what? Do I have wings and a halo? We're talking like I'm a normal . . . yeah. Like no, you know. But I get these clichés, you know, those that need it the most don't get it, kids like S. fall through the cracks, and there's no money. I am so sick of hearing it. Now when they call a meeting I just say look, if you're gonna say either of these three things, please do not attend the meeting. If you have some positive ideas to help me, I wanna hear them. But otherwise don't come. I don't need it. I've heard it eight million times. [16]

This mother described how she was frustrated by her perception of the lack of understanding that many of the health care professionals whom she had to deal with demonstrated about her situation. She felt that their comments seemed to imply that the child didn't deserve care. This was apparent in the comments that professionals made to this mother in order to justify their inability to provide more care. Her comment "Do I have wings and a halo" relayed her perception that the expectations placed on her

required superhuman capabilities. In an attempt to maintain a positive outlook, she limited her involvement with those individuals who she perceived were not helpful to her by making it clear they should not come to meetings if they were to portray a negative picture.

One mother contrasted the help received from her family with that from another parent. She said,

It's the adults that really tick me off sometimes. . . . My younger sister she has a little girl that's Down's. So, my mother felt that when she had this little girl they didn't know anything beforehand that it was Down's. She said, "So why don't you call your sister, you know, and tell her you're there for her and stuff like that." I said, "Yeah, if she wants me or needs me I'm here." You know, nobody was here for me. Ahm . . . I don't think anybody really understood because nobody in our family was really involved with any kind of child with a disability so they probably didn't know what to do. I didn't know what I wanted from them but I wanted something. You know, I didn't, you don't want pity, because that would just set me off in tears. I think for the first year I cried every night and then when somebody would say, "Oh, you're doing a great job, I'd break down and cry; don't tell me that. . . . There were two other children there (at the Y) that were similar to E.; and I got to know the mothers quite well. . . . I remember talking with one mother on the phone for an hour one night and that woman made me feel so good. . . . We got on the phone and we talked for an hour . . . and the relief I felt just talking to her for that hour, you know, finally, someone understands, you know, and we got to be quite close friends. . . . Like support groups were great, but you can't—like you have to get a one-on-one with somebody, and someone that you

like. And it's hard finding someone like that. . . Like you need more than finding out just what services are out there. . . . Like I couldn't talk to my mother about it, I couldn't talk to my sister about it, you know. How would they know? [36]

This mother perceived that her family was not there for her when she needed their support. She felt that they couldn't support her because they would not be aware of her needs and how to help her. In addition, she described support groups that were helpful for learning about resources and funding, but for little else. She contrasted this experience with her family and support groups with the support she received from another mother with a child similar to her own. The support she received from this woman was described as helpful because the other mother was sensitive to her needs and could assist her to anticipate resources she would require. This difference in the support offered might have been a result of experiential knowledge that the friend had gained through raising a child with physical and cognitive disabilities. As a result, this mother sought help from those who could provide assistance in a sensitive but useful way and limited the assistance she sought from those who did not understand her situation and who responded with pity. Responding to the mother's situation with pity did not permit her to normalize her family situation. Hence, her relationship with these individuals was purposefully limited.

Portraying conventional family life. Mothers described their family life in their accounts of raising a child with disabilities. One mother of a child indicated the following about her family life:

Everybody loves him. They respect him. Like you know, I have two sister-in-law, they . . . before not much, but now, you know, they are really getting close to him too. He loves to go there; have supper with them. They live on the other side of there [pointed to neighborhood], so we are close. [41]

This mother described how her extended family was an important support to her. These relatives lived across the street and assisted the parents with childcare. Early on there seemed to be tension amongst family members; however, this mother explained how her sisters-in-law had accepted her son despite his differences. Family members were described as wise to the mother's and child's situation. Although being close is once again portrayed as conventional family life, the family's circumstances were not conventional. Access to extended family was helpful to this mother in managing the extraordinary demands that she and her son experienced.

Another mother described her family life. This mother, who was divorced and raised her two children alone, said,

I was an ever present mother, even though I had to drive 5 hours to get there and every other weekend I was there and made attempts to bring B. home until he became ill and then I was basically living there, so, he never was not a part of the family, but the way I tried to look at it was once I looked at the Rehabilitation Centre was that they became an extended family. And that um, we try and work together. [32]

This mother's dedication to her son was apparent in her effort to bring her child home from the Rehabilitation Centre whenever she could. When this was not possible due to his illness, she stayed with him. She portrayed the staff at the Rehabilitation Centre as extended family, in an effort to depict a normal appearing family life despite the extraordinary changes that had occurred for her son and herself.

Summary. In summary, all mothers of children with cerebral palsy used humour to release the tension that they experienced. This humour was delivered with sarcastic undertones. Efforts to maintain normalcy involved seeking affiliation with those

considerate to the mother's situation and dissociating from those who were not deemed helpful, while portraying an ordinary family life despite the extraordinary demands that mothers experienced.

Strategies employed to cover courtesy stigma experienced by mothers of children with spina bifida.

Use of humour. The following are examples of humorous remarks. A mother discussed a principal's efforts to transfer her child to another school because he refused to put in a wheelchair ramp as she requested. This mother responded, "But hopefully he'll be gone by the time she hits grade seven. . . . I hope so, or make him some big shot Board of Director or something" [11]. This mother described how she was advocating for her child, attempting to have the standardized architectural configuration of the school modified to meet her child's needs. This mother perceived a difference of opinion between the principal and herself. She described how the request was outrightly rejected numerous times by the school principal. The solutions this mother expressed—"hopefully he'll be gone," "make him some big shot Board of Director or something"—were delivered in a humorous manner. They represented an emotional release of the frustration she experienced.

A mother of a 10-year-old child made light of the situation the family found themselves in as a result of the numerous appointments that her child required. In order to meet her child's needs, she solicited help from family members. In describing their situation, she said, "We were kidding when the song, The Travelling Willbury's came out that that's what we were. We always seemed to be on the highway going to and from doctor's appointments" [18]. This mother describes how her family joked about their

situation in order to deal with the numerous appointments that were required and that disrupted family life.

Establishing relationships with the considerate. Mothers of children with spina bifida discussed the following about the considerate.

One mother of a 10-year-old child described her family members as being helpful: Everyone has become involved. In our situation, as far as trying to help out, become educated about the situation, basic care, trying to figure out and learn the kind of care L. would need if she was visiting in their home. Trying to help out on our visits to the hospital, visiting us down here when we're down. And it opens up a whole new world of experience, having this happen, for you and the whole family, too, I would say. [18]

The considerate attention received by the child during her hospitalizations was particularly important to this mother. "Helping out" was described as learning about L.'s needs, participating in caregiving, and visiting the family. This sensitivity to L.'s needs and the family's needs were recognized as considerate attention from those wise to their situation.

Another mother of a 9-year-old child described the helpfulness of a neighbour: He has one little friend at school. . . . But this little friend's mom is really good; and when N. was still in diapers, we would send a couple over in a paper bag and she had, you know, no qualms at all about changing him. Her biggest concern was, will it be okay with N. if I change him? And in the case like that I'll talk to N. ahead of time. Ahm, and say, you know, you're going over to K.'s. mum, you know, doesn't mind changing you because you're going to be there, you know, from lunch time and have supper. [10]

This mother described how the neighbour demonstrated sensitivity toward the child's special needs. Not only did she offer to change a 9-year-old child's diaper, but also she respected his dignity by asking his mother if he would mind if she did this. This gesture of kindness, changing a diaper, also permitted a social act of kindness, ensuring that the child could cover his difference. In addition, this action allowed the child more time to play with her son. The kindness and sensitivity demonstrated by the neighbour were recognized as considerate attention toward this child and mother. In this way, the neighbour was wise to the mother and child's situation, and she assisted the mother to cover the child's differences.

Limiting relationships with others. One mother of a child described her involvement with parent support groups. She said,

I feel in groups . . . we can talk, and whatever, but nothing gets done. Nothing. That's why I don't like attending these things, and I don't go to any functions. because I find like I try to find my own way. . . . I don't like getting involved in parents' groups, because if we talk where does our word go? It goes where? Just between us? We're getting our feelings out. So what. So what that's what we feel. Nothing is getting done. Like I'd love to see a parent that, like, if something was done, they'd be going, "Oh great," you know, "Thanks." It's a waste of time for me. I can't be bothered. [35]

This mother described how she limited her involvement with parent support groups because she felt that there was little action taken on what was said in them. This, she felt, was a waste of her time. She preferred to find her own way.

Another mother described what it was like to be a first-time mother bringing her child with spina bifida home. She said,

I think you need more support in the home. But you're terribly protective of your time when that happens to you, you don't want to see anybody or talk to anybody. So that's the time when I didn't want to talk to anybody about this, I needed to deal with it myself first. So as I said, we need support. [18]

This mother described not wanting to talk to anyone at the time she brought her child home. She rationalized her decision, stating, "I needed to deal with it myself first." It was during this time that she limited her contact with others, despite the need she identified for support.

Portraying conventional family life. A mother described her family life as follows:

She gets along with her sister, and they play their own games, and make up their own things. . . . She only knows what's in here because we can't, like, expand horizons for her because it's difficult, and that's why we have a close bond together. You know, we get along, we laugh and we take her out and whatever. It's great, excellent. . . . My daughter loves me so much. I'm her best friend. I'm like her sister, and all the time it's, "mummy, mummy, mummy." She's a very happy girl. She's very talented. Um, she enjoys being around people. She's caring. She's gentle. Um, we've got a great relationship, excellent. There's no problems: nothing at all. She's a very happy little girl, very happy. [35]

This mother spoke about the harmonious relationships her daughter had with her sister and mother. Although she regretted not being able to provide more for her child, a positive family life was one good aspect that she could provide. She recalled being able to take her child out and having a good time doing so. This was important to portray since it was an aspect of normality.

Another mother of a child identified aspects of their family life:

We look at N. as a normal little boy. I guess the biggest difference is fitting his clinic or doctors' appointments in. Other than that, ahm, N. downhill skis, N. swims like a fish, N. rides his bicycle, N. plays baseball. There's very little N. can't do. He goes on all our family outings with us, ahm, we really have not had to alter or adjust our lives in any way shape or form. [10]

This mother described N. as "a normal little boy" and a member of a typical family. The mother made a point of saying that N. went to "all family outings" and required no changes to their lives in order to do so. This comment stressed the importance of portraying a normal family life despite the extraordinary accommodations required for the child's particular disabilities.

Summary. In summary, mothers of children with spina bifida employed humour to release the tension that they experienced. This humour was delivered with sarcastic undertones. Efforts to maintain normalcy involved seeking affiliation with those considerate to the mothers' situation and dissociating from those who were not deemed to be helpful, while portraying an ordinary family life despite the extraordinary circumstances the mothers dealt with.

Summary comparing mothers of children with cerebral palsy and spina bifida. Mothers of children with cerebral palsy (88%) and spina bifida (20%) employed humour to release the tension that they experienced. This humour was delivered with sarcastic undertones.

Mothers of children with cerebral palsy and spina bifida described the consideration that some people gave to them and their children, as well as the comments and actions of people whom they perceived as not helpful. In addition, they portrayed a conventional family life, despite the extraordinary circumstances they dealt with.

Seventy-two percent of mothers described considerate individuals. Of these mothers, 80% of mothers of children with spina bifida and 63% of mothers of children with cerebral palsy found individuals considerate to their situation. Those considerate individuals recognized the mother's plight while they respected the awkwardness of her situation. Moreover, they also paid considerate attention to the child's needs. It is for these reasons that the mothers maintained their relationships with the considerate. On the other hand, mothers commented on how it was difficult to talk to others when they perceived that this discussion was not productive or helpful to them. As a result, they described their attempts to limit their involvement with these individuals. Fewer mothers limited relationships (22%). These included 20% of mothers of children with spina bifida and 25% of mothers of children with cerebral palsy. Forty-five percent of mothers described a conventional family life that depicted a stereotypical image of normality. This strategy was used to cover the extraordinary circumstances they found themselves in because of their child's disabilities. Mothers described in their accounts how they were close, happy and active as a family unit. These included 50% of mothers of children with cerebral palsy and 40% of mothers of children with spina bifida.

CHAPTER IV

DISCUSSION AND IMPLICATIONS

Discussion

The purpose of this study was to describe similarities and differences in the stigma described by two subgroups of mothers whose children had spina bifida or cerebral palsy. I reanalyzed interview transcripts that had been transcribed for a larger study (McKeever, 1993). Eighteen mothers met the inclusion criteria used to determine the sample for this thesis. Eight mothers had children with cerebral palsy and 10 mothers had children with spina bifida. All children had physical disabilities that impaired their mobility, and those children with cerebral palsy also had a cognitive impairment. Many of these children had profound disabilities and had multiple diagnoses.

A two-part home interview had been conducted in the original study to determine the daily activities, subjective experiences, and life circumstances of mothers of children who had severe disabilities due to a variety of conditions. Mothers' narrative accounts were elicited using open-ended questions in a focused interview. A structured interview format elicited descriptive information about the children and descriptions of their daily care requirements. I reanalyzed the interview transcripts of mothers whose children had cerebral palsy or spina bifida.

The data were reanalyzed according to the steps outlined by Miles and Huberman (1994). Goffman's conceptualization of stigma provided the framework used to re-interpret the interview data. The goal was to identify and compare experiences of stigma that were embedded within mothers' accounts of raising children with one of two disabling conditions in order to determine if more stigma was described for children with

cerebral palsy and their mothers. Mothers recounted stigmatizing behaviours directed towards their children, courtesy stigma that they experienced by virtue of their close affiliation with their children, and strategies they employed to manage both types of stigma.

All of the mothers described numerous examples of how their children deviated from the stereotype of the ideal child. Mothers spontaneously recalled examples of these deviations from both the past and described those that were ongoing. Many examples were given from situations such as the child's birth, communication of the child's diagnosis, and various transition points associated with developmental stages of childhood. All mothers emphasized their children's abilities to master some developmental milestones even if they occurred at delayed rates. In addition, they described the children's attributes that could be compared successfully to the virtual social identity of the ideal child. These attributes included having a close to or partially normal appearance, as well as functional abilities that allowed participation in childhood activities such as skating, riding a bike, and playing baseball. Children with spina bifida were more often described by their mothers in a way that revealed their abilities to approximate the stereotypical norm in many contexts. Efforts to minimize or compensate for the children's discrediting attributes were also described. In contrast, children with cerebral palsy were described as being unable to meet expectations associated with the norms of childhood. All mothers used adjectives to describe their children's actual social identity. These descriptions denoted that their children were very different from the ideal child. All mothers of children with cerebral palsy used negative adjectives that commonly are used to describe damaged goods, such as imperfect, damaged, and bad; whereas

mothers of children with spina bifida used less pejorative adjectives to describe their children, such as special and different.

According to Goffman (1963), ideas about discrediting attributes are based upon stereotypes, or virtual social identities, against which individuals are judged. In situations in which a stigmatizing attribute is recognized, for example, when a child with spina bifida attempts to run during a baseball game, a discrepancy is noted between the social identity of the ideal child and the actual social identity of the child with a disability. Goffman (1963) described how those *wise* to the discredited person's situation not only recognizes these discrepancies, but may attempt to manage information about the discredited attribute in order to make it less evident to others and thus minimize stigma. According to Goffman (1963), these individuals provide a model of *normalization*, extending the realm of what is considered normal by treating the individual as if he or she did not have a stigma. This applied to mothers in this study because they highlighted their children's normal attributes to enable them to be compared successfully to non-stigmatized children. Even the children with cerebral palsy who had profoundly discrediting attributes had attributes that were normal, such as genetic makeup. Children with spina bifida had many crediting attributes, such as academic giftedness.

Mothers' descriptions of interactions highlighted how unsolicited attention served to increase the obtrusiveness of the childrens' differences because it revealed the childrens' discrediting attributes. Goffman (1963) argued that recognition of these discrepancies results in the discrediting or spoiling of the child's social identity. Mothers of children with spina bifida described more instances of unsolicited and unwanted attention (80%) and remarks from others than did mothers of children with cerebral palsy (50%). This discrimination occurred during interactions and focused on both the

childrens' and mothers' differentness. Mothers perceived these interactions to be distressing because they were unable to protect their child from the stigma that the children experienced.

These findings resembled those of other investigators who have examined the impact of discrimination on children (Tackett et al., 1990; Tobiasen, 1987; Turner et al., 1997; Turner-Henson et al., 1994). Other investigators have found that children with disabilities experience negative evaluative connotations about their differences (Tackett et al., 1990; Tobiasen, 1987; Turner et al., 1997; Turner-Henson et al., 1994). Turner-Henson and colleagues (1994) found that the visibility of the child's disability and the severity of his or her disability increased negative discrimination directed towards the child. Moreover, investigators in two studies found that parents experienced stress about the reactions of others to their children (Baxter, 1989a; Tackett et al., 1990). These reactions included staring at the child, treating the child differently from siblings, drawing the attention of others to the child, changing the tone of voice, treating the child as if he or she were much younger, displaying discomfort, ignoring the child, or being overly sympathetic. These discriminatory behaviours were made by adults (Baxter, 1989b; Tackett et al., 1990; Turner-Henson et al., 1994) and by children (Tackett et al., 1990; Turner et al., 1997; Turner-Henson et al., 1994).

Although mothers in this study had not been asked about the stress they felt with regard to their negative interactions with health care professionals, they spontaneously described that they found these interactions disturbing. Other investigators have also examined the relationship between professionals and parents of children with disabilities. Many described discriminatory attitudes or remarks made by health care professionals as having a negative influence on relationships with parents (Baxter, 1989; Knafl et al.,

1992; Patterson et al., 1994; Van Riper et al., 1992). Baxter (1989) concluded that such remarks were distressing to parents. Stewart and colleagues (1996) found inappropriate or absent support to be very stressful to parents. These findings support the concerns by mothers in this study. Mothers in this study also described positive interactions with health care professionals who demonstrated respect, compassion, and professionalism. Goffman (1963) would describe these individuals as the considerate wise, privy to the mother's situation and helpful to her in times of need. Only two studies have reported supportive interactions between mothers of chronically ill children and health care professionals (Baxter, 1989; Stewart, et al., 1996). Stewart and colleagues (1996) reported health care professionals as key members of mothers' social support network. The support they provided was practical, emotional, informational, and affirmational. Baxter (1989) found that parents positively appraised health care professionals when they fulfilled their role expectations. The professionals did this by demonstrating a professional interest in the child and treating parents with consideration and respect.

In this study, mothers described their experiences of courtesy stigma. They described how their children's visible differences created social barriers for themselves. The social barriers included stigmatizing attitudes and actions that were directed to mothers during social interactions. Although mothers described negative interactions, they also described many positive interactions with professionals, family members, friends, and neighbours. Those positive interactions that were described by mothers were characterized by respect and consideration that was given to the children and/or mothers. Gestures of kindness from friends, neighbours and family members described by mothers included providing babysitting services, driving the child to medical appointments or school, and assisting with household chores. Professionals were helpful by treating

children with respect, assisting mothers to come to terms with the children's disabilities and teaching mothers covering strategies. Mothers of children with cerebral palsy described vigilant efforts to provide and secure optimal care for their children. However, these mothers perceived that their advocacy efforts were devalued by some family members and health care professionals, who implied that the children were unworthy of such care. Mothers of children with spina bifida described how some family members, school personnel, and health care professionals had made discrediting comments toward them. These comments were perceived to be disrespectful of the mothers' efforts to advocate on behalf of their children. More mothers of children with cerebral palsy described devaluing comments directed toward them than did mothers of children with spina bifida (100% cerebral palsy; 40% spina bifida). Goffman (1963) identified sympathetic individuals as the wise. They are at risk of being stigmatized through their affiliation with the child (Goffman, 1963). Although the mothers did not have discrediting attributes, they were recognized as being different from the stereotypical norm. This aspect of Goffman's (1963) conceptualization of stigma is not well developed.

Mothers expressed feelings of inadequacy about having produced a child with disabilities and feelings of anxiety about anticipating devaluing interactions with others. More mothers of children with cerebral palsy described feelings of inadequacy than did mothers of children with spina bifida (100% of mothers of children with cerebral palsy; 40% of mothers of children with spina bifida). Forty percent of mothers of children with spina bifida and 38% of mothers with cerebral palsy expressed anxiety. Other investigators have not focused on the emotional responses to stigma; however, in two studies investigators focused on parents' stress responses. These investigators reported that the discriminatory ways in which others treated their children were perceived to be

stressful (Baxter, 1989; Tackett et al., 1990). Baxter (1989) examined the relationship between parental stress attributed to social stress, discrediting attributes of the child, and distressing reactions of others. In this study, she found that the noticeability of the child's unusual behaviour and speech were positively associated with high parental stress. Moreover, the capacity of the behaviour to draw the attention of others to the disability and the parents' ability to cope in the particular situation were stress inducing. Tackett and colleagues (1990) examined the everyday events perceived as stressful by children with physical disabilities. Seventy percent of the mothers and 75% of the children listed at least one stress related to the ways in which others treated the child. Goffman (1963) also described how anticipated responses of others are anxiety provoking for the stigmatized and the wise. This supports findings in this study.

All mothers described strategies to manage their child's stigma and their own courtesy stigma. Goffman (1963) would argue that mothers who are sympathetic to their children's situation *collude* with them in order to minimize the stigmatizing behaviour. However, Goffman (1963) does not specifically describe how mothers manage their own courtesy stigmas. In Birenbaum's (1970) study of mothers of children with developmental delay, mothers were found to employ strategies to maintain a normal-appearing life by seeking affiliation with considerate individuals and by limiting relationships with individuals who may discriminate against them or threaten the conventional identity they attempted to establish for themselves. In addition, mothers presented themselves and their families in a manner that portrayed conventional family life.

All mothers spontaneously described strategies that were used to cover up their children's discrediting attributes to prevent them from being the focus of attention. They described how aids such as walkers, wheelchairs, and computers were used by their

children to assist them in managing their disabilities. Mothers also described how these aids enhanced the children's abilities and/or corrected the children's differences.

Strategies used assisted the children in assimilating into mainstream society. Avoidance strategies were also described by mothers as being used to stop their children from doing things that highlighted their disabilities or to avert an obvious barrier to their child (e.g., stairs). Avoidance strategies were used more often by mothers of children with spina bifida (60% of mothers of children with spina bifida; 38% of mothers of children with cerebral palsy). Goffman (1963) described assimilative and avoidance strategies that can be used to cover up discrediting attributes, which supports these findings. These techniques restrict the way in which the discredited attribute obtrudes itself into the centre of attention. In addition, mothers described attempts to minimize their children's differences by comparing their children to others with more severe disabilities. Mothers of children with spina bifida (40%) reportedly used this strategy more often than did mothers of children with cerebral palsy (25%). This strategy was more difficult for mothers of children with cerebral palsy to use because of the severity of the children's disabilities. No studies were found to support these strategies.

Mothers also described their attempts to assist the children to master activities related to basic developmental milestones (80% of mothers of children with spina bifida; 75% of mothers of children with cerebral palsy). Wise to their children's needs, they described how they ensured that modifications were employed to assist the children to successfully master these activities. Activities that mothers described included crawling, walking, talking, running, baseball, skiing, and skating. Children with cerebral palsy were more restrained in the activities they could perform because of their functional limitations. Children with spina bifida were able to perform more activities, and many of

the activities that mothers focused on assisted children in their independence. Goffman (1963) described how individuals attempt to correct their discredited attribute by devoting effort to mastering areas of activity felt to be closed to them by their limitations.

Examples of these activities included relearning to swim, ride, and play tennis. This strategy supports the findings in this study. However, Goffman (1963) did not specifically delineate how mastery could be employed for children or specify the role mothers could play in assisting with mastery.

Mothers described attempts to cover their courtesy stigmas. They described the use of strategies involving humour to release tension and patterns of adaptation to maintain normalcy. Mothers used black humour when they described their personal situations (20% of mothers of children with spina bifida; 88% of mothers of children with cerebral palsy). This humour seemed to be delivered with sarcastic undertones and may have released tension that mothers experienced. Patterns of adaptations included mothers' efforts to associate with some people and to dissociate from others. More specifically, mothers described establishing relationships with considerate individuals (80% of mothers of children with spina bifida; 63% of mothers of children with cerebral palsy), limiting relationships with those who were not helpful (20% of mothers of children with spina bifida; 25% of mothers of children with cerebral palsy), and seeking opportunities to portray a conventional family life (50% of mothers of children with cerebral palsy; 40% of mothers of children with spina bifida).

Implications for Nursing

Practice

This study illuminates the stigma experienced by children with disabilities and their mothers, as well as, the mothers' vigilant efforts to manage this stigma. These findings have important implications for nurses caring for children with disabilities and their families. They can assist nurses to develop an understanding of the issues and concerns that mothers' experience raising children with disabilities. A deeper understanding of these mothers' experiences would assist nurses to collaborate with mothers in meeting their children's health care needs.

Health care professionals are in a position to provide or influence care delivery based on identified needs. Mothers described both positive and negative interactions with health care professionals and others. Those individuals that mothers found helpful could be described as *wise* to both the child's and the mother's situation. These individuals were described by mothers as *knowing* the child. However, those health care professionals that mothers described as unhelpful appeared to hold different views and priorities than did the mothers in this study. These individuals were described as making inappropriate judgments and decisions because they appeared not to know the child as a distinct person. Primary nursing might enable nurses to become more familiar with the needs of these mothers and their children and strive to meet their needs. This model of care would permit nurses the time needed to establish a trusting relationship with mothers and to become more familiar with the needs of these children. In order to accomplish this nurses would need to actively listen to mothers concerns, negotiate participation in care and tailor the child's care to meet identified needs. They could assist mothers to express their thoughts and concerns to team members, recognize their contributions as a member of the

team and advocate for their needs in team meetings. Nurses need to understand characteristics of the wise in order to implement strategies that would be helpful to mothers and their children. Those health care professionals that know the child would ultimately be better prepared to advocate for the child's needs, influence care decisions and assist mothers to positively manage the stigma experienced. In order to gain this insight, nurses need to engage in reflective practice to examine their own behaviours, identify role models who have been successful in modeling characteristics of the wise and seek out opportunities to learn from mothers about their unique experiences.

The College of Nurses Quality Assurance Program mandates that nurses participate in continuing education programs. This direction provides an impetus for nurses who work in settings that provide care for children with disabilities to seek out continuing education programs that address the needs of this unique population. Nurse Educators who design continuing education programs should include research-based content that informs nurses about mothers' experiences of raising children with disabilities. Mothers should be invited to speak about their personal experiences in order to sensitize nurses to the stigma that both the children and mothers experience. Mothers in this study described numerous strategies that were employed to address the stigma that they and their children experienced. They also described individuals whom they felt were helpful to them. The content of this program should also include characteristics of those wise to the mothers situation and strategies mothers employ successfully to manage stigma. Reflective practice and role modeling are teaching strategies that could be incorporated into the continuing education curriculum in order to assist nurses to model characteristics of the wise successfully in their practice.

Nurses are in a position to facilitate support, whether it is found one-on-one, within small groups, or in community programs. Community programs, as well as one-on-one consultation, could be tailored to include those practical “covering” strategies that mothers in this study employed. Nurses who design support programs should ensure that a nonjudgmental and caring milieu is established to encourage mothers to express their thoughts and concerns. The findings from this study suggest that other mothers who have lived through similar experiences could be helpful. Nurses should be careful not to assume that health care professionals would provide the only or the best support for mothers. Therefore, nurses could facilitate contact between mothers who have shared similar experiences. This contact could provide a basis for mothers to share their knowledge, provide mutual aid and support to each other. A group of mothers who share common concerns could be supported by nurses to lobby government agencies in order to facilitate change. Nurses could also encourage mothers to describe and model to others strategies that were helpful to them. Mothers in this study described comparisons of their children to others. This could result in further stigmatization. As a result, nurses who facilitate support should plan one-on-one and small-group support carefully to ensure that mothers do not feel stigmatized by those providing support.

Research

Mothers described greater stigma associated with those children with cerebral palsy than with spina bifida. However, the findings of this study were limited by the small sample size and the data source. As a result, the findings cannot be generalized. Further research should focus on the concept of stigma and include a larger sample in order to expand this body of knowledge. Several other studies have employed stratified sampling procedures, which limit the ability to generalize findings. In this study, a homogenous

sample was delineated to reduce sampling bias and facilitate comparisons between two subgroups of children with disabilities. Further research should delineate specific subgroups of children with disabilities and define the abilities and limitations of the sample so that findings can be generalized to similar groups. Furthermore, research comparing the stigma experienced between groups of children with disabilities are needed. This body of knowledge would be useful to inform nurses about the similarities and differences experienced by children with disabilities.

The qualitative approach used in the original study from which data were collected was appropriate in eliciting mother's descriptions of their experiences of raising children with disabilities. Mother's descriptions of perceived stigma were found to be embedded within these accounts. However, the research findings are limited because the interview questions were not designed to permit further exploration of the concept of stigma. The credibility of the study findings are further limited by the fact that only mothers were interviewed and the data collected reflected only mothers perceived stigma. Further qualitative research could delineate mothers' thoughts, feelings, and perceptions about stigma and observational studies would reveal the strategies employed to manage the stigma experienced within specific contexts. Future research that focuses on a specific stage of the child's development would expand our knowledge of the various dimensions of stigma experienced during the child's lifespan and permit comparisons to be drawn. This body of knowledge would be helpful to nurses assisting mothers to utilize strategies appropriate at specific points of the child's development. In order to validate mother's perceptions of their experience data should be obtained from multiple sources. These sources could include open-ended interviews and participant observations with mothers, health care professionals, children with disabilities and family members. An

observational study design would enhance the credibility of study findings. Observations of stigma during interactions with others could be obtained within the home, school/day care, hospital and follow-up clinic over a six-month period of time.

Only one other investigator has examined mothers' adaptations to courtesy stigma (Birenbaum, 1970). This study was conducted in the 1970s and reflects the social attitudes prevalent at the time. Lacking in the research literature are current studies that investigate mothers' experiences with courtesy stigma. Although a theoretically deductive approach used in this study illuminated the experiences of courtesy stigma and the strategies used as described by mothers of children with cerebral palsy and spina bifida the framework used failed to delineate details relevant to the child with disabilities and to the mothers' experiences of courtesy stigma. Further research is necessary to extend Goffman's (1963) conceptualization of courtesy stigma.

Mothers described their awareness of the positive and negative interactions with family members, with the community, and among school and health care professionals. This awareness influenced their interactions with others. Although negative relationships between the mothers and the health care professionals have been explored, investigators have not examined the influence of stigmatizing attitudes and actions on relationships established with mothers of children with disabilities. Only two studies have reported supportive interactions between mothers of chronically ill children and health care professionals (Baxter, 1989; Stewart et al., 1996). These studies illuminate the importance of the health care professional role in providing support while demonstrating consideration and respect toward the parents and child. Further research in this area would assist health care professionals to develop a deeper understanding of the dynamics of their relationship with mothers of children with disabilities and would illuminate

characteristics of the wise that they could model. A qualitative study design would be useful in delineating characteristics of the wise as well as supportive strategies used by them, and a quantitative randomized control study that addressed supportive interventions offered by health care professionals would be useful to delineate the effectiveness of these strategies.

Westbrook et al. (1992) examined the stigma experienced by children with epilepsy and Turner-Henson et al. (1994) examined the parents' perceptions of the types of discrimination experienced by children with chronic illnesses. Other investigators examining various dimensions of chronic illness determined the negative effects of discrimination on children with disabilities. Although these studies inform us about the discrimination experienced by children with disabilities, further research is needed to investigate the impact of stigma at various stages of the child's development. A correlational study design could examine variables such as self-esteem, anxiety, depression and stress. Such research would determine the effect of stigma on children with disabilities.

The experiences of other family members, such as siblings, could be studied to further our understanding of stigma, as well as of the family dynamics that unfold in adapting to stigma. Only one study was undertaken that delineated siblings' perceptions of stigma (Gallo et al., 1991). Mothers in the current study repeatedly described comparisons between their child with disabilities and well siblings; however, the perceptions of the siblings were not elicited in this study. Research exploring the experiences of siblings would be useful to nurses who have therapeutic contact with family members. It would also be useful in extending the theoretical concept of courtesy stigma.

Summary

In this study, mothers described how their children experienced discrimination as a result of their discrediting attributes and how they themselves experienced courtesy stigma due to their affiliation with their children. This discrimination was hierarchical in that mothers of children with cerebral palsy described greater stigma than did those of children with spina bifida. Moreover, mothers described being acutely aware of those individuals who were wise to their situation. These individuals were described as being helpful and with whom they sought affiliation. They chose to dissociate from individuals who were described as being unhelpful to their children and themselves.

Findings from this study suggest that health care professionals must develop a deeper understanding of mothers' experiences of raising a child with a disability in order to meet the needs of these mothers and their children and to advocate with and for them. This could be facilitated through the development of education programs that inform nurses about mothers' needs.

Future research that extends our understanding of the concept of stigma is needed. Qualitative research is required to further examine descriptions of stigma and courtesy stigma, as well as, those strategies employed to manage stigma. In addition, a qualitative approach would be useful in delineating characteristics of the wise and supportive strategies used by them. Quantitative methods could be used to evaluate the impact of stigma on variables such as self-esteem, anxiety, depression and stress at various stages of the child's development. In addition, a quantitative approach would also be appropriate to evaluate the effectiveness of supportive interventions used by health care professionals.

Research designs should include large samples that facilitate comparisons between subgroups of children with disabilities in order to reduce sampling bias and increase the ability to generalize findings.

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