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Parental Internal Attributes as Factors in Family  
Adaptation to a Child with a Disability

BY

Lorna Ellen Hall ©

A thesis submitted to the Faculty of Graduate Studies and  
Research in partial fulfillment of the requirements for the  
degree of Doctor of Philosophy.

IN

Counselling Psychology

Department of Educational Psychology

Edmonton, Alberta

Fall, 1994



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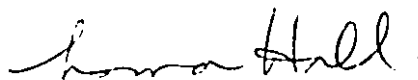


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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Parental Internal Attributes as Factors in Family Adaptation to a Child with a Disability submitted by Lorna Hall in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Counselling Psychology.

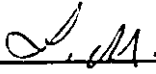
  
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Dedicated to my husband, Doug deVries, and my  
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## Abstract

Trends in research with families of children with disabilities have moved towards identifying resources which contribute to adjustment in those families who cope effectively. Bristol (1987) found that adaptation was positively predicted by adequate social support and coping strategies, and discussed the potential influence of parental attributes such as locus of control, self-esteem, and belief systems. This research, therefore, investigated the role of social supports and coping strategies as well as these parental attributes in predicting successful family functioning. Fifty-seven families participated in the study, including 32 families having a child diagnosed as autistic, and 25 families having a child with cerebral palsy (mean age of child = 6 years). Self-report measures were used to evaluate each of the variables of coping strategies, social support, self-esteem, locus of control, irrational beliefs, family functioning, and child's level of adaptive functioning. A comparison of the results with normative data, where available, indicated no significant concerns overall in parents' coping strategies, self-esteem, locus of control, views of family functioning, or pile-up stress from normal life events. The data demonstrated significant relationships among parental attributes, specifically correlating high overall self-esteem,



internal locus of control, and a low level of irrational beliefs. These parental attributes as well as coping strategies and social support were significant predictors of family functioning, and a proposed model of relationships among these variables accounted for approximately 88% of the variance in family functioning. A comparison of parents of children diagnosed as autistic and children with cerebral palsy across all variables indicated no significant group differences. Post hoc analyses suggested a positive relationship between measures of socioeconomic status and family functioning. The child's gender, chronological age, and age at diagnosis were not related to parent attributes or family functioning. The results indicated the need for more parent-focused interventions for both mothers and fathers, assistance in building social support networks and coping strategies, and efforts to foster feelings of self-efficacy and personal control among parents.

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## CHAPTER I

### Introduction

#### Background and Rationale

In the area of mental and physical disabilities, family stress, problems, and pathology have been well documented among families of children with special needs (Abbott & Meredith, 1986; Singer & Irvin, 1989). With more families choosing to care for their child at home (Hodapp & Zigler, 1993), recent trends have moved towards identifying resources which contribute to adjustment in those families who cope effectively.

In order to maintain families as supports for individuals with disabilities throughout their lifetime in the community, bonds dependent on family cohesion and adaptability should be encouraged by providing resources which strengthen families (Singer & Irvin, 1989). Successful adaptation, therefore, holds benefits for the family as a whole (Bristol, 1987), as well as for the child with a disability. Research has identified specific child benefits of increased family functioning, including increased adjustment (Perrin, Ayoub, & Willett, 1993), gains in the child's functioning and overall

health (McCubbin, Sussman, & Patterson, 1983), and improved adjustment at school (Nihira, Meyers, & Mink, 1980). As noted by Fisher (1983), some traditional models of helping may unintentionally decrease parents' feelings of competence and increase distress within the family. Resources should instead be based on needs identified by families in order to build capabilities (Dunst, Trivette, Gordon, & Pletcher, 1989) and develop feelings of self-efficacy. Researchers have therefore called for more parent-focused interventions which recognize the importance of personal coping skills and social supports (Hawkins & Singer, 1989) as well as specific characteristics which assist in adaptation.

Bristol (1987) viewed family adaptation as a multi-factorial and dynamic process, and found that adaptation was positively predicted by adequate social support and coping strategies. She and other researchers (Antsey & Spence, 1986; Glidden, 1990; Tuttle, 1986) also discussed the potential influence of parental attributes such as locus of control, self-esteem, and belief systems. Further, Jones (1987) added that the certainty of diagnosis and prognosis regarding the child's disability was a primary factor in family stress.

In summary, much of the research among families of children with disabilities has become increasingly needs-focused with a focus on identifying those positive

characteristics which seemed to assist in family functioning. Summers, Behr, and Turnbull (1989) identified the benefits of learning from families who are successful in order to better collaborate with families and meet their diversity of needs. Three important goals identified by Summers et al. (1989) included: 1) assisting in the parents' search for causal attribution, 2) facilitating a sense of mastery, or feeling of control, so that the parents may be more likely to persist and less vulnerable to stress, and 3) developing self-esteem to increase their own view of themselves as competent and effective. In addition to resources such as social supports and coping strategies, parental attributes such as irrational beliefs, locus of control, and self-esteem clearly presented as important factors for investigation.

### Objectives

This research investigated the role of parents' internal attributes in predicting the success of social supports and coping strategies as factors in adaptation. Families of children diagnosed with autism were compared to families of children with cerebral palsy in order to evaluate any differences in two instances of disability which vary in demands and certainty of diagnosis/prognosis. Self-report measures were used to assess the variables of coping strategies and social supports, evaluate

family functioning, and determine the parental attributes of self-esteem, locus of control, and irrational beliefs. Each of these attributes were tested for their ability to predict family adaptation, and for their ability to predict the role of coping strategies and social supports in family adaptation. Such predictive value would be most useful clinically in intervening with individual families who may be having difficulties or who may be new to the diagnosis, and also in planning programs to achieve the "best fit" between services and families in order to ensure optimal adjustment and satisfaction.

#### Outline

A comprehensive review of the literature is presented in Chapter II, and relevant research on the topic of adaptation among families of children with disabilities is discussed. At the conclusion of Chapter II, a summary of the literature is presented with an identification of essential research questions arising from the results and recommendations of past studies.

The method employed to address these research questions is presented in Chapter III, and includes a description of participants, procedures of data collection, instruments, and data analysis.

Finally, the results of the study are presented in Chapter IV with respect to the research questions. These results are

further discussed in Chapter V with implications for clinical practice, program planning, and future research in the area.

## CHAPTER II

### Review of the Literature

#### Introduction

In reviewing the literature in the area of mental and physical disabilities, a traditional emphasis on family stress, problems, and pathology has been apparent (Abbott & Meredith, 1986; Seligman, 1993). Embry (1984) commented on the general assumption that having a family member who has a disability is in itself a stressor. Singer and Irvin (1989) noted past research indicating that stress in families of children with disabilities was associated with higher rates of dissolution, and Breslau, Staruch, and Mortimer (1982) found that parents of children with disabilities reported higher levels of distress, but not a higher incidence of diagnosed psychiatric problems. Seligman (1993) reported that such families may experience feelings of guilt and anger, worry about the future, financial stresses, a lower sense of independence, and disruption in the normal progress of family development. Over the past number of years, however, clinicians and researchers have been moving away from a problem-oriented approach towards considering the existing strengths and positive experiences of families (Bristol, 1987; Featherstone, 1980; Kazak & Marvin, 1984). By



identifying resources, particularly those which seem to differentiate those families who successfully adjust from those who do not, treatment and provision of services may be facilitated.

### Positive Trends in the Literature

Certainly, research in this area over the past two decades has shown increased recognition of positive experiences reported by families. In contrast to problems documented in the past (Friedrich & Friedrich, 1981), Hirst (1991) found that families with a child with a disability had no greater likelihood of break-up or reconciliation compared to a control group. Numerous studies, both qualitative and quantitative, have described the positive experiences of parenting a child with a disability (Singer & Irvin, 1989). Simons (1987) reported that parents found their lives with their children mutually beneficial, and Ferguson and Asch (1989) described parents' experience of personal growth as a result of raising a child with special needs. Of parents studied by Abbott and Meredith (1986), 88% reported a positive contribution from their experience of raising a child with a disability. Parents have reported that they have acquired more depth and understanding of faith and love (Singer & Irvin, 1989), as well as greater tolerance, strength, and professional and personal

development (Featherstone, 1980; Turnbull, 1985). Turnbull, Guess, and Turnbull (1988) further found that parents reported feelings of joy, pride, strength, blessing, and learning. In 1987, Mullins conducted a qualitative analysis of autobiographical books written by parents of children with disabilities, and found themes relating to realistic appraisal of their children's needs, remarkable demands and emotional stress, and resolution and growth towards a more meaningful life. In a survey of parents by Wikler, Wasow, and Hatfield (1983), three quarters of a sample of parents felt that their experience had made them stronger, in contrast to lower estimates made by professionals who were working with these families.

McCubbin, Sussman, and Patterson (1983) noted that some families thrive in the face of challenge, and Summers et al. (1989) added that individuals may use stress as a catalyst to improve their overall life and level of functioning. Summers et al. also commented on the reported bias of professionals in dealing with families, in that focusing on problems and distress may become an obstacle to helping families to build on their strengths.

In regarding the family as a unit, reports have been made of increased cohesion and adaptability (McCubbin et al., 1983), as well as stronger family ties and an appreciation for the simpler things in family life (Abbott & Meredith, 1986).

Kazak and Marvin (1984) reported that the cooperation and joint sense of purpose in parenting a child with special needs strengthened marriages. Other researchers have approached the topic more normatively, commenting that, as with any child, parenting involves "profound ambiguity" with changing views including both positive and negative perceptions (Summers et al., 1989). In a study by Turnbull et al. (1988), parents of children with disabilities reported closer family ties, an improved social network, opportunities for career development, and increased feelings of personal control. Turnbull et al. (1988) noted, though, that these findings were also reported by a control group of parents having children without disabilities, and remarked on the similarities of parenting experiences. Parents have reported that children with disabilities offer their own unique combination of positive and negative contributions, like other children (Turnbull, 1985).

With the more "normal" or positive views of the experience among some parents of children with disabilities, there has been an increasing focus on resources which contribute to adjustment in those families who cope effectively and who report personal satisfaction (Byrne & Cunningham, 1985; Zeitlin, Williamson, & Rosenblatt, 1987). Singer and Irvin (1989) noted the importance of the context in which

stress occurs, and the contribution of coping skills, personal resources, social support, formal services, and financial assistance. Beresford (1993) also reported on the significance of practical assistance, and found that a financial fund grant had a significant effect on mothers' perception of stress as well as their feelings of personal well-being and adjustment, with recognition that money in itself did not change the reality of their child's disability or the impact of the disability on family life. Community resources, such as respite and educational services, have also been linked to decreased institutionalization rates (Hill, Lakin, & Bruininks, 1984). In addition to identifying the importance of social support, general community support, and formal services such as respite and financial help, Summers et al. (1989) commented on more personal coping skills and resources, such as problem solving and behavior management strategies, and communication and negotiation skills for use in dealing with professionals. They also defined positive adaptation as an ability to move on to finding appropriate services, an acceptance of the child and the disability, maintaining a successful marriage with well-adjusted children, and providing support to other families.

### Past Research of Family Difficulties

Despite efforts to identify coping skills and resources associated with positive adjustment, family dysfunction and marital difficulties have also been well documented in the literature. (Friedrich & Friedrich, 1981; Hansen, 1984). In 1990, Singhi, Goyal, Pershad, and Singhi (1990) investigated family stress among three groups including one group of parents of children diagnosed with mental retardation, one group of parents of children with a physical disability, and one control group. Parents of children with mental disabilities and children with physical disabilities both reportedly experienced greater financial stress, more frequent disruption of routine and family activities, poorer social interactions, and more problems with personal health (mental and physical). Social burden scores were higher in these two experimental groups compared with the control group, and further suggested that distress decreased as the educational status and socio-economic status of the parents increased. Breslau et al. (1982) found that mothers of children with disabilities reported more feelings of depression than mothers of children without disabilities, and added that a key factor appeared to be the amount of assistance that their child required with daily living skills. Breslau and Davis (1986) further distinguished "demoralization" from clinical depression and found that

mothers of children with disabilities were more demoralized than mothers of children without disabilities, but that there was no difference between these groups in terms of diagnosed mental illness or major depression. Cummings (1976) similarly reported that fathers of children with disabilities showed higher rates of demoralization compared to a control group. Other adverse effects on parents as individuals have been identified, with some findings of decreased self-worth (Childs, 1985) and persistent feelings of vulnerability and powerlessness resulting in depression (Goodyer, 1986).

Research on marital difficulties among families has varied widely, ranging from studies indicating a higher rate of divorce among families having a child with a severe disability (Gath, 1977; Murphy, 1982; Tew, Payne, & Lawrence, 1974), to contradictory evidence of no difference in divorce rates when comparing families of children with and without disabilities (Hirst, 1991; Kazak & Marvin, 1984; Williams & McKenry, 1981). Certainly, the mother-father dyad has been identified as an important relationship in adaptability and cohesion (Martin & Cole, 1993). Other studies have commented on the role of social isolation in understanding the variable impact on the family (Moroney, 1986), or have attempted to identify other key factors (Singer & Irvin, 1989). Fong, Wilgosh, and Sobsey (1993) conducted a qualitative study of the experience

of parenting a child with autism, and found that parental concerns extended across the areas of behavior, socialization, communication, family relationships, education, professional development, independence, and the future of the child. Quine and Pahl (1985) examined specific factors in the family's experience, such as difficulties in coping with the child's diagnosis, daily care of the child, isolation, added physical demands, sleep disturbances, and behavior management problems. While some community resources have attempted to meet some of these needs through a behavioral approach towards the child and a supportive approach towards the parent (non-directive support groups), Hawkins and Singer (1989) expressed concern about the limited documented evidence of decreased stress resulting from these two traditional methods of assistance.

In addition to research about the family in general or the marital relationship, concerns have also been expressed about the well-being of siblings of children with disabilities (Cavanaugh & Ashman, 1985). Breslau and Prabucki (1987) found that siblings were more demoralized and aggressive among families having a child with a disability, but added that no difference was found between groups in terms of a significant mental illness. They further suggested that social isolation may also be a factor in the impact on siblings of

children with disabilities, due in part to limited respite care, sensitivity to negative attitudes in the community, and fewer resources for leisure activities.

Certainly, as with the birth of any child, the birth of a child with a disability profoundly alters the family structure and the experiences of all family members. With the diagnosis, typically of a condition with which the family has little experience and the immediate and ongoing changes necessitated in the family system, in family expectations, and in daily functioning, it is not surprising that stress and adjustment problems may be magnified in many families (Featherstone, 1980). Various models of conceptualizing family stress have been proposed in the literature, and reflect the changing focus of the area.

#### Models of Family Functioning

Although recently contradicted and criticized, one of the most prominent models of conceptualizing stress in families of children with disabilities in the past was the application of stage theory consistent with those identified in the grieving process (Opirhory & Peters, 1982). While some researchers focused on the reaction to diagnosis, others suggested that the stage theory model might be applied to the ongoing adaptation



and stresses experienced throughout the life of the family (Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975).

### Stage Theories

Post-Kammer and Nickolai (1985) described the stage model as applied to families of children with disabilities in the following manner. The initial experience of denial includes responses such as deeming the diagnosis to be a mistake, underestimating the severity of the disability, or insisting that the child will outgrow the disability. The second stage, anger, may be vented on family members or on the medical community. The next stage, bargaining for a cure, is followed by depression and withdrawal as the family member realizes that nothing can eliminate the disability. The final stage is acceptance, enabling the parent to make decisions about child care and programming, develop a role for the child in the family, and consider how to present the information and their child to others. Drotar et al. (1975) varied the stage model somewhat to include the initial reaction of shock, followed by denial, emotional disequilibrium, adaptation, and finally reorganization. Most applications of this model, including the two here, involve three common themes or stage groupings including the initial crisis period (shock, denial, disbelief), ongoing emotional disorganization (anger, disappointment,

guilt), and finally adjustment or acceptance (Blacher, 1984). Some proponents of the stage theory have acknowledged difficulties and cautions in application, most specifically that stages are not necessarily always sequential or inevitable (Drotar et al, 1975; Post-Kammer & Nickolai, 1985). Blacher (1984) went further to state that the stage concept is popular but is essentially unsubstantiated by data.

Allen and Affleck (1985) addressed problems with stage theories in detail, and discussed the dangers of implying a definite hierarchical sequence of stages. They argued that, should the model be indiscriminately applied to any family experience an adjustment to a child with a disability, clinicians and families themselves may inaccurately view their experience as deviant from the "normal" process, as slower than expected, or as regressive if the sequence is not adhered to. Allen and Affleck (1985) also suggested that such preconceptions may hinder the development of a counselling relationship since clinicians may tend to push the family to move in accordance with the model rather than moving at the family's pace. While an advantage of the stage model may be that it provides a normal framework for the experiences of families and validates the grieving process (Roberts, 1984), many theorists and clinicians have acknowledged the risks of globally applying the model, as well as the possibility that not

all parents will reach the final stage of acceptance (Allen & Affleck, 1985). Singer and Irvin (1989) recognized that stage theories may be too narrow, as stressors vary in content or intensity, and stress reactions are similarly changing. This is particularly true when considering the view that the family may experience recurring adjustments and periods of non-acceptance throughout the child's development, and throughout the life cycle of the family (Werth & Oseroff, 1987). With each change in the family system, addition or loss of members, or rearrangement in roles, adaptation is again necessary. Concordant with this view is the life-cycle transitions model which proposed that acceptance is not a realistic goal as adjustment is a life-long process (Deluca & Salerno, 1984).

#### Life-Cycle Transitions Models

Other research has further proposed that adjustment is not one end result, but is an ongoing process in the life of the family. Summers et al. (1989) elaborated on McCubbin and Patterson's (1983) term "bonadaptation" to describe adaptation or accommodation which results in an upward spiral of development and growth. "Maladaptation" was described as the process of a more downward progression, with a series of difficulties (Summers et al., 1989). A study by Wikler, Wasow, and Hatfield (1981) also provided some support for the

continuity view of adjustment. Designed to compare parents' and professionals' perceptions of adjustment, results indicated that professionals tended to overestimate the distress around the diagnosis, and underestimate the impact of later experiences. The authors suggested that grief is therefore chronic and normal, and that adjustment rather than acceptance is more realistic. Through periodic grieving, families are strengthened and adapt. Other authors have proposed that this periodic grieving, or readjustment, occurs at specific transitional stages of the family developmental life cycle (Combrinck-Graham & Higley, 1984). Beavers, Hampson, Hulgus, and Beavers (1986) identified critical transitions for the family of a child with a disability as preschool developmental milestones, entering school, beginning adolescence, and reaching chronological adulthood. The normal life cycle of bearing and raising children is disrupted in that some children with disabilities may never reach adult independence.

Roberts (1984) examined the life cycle issues salient during the birth and infancy of a child with a disability. In some instances, through prenatal diagnosis, parents may be aware of the existing or potential disability before the child's birth. Therefore, the normal preparation and rites of passage around pregnancy and childbirth may be affected. Bonding

and attachment may be tentative due to fears that the child may not survive, and the actual entrance of the baby into the family may be undefined due to repeated hospitalizations. With each developmental milestone anticipated by parents, siblings, and extended family, all involved are reminded of the diagnosis and may experience many of the same emotions as they did when the diagnosis was initially made. However, according to Roberts (1984), during the preschool years, family units may be insulated somewhat from outsiders, aside from health and social service personnel.

Combrinck-Graham and Higley (1984) recognized the impact of school entrance on the family life cycle and parental adjustment, as a time when the family is thrown into a world that may not be as protective and accommodating as their circle of agencies and support groups. The development of individuals and families may be altered because the family never has an opportunity to become an autonomous, self-contained unit from which individual's differentiation can take place (Combrinck-Graham and Higley, 1984).

#### Factors in Family Adjustment

While both the stage and life-cycle models have suggested a somewhat predictable course of adjustment, it has been widely recognized that there are many factors involved in

initial and subsequent adjustment to a child with a disability in the family (Featherstone, 1980; Singer & Irvin, 1989). These factors can be described as child-specific or family-specific.

### Child-Specific Factors

Specific to the child and the disability, many factors potentially affect the reaction and adjustment of the family. Innocenti, Huh, and Boyce (1992) studied various disabilities, including hearing or visual impairment, cognitive impairment, and developmental delay, and found that parents of children with disabilities reported significantly more child-related parenting stress. Frey, Greenberg, and Fewell (1989) studied many factors including social network, parent belief systems, and parent coping styles, and similarly found that child characteristics were the best predictor of stress among mothers and fathers of children with disabilities. In a 1983 study by Bristol, the personality, dependency, and physical needs of a child with a disability were most significantly associated with increased stress among parents.

The child's age at onset and diagnosis, and the nature of the child's disability (severity and visibility), also have implications for the family (Roberts, 1984). The severity of a child's disability as a factor in parenting stress has been investigated with varying results (Singer & Irvin, 1989).

Research by Pahl and Quine (1987) identified the highest level of psychological distress among the parents of the children with the most severe disabilities in the sample. While Mahoney (1992) found that the general family environment was not associated with the level of the child's disability, he did report that the most distressed families in his sample tended to be those having children with more severe disabilities as well as a lower socio-economic status. More positively, Saddler, Hillman, and Benjamins (1993) were interested in factors such as the severity and visibility of a child's disability on family functioning, and compared groups of parents having children with diabetes, cerebral palsy, or without disabilities. All three groups reportedly demonstrated a high level of family functioning, regardless of visibility or severity of disability among the children, and no difference was noted between mothers' and fathers' views of family functioning.

In other studies, the specific diagnosis or the nature of the child's disability has been a predominant factor. Fisman and Wolf (1991) found that parents of children with autism reported significantly more stress than parents of children with Down's Syndrome or parents of children without disabilities. Gillberg, Gillberg, and Steffenburg (1992) compared mothers of children with autism with mothers of children with an attention deficit disorder and mothers of children without

special needs. In their study, clinical emotional concerns were more pronounced among the mothers of children with autism. Past research has also documented the high levels of stress reported by parents of children with autism (DeMyer, 1979; Holroyd, Brown, Wikler, & Simmons, 1975; Holroyd & McArthur, 1976). In a Canadian study, Konstantareas and Homatidis (1991) conducted research with parents of children with autism, children with mental disabilities of unknown etiology, children with learning disabilities, and children without disabilities. They found that parent-reported stress increased across the groups, with the lowest level among the normal control group, a higher level among parents of children with learning disabilities, greater stress among parents with children with mental disabilities of unknown etiology, and the highest level of stress reported by parents of children with autism. In comparing mothers and fathers across the groups in an earlier study, Konstantareas and Homatidis (1989) also found that mothers' stress seemed to be most affected by body, perceptual, and affective concerns, and fathers' stress seemed to be most affected by the child's anxiety reactions and lack of communication skills. An additional finding in their study was that, among parents of children with autism, the child's level of self-abusive behaviors was the best predictor of stress.



The specific needs of the child, dependent on many factors including the nature of the diagnosed condition, have therefore also appeared important in predicting parental experiences. Donenberg and Baker (1993) compared three groups of parents, including families of children with autism, families of children with "externalizing behaviors" such as hyperactivity and aggression, and a control group. Results indicated that parents with externalizing children reported more effects related to their social lives, their own feelings about their parenting skills (more negative and less positive), and greater child-related stress. Interestingly, Donenberg and Baker (1993) found little difference in reported stress between parents of children with autism and parents of children with externalizing behaviors, and no difference among the three groups in terms of parental and marital well-being. Waddington and Busch-Rossnagel (1992) reported that child-specific factors such as physical limitations and emotional/behavioral problems directly affected the mother's role functioning as well as her sense of well-being. These results generally agreed with Baker's (1984) report that behavioral intervention at home was associated with increased adaptation and decreased stress in the family.

Other significant factors in stress and adaptation have included issues related to the age of the child, the position of

the child in the family, and the size of the family. McGrath and Grant (1993) found that age was one of the factors related to differing expectations about services and vulnerability to stress. The method and nature of diagnosis also varies as professionals may differ in their method of sharing the information (Quine & Pahl, 1985) or disagree about the diagnosis, and as there may be considerable ambiguity about etiology and prognosis. Slater, Martinez, and Habersang (1989) also noted the difficulty of living with ambiguity. In considering various diagnoses and implications for family adjustment, there are a wide range of possible experiences.

For example, in the diagnosis of Down Syndrome or Cerebral Palsy which may be made shortly after birth, bonding and attachment might be impeded and medical issues may complicate the family's reaction. This is, however, a potentially different experience from the parent who suspects a delay which is confirmed at age two years, which in turn is different from the case where a child's development is normal until a head injury at age three years. Also presented for consideration is the child with muscular dystrophy or neurofibromatosis where the child's condition is continually changing, or the diagnosis of autism or non-specific developmental delay where etiology is unclear or unknown. The implications for varied emotional reactions are endless and

complex. Uncertainty and apprehension about the diagnosis or prognosis, grief reactions, acceptance of professional support, and communication with extended family are likely all affected by the information available about the child's condition. The nature of the child's disability affects not only the family's reactions, but potentially also the professionals' perceptions of parent needs (Bristol, 1985). Other factors such as family size, position of the child in the family, income level, time demands, and fatigue are also significant (Byrne & Cunningham, 1985; Gray & Holden, 1992; Roberts, 1984) in that they help to determine the resources available.

In understanding the reaction and adjustment of the family of a child with a disability, then, several child-specific factors must be considered, including the nature of the disability itself (Fisman & Wolf, 1991), the severity of the disability (Saddler et al., 1993), the child's level of independence (Bristol, 1983), and the child's specific needs (Donenberg & Baker, 1993). Other factors such as the make-up of the family and family characteristics affecting the perception of the child have also been explored.

### Family-Specific Factors

More specific to the family, many researchers have identified characteristics which have implications for family

adjustment. Roberts (1984) suggested that a family's belief system affects the way that they define and understand the disability (i.e., a gift, a punishment, an opportunity to help others), as does their level of pessimism regarding the child's future functioning (Blacher & Bromley, 1988). Roberts also indicated that the family reaction depended, in part, on the structure of the family before diagnosis, and the prior involvement of extended family and community. Borkan, Yeheskel, and Biderman (1993) wrote of a family's and community's attempts to adjust to a child with cerebral palsy born in a kibbutz. They described the experience of disorganization when the usual patterns and expectations that the community used to make sense of the world were threatened, and of the adjustment towards new modes of thinking first in the family and later in the community prior to developing new routines and recovering some balance. Clearly, beliefs related to cultural, ethnic, and religious backgrounds have an additional impact (Fish, 1990; Leonard, 1985).

Practical considerations such as the size of the family, income, and education about the disability have also proven to be important, particularly with the changing trends in family size, extended family, and the general aging of the population (Singer & Irvin, 1989). Single parent families have been researched with mixed results. Wahler and Dumas (1984)

found that single mothers of children with disabilities who were socially isolated tended to show a higher number of psycho-social problems. In contrast, Groze and Rosenthal (1991) found that one-parent families experienced less difficulty associated with the child's emotional-behavioral problems. McCubbin (1989) also assessed one and two parent families having a child with cerebral palsy and found that while there was little difference between one and two parent families in terms of strain, family cohesion, or adaptability. Single parent families tended to have more concerns about financial well-being. Breslau et al. (1982) reported that financial costs and stresses were greatest among those families with low-mid socio-economic status.

Families at risk for adjustment problems traditionally have been identified as rigid and restrictive (Berger, 1981; Goodyer, 1986), lacking in sufficient boundaries (Featherstone, 1980), demonstrating patterns of poor conflict resolution (Berger, 1981), and lacking in a balance of power (Beavers et al., 1986). Feelings of social isolation, chronic stress, and loss of independence have presented as primary concerns across the literature (Slater et al., 1989). Qualities favorable to successful adjustment include a balance between cohesion and individuality, present rather than future orientation, high levels of conflict resolution, commonality of perceptions, and

freedom for individual responsibilities and rights within the family (Beavers et al., 1986; Turnbull & Turnbull, 1986). Other researchers have identified factors such as the degree of connectedness within the family (Bernier, 1990), congruent views of the child's disability (Bristol, 1987), and family adaptability (Turnbull & Turnbull, 1986). Positive adaptation has also been linked with informal social support and support within the marital relationship (Fewell & Vadasy, 1986; Frey et al., 1989; Friedrich, Wilturner & Cohen, 1985), as well as with strong religious affiliation (Fewell, 1986). In addition, Byrne and Cunningham (1985) recognized that the particular life cycle stage of the family is a significant factor. These characteristics or resources available to the family could affect both their reaction and their success in coping and adjusting.

In their discussion of coping resources, Friedrich et al. (1985) indicated that although child and disability characteristics have been significant factors, coping resources alone were an adequate predictor of parental functioning. Hanline and Daley (1992) indicated that the use of coping strategies alone was more predictive of family strength than was the presence of social supports. Frey et al. (1989) found that coping styles predicted psychological distress and the fathers' perception of family adjustment. Similarly, Reddon (1989) reported that coping strategies were significantly

associated with adaptive family functioning. Rather than viewing families as passively reacting to stress, families might best be perceived as capable of actively handling their situation through the development of coping strategies (Byrne & Cunningham, 1985; Zeitlin et al., 1987). These strategies may include problem solving skills, beliefs and perception of the situation, assistance through services, and the use of social networks (Friedrich et al., 1985). The need for stress management counselling specifically focusing on improving self-awareness and coping skills has been recognized in the literature (Walton, 1993), as well as the need to provide opportunities which enhance feelings of competence and self-esteem (Hobbs et al., 1984). Parents have also identified the need for information (Gowen, Christy, & Sparking, 1993), specifically guidance on how to assist in the development of their child, help in identifying appropriate resources, legal rights, methods of dealing with daily demands, and future planning concerns.

Overall, several factors specific to the family presented as worthy of consideration, including family beliefs (Fish, 1990; Roberts, 1984), the make-up of the family (Groze & Rosenthal, 1991; Wahler & Dumas, 1984), and characteristics of the family system (Bernier, 1990) such as cohesion and flexibility (Beavers et al., 1986) and coping skills (Hanline & Daley, 1992;

Walton, 1993). Clearly, there are numerous child and family characteristics which may affect the family's experience, reaction, and adjustment.

### Multi-factorial Views

In reviewing the literature, researchers have increasingly recognized the complexity of family adaptation as a multi-factorial and dynamic process. Gallimore, Weisner, Bernheimer, and Guthrie (1993) discussed the specificity of the child's problems and the impact on family routine, while other researchers (Brantlinger, 1991; Todis & Singer, 1991) have identified factors such as the difficulty in accessing services, concern about future services, medical crises, behavior problems, and religious and ethnic background. Among adoptive families, Glidden (1990) also identified factors significant in adaptation such as commitment to the child, preparation for the child, family strength, social support, and parents' personal attributes. McCubbin and Patterson (1982) and Pahl and Quine (1987) discussed the combination of events which seemed to be most stressful, and identified the vulnerability of the family where a number of chronic problems exist and an acute stressor is introduced. The significance of the stressor to the family may depend on factors



such as religion, ethnic background, information base about the disability, and exposure to individuals with disabilities (Brantlinger, 1991).

Bristol's (1987) application of the Double ABCX Model attempted to incorporate a number of potential factors and measures in predicting successful adaptation. In the classic ABCX model of family stress introduced by Hill (1958), the nature of the stressful event (A), the family's inner resources in crisis (B), and the family's definition of the event (C) contribute to either the occurrence or prevention of a family crisis (X). McCubbin and Patterson (1983) elaborated on Hill's model, and proposed the Double ABCX or Family Adjustment and Adaptation Response Model (FAAR) to incorporate further factors such as additional family stressors, social and psychological resources, coping strategies, subjective meaning of the event, and the outcome of the event.

Bristol (1987) applied McCubbin and Patterson's Double ABCX model to assist in predicting healthy functioning in families of children with autism or severe communication disorders. Impact on quality of parenting, marital satisfaction, and maternal depression were assessed. She found that the Double ABCX model accounted for 38% of the variance in parenting stress, and 61% of the variance in marital adjustment. Notably, she found that family adaptation was

positively predicted by adequate social support and coping strategies. This was consistent with other research identifying that active coping styles were significant (Sargent & Liebman, 1985; Singer & Irvin, 1989), and has been further documented by researchers examining the importance of social support (Gray & Holden, 1992). Added family stresses, maternal self-blame, and maternal definition of the event all predicted poorer adaptation in Bristol's (1987) study. She concluded that resources and beliefs were more predictive of adaptation than the severity of the child's disability. Bristol (1987) further suggested, based on her results, that the use of coping strategies and social supports may be mediated by parental characteristics such as self-esteem or locus of control. Henderson and Vandenberg (1992) also studied parents of children with autism, and found that stress, social support, and locus of control were all significant factors in family adjustment.

In psychology in general, relationships between self-esteem, beliefs, and locus of control have been investigated with respect to stress and coping. Billings and Moos (1984) indicated that the ability to sustain morale and functioning under stress depended on the nature of the stressor, the individual's resources, coping strategies, and significantly, their appraisal of the stressor. In a study of stress among teachers

by Zingle and Anderson (1990), belief systems about the stressful event were significantly correlated with the individual's level of stress. Although the direction of this relationship was unclear, a higher level of stress was associated with a higher level of irrational beliefs. McPhail (1969) also examined belief systems, and found some relationship between beliefs about locus of control and some irrational beliefs based in Ellis' work (1962). Beliefs may in turn be influenced by the social network or culture surrounding the individual (Bronfenbrenner, 1979), and further strengthen family functioning by providing a connection with others sharing the same values and goals (Hobbs et al., 1984). While the relationship among these beliefs, stress, social supports, and coping may therefore be complex, it is clearly critical in differentiating those families who cope well from those who experience more difficulty (Singer & Irvin, 1989). Taylor (1983) stated that adjustment to stressful events is generally mediated by three processes including 1) attributing a cause, 2) gaining a feeling of mastery or control over the stressor or life events, and 3) increasing self-esteem. Of interest, then, is the role that beliefs about self-efficacy, personal control, and events in the world, may play in adjustment to specific life events.

Researchers have similarly questioned the roles of self-esteem, locus of control, and beliefs in family adaptation to potentially stressful events such as the birth of a child with a disability. The family's interpretation of the event may play a critical role in their perception and experience of stress, as well as their use and development of resources (Olson et al., 1983). In a review of the literature, Turali and Power (1993) described the patterns of appraisal and coping subsequent to perceived stresses, indicating that families do not react passively but instead are active participants in the event. Dyson (1991) and Sloman and Konstantareas (1990) also suggested that the parents interpretation of the event is a factor in coping, in their personal level of happiness, and in their need for assistance. The degree of stress or threat associated with the birth of a child with a disability may be interpreted differently depending on individual perceptions, which in turn may be key factors in the parent's ability to cope (Summers et al., 1989) and central considerations in clinical treatment (Biglan, 1989). Such perceptions may be affected by different values, different learning histories, (Singer & Irvin, 1989), or the beliefs and influence of social networks (Shumaker & Bownell, 1984).

As part of the process of adjustment, attributing cause may also play a role in establishing some sense of control and

orderliness (Rothbaum, Weisz, & Snyder, 1982; Taylor, 1983; Taylor, Lictman, & Wood, 1984). Affleck, Tenner, and Gershman (1985) discussed the importance of the ability of families to find purpose or meaning in their experience with a child with a disability, and found that this ability was positively correlated with psychological health. Sloman and Konstantareas (1990) further elaborated on the role that this appraisal of the situation can play in the case of an ambiguous diagnosis (e.g., autism). A clear cause also appeared to be a factor in a study of mothers of children with Down Syndrome conducted by Bernheiner, Young, and Winton (1983). These mothers reported experiencing less stress than mother's of children with developmental delays where the origin of the problem was unknown. While a cause in itself has been found to be significant, regardless of content (Lowery, Jacobsen, & Murphy, 1983; Taylor, 1983), others have focused more on the direction of cause and the issue of control. Bulman and Wortman (1977) and Taylor (1983) found that those parents who tended to blame others for their child's disability demonstrated a lower level of adjustment. In contrast, parents who have attributed some of the cause to themselves have demonstrated a higher level of adjustment, possibly because this process has allowed them to have a greater sense of control over the situation (Affleck, Allen, McGrade, &

McQueeney, 1982). This finding raises the issue of locus of control as a potential factor in parental attributions and appraisals.

In a study of parents of children with autism conducted by Henderson and Vandenberg (1992), adjustment was dependent on factors such as locus of control, social support, stress, and agency affiliation. This was consistent with other studies in the area of locus of control which have suggested that individuals who feel a greater sense of personal control over their life circumstances may experience less stress and more adjustment (Affleck et al., 1985; Taylor et al., 1984). Affleck et al. (1982) similarly found that parents having an internal locus of control were better adjusted, more active in seeking resources, and more active participants in their child's treatment programs. Feeling a sense of control may indeed be powerful in decreasing stressful reactions (Summers et al., 1989), and, further, may be associated with a sense of mastery, competence, and the ability to find some positive benefits and meaning in the event (Taylor, 1983).

The ability to selectively attend to positive aspects of situations has also been identified as a coping strategy (Pearlin & Schooler, 1978), as well as a factor in building and maintaining self-esteem (Summers et al., 1989). Dunst, Cooper, and Bolick (1987) discussed the importance of encouraging

independence and feelings of competence, and subsequently self-esteem, among parents of children with disabilities in order to foster coping and discourage isolation. Morgan, Owen, Miller, and Watts (1986) conducted a study of general stress responses and found that variation was significantly related to self-efficacy. Among mothers of children with intellectual disabilities, Antsey and Spence (1986) also concluded that self-esteem was the best predictor of response to stressful events. Self-esteem may be closely linked, however, to beliefs, as suggested in McLennan's (1987) study of irrational beliefs in relationship to self-esteem and depression.

McLennan (1987) found that six irrational beliefs were closely related to self-esteem, including 1) demand for approval, 2) high self expectations, 3) frustration reactivity, 4) anxious overconcern, 5) problem avoidance, and 6) helplessness. In one of the few studies of belief systems among families of children with disabilities, Tuttle (1986) suggested that the family's philosophy and beliefs helped to determine the quality of their adaptation to a child with a visual impairment. In 1989, Frey et al. found that mothers having a positive belief system and a supportive, non-critical family background reportedly significantly less distress in their experience with their children with disabilities. Vestre and Burnis (1987) also wrote of a more general finding that

individuals with a high level of irrational beliefs may be more reactive to stressful life events and more vulnerable to adverse consequences. In a review of the literature by Summers et al. (1989), they identified the role of beliefs, a sense of mastery or self-esteem, and the search for a cause, as key strategies in the process of coping and adjusting among families of children with disabilities.

The complexity and combination of events in family experiences has been considered (McCubbin & Patterson, 1982; Pahl & Quine, 1987), and researchers have made efforts to incorporate numerous factors into models of family adaptation (Bristol, 1987). Throughout the research discussed in this section, parental beliefs and personal resources have consistently been identified as important factors in the family's experience of having a child with a disability. Clearly, the factors such as self-esteem, irrational beliefs, and beliefs about locus of control must be considered as potential factors in the variable responses of families in the process of adaptation.

### Synopsis of the Literature

Research conducted to date has attempted to describe both the positive and negative experiences of families, and to identify key factors in adjustment (Singer and Irvin, 1989). Social supports and coping strategies have been linked to



successful adaptation in much of the literature (Bristol, 1987; Friedrich et al., 1985; Summers et al., 1989), in addition to other child and family characteristics. However, these factors alone do not fully account for the wide range of family experiences, levels of functioning, or use of services. Attempts have been made to identify additional variables which differentiate families who adjust well from those who do not, in order to better provide appropriate services and better respond to the varying needs of specific families. Authors have suggested the role of parental attributes (Bristol, 1987; Glidden, 1990) including beliefs, feelings of competence, and feelings of control, which may be related to the parents' view of their child with a disability and their use of resources or supports. While the directionality of such a relationship is difficult to ascertain, it is essential to better recognize and understand the complexity of these variables and needs in order to provide necessary services and facilitate family functioning.

#### Research Questions Based on the Literature Review

The following research was conducted as a comprehensive investigation of the role of parents' internal attributes in predicting the success of social supports and coping strategies as factors in adaptation. Based on the

literature, particularly Bristol's conclusions (1987) and the research on the interrelationships among irrational beliefs, self-esteem, and locus of control (McLennan, 1987; Vestre & Burnis, 1987), it was important that these internal attributes be evaluated as potential factors in successful family adaptation.

Child-specific factors such as the nature of disability were also considered. Jones (1987) recognized that although the severity of the disability contributed to family stress, the greatest factor was the degree of certainty regarding diagnosis, cause, and prognosis. Children with the diagnosis of autism and children with cerebral palsy presented as two groups with different disabilities and different experiences with diagnosis/prognosis. The Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R; American Psychiatric Association, 1987) defined autism as "...one subgroup of the general category Pervasive Developmental Disorders...", and identified diagnostic criteria such as "...qualitative impairment in reciprocal social interaction...", "...impairment in communication and imaginative activity...", "...markedly restricted repertoire of activities and interests...", and "...onset during infancy or childhood..." (p. 34-35). Cerebral palsy has been defined (Weiner, Bresnan, & Levitt, 1982) as "...a fixed non-progressive neurologic deficit acquired before, during, or

in the months after birth..." with motor impairment and recognition that "...clinical expression may change as the child matures..." (p. 17). Of interest, then, was the possibly different role that parental attributes play dependent on the nature of the child's disability, in this case comparing parents of children with autism with parents of children with cerebral palsy. In order to address concerns discussed by McCubbin and Patterson (1982) and Pahl and Quine (1987) regarding the combination of stressful events, the pile-up dimension of normal life stressors should also be considered.

This study was therefore designed to answer the following research questions:

Question 1.

Is healthy family functioning positively predicted by the availability of social supports and coping strategies?

Question 2.

Are parental locus of control, self-esteem, and irrational beliefs correlated with each other, in that there may be a relationship between higher self-esteem, internal locus of control and lower report of irrational beliefs, or between lower

self-esteem, external locus of control and higher report of irrational beliefs?

Question 3.

Do the internal parental attributes of locus of control, self-esteem, and irrational beliefs account for some of the variance in family adaptation to a child with a disability?

Question 4.

How much of the variance in family functioning among families with a child with a disability is accounted for by the variables of coping strategies, social supports, self-esteem, irrational beliefs, and locus of control?

Question 5.

Do these internal attributes of parents play a greater role as predictors and variables in adaptation in the case of families with a child diagnosed with autism as opposed to cerebral palsy?

## Definition of Terms

### Social Supports

Social supports refers to the support received from family, relatives, friends, church, groups, and other resources. Support includes feeling understood, cared for, valued, respected, and secure.

### Coping Strategies

Coping strategies are defined as behaviors which parents find helpful in dealing with the daily demands and stresses of raising a family.

### Self-Esteem

Self-esteem refers to an individual's beliefs about their own worth and competence (Battle, 1992).

### Irrational Beliefs

Irrational beliefs are defined as ideas or values which are negative or self-defeating, and which Ellis (1962) described as illogical, senseless, or superstitious (e.g., a person must be loved or approved of by everyone).

### Locus of Control

Locus of control refers to the extent to which an individual believes that an event is contingent on their own behaviors or abilities (internality), or contingent on the behavior of others, luck, chance, or fate (externality) (Rotter, 1966).

## CHAPTER III

### Methodology

#### Introduction

This research was conducted to investigate the role of parent's internal attributes in predicting the success of social supports and coping strategies as factors in adaptation. Families of children with autism were compared with families of children with cerebral palsy to evaluate any differences in two instances of disability which may vary in demands and certainty of diagnosis/prognosis. This research focused on families of children below the age of 11 years. Families of older children who contacted this researcher were referred to a collaborative study conducted by Dr. Keith Goulden at the Glenrose Rehabilitation Hospital in Edmonton. Some of the parents of younger children also decided to take part in Dr. Goulden's research following their participation in this research. The studies were run separately with some overlap in instruments, and some collaboration was undertaken in order to minimize demands on families. This chapter includes a description of the participants in this research, procedures, and instruments.

### Participants

Parent associations were contacted in order to inform parents of this research project, and invite their participation. Announcements were made in the newsletters of parent associations, and follow-up letters were sent anonymously to parent members through the associations, similarly inviting their participation. Parents voluntarily contacted the researcher for more information prior to making a decision regarding their participation in the project. Eligibility criteria for inclusion in the study required that the family have at least one child with the primary diagnosis of either autism or cerebral palsy, between the ages of approximately 2 years to 10 years. Of the families who agreed to participate in the research, 58 had children within the age range of 22 months to 10 years 11 months, with the diagnosis of autism or a diagnosis of cerebral palsy. Among the families of children with autism, many children below the age of 5 had reportedly been given the diagnosis of Pervasive Developmental Disorder with autistic features due to the reluctance of professionals to make the diagnosis of autism at a young age. These children were included in the sample of children with autism with the agreement of the parents, and the inclusive group is referred to throughout the remainder of this dissertation as children with the diagnosis of autism. All of the children in the sample had



been diagnosed by their doctor or through a team of professionals specializing in developmental disorders. One of these 58 families chose to withdraw from the research during data collection, and stated that they did not foresee any practical benefits for their child. Data collected from this family were therefore discarded. Of the remaining 57 families, 32 had at least one child with the diagnosis of autism, and 25 had at least one child with a diagnosis of cerebral palsy (see Table 14 in Appendix B for more information about participants). Families lived in both rural and urban centres throughout Alberta and Saskatchewan. The structure of families varied, ranging from single-parent homes, two-parent-homes, adoptive parents, and long-term foster parents. Although both parents of two-parent families were invited to participate, only one parent chose to complete the questionnaire in many of the cases. Of the total sample of participants, seven families had more than one child with the identified diagnosis. Parents were encouraged to base their responses on the child that they perceived as having a higher number of clinical features relating to the diagnosis.

### Procedure

During the first contact, parents were informed about the purpose and procedures of the project as well as their rights as

voluntary participants. They were advised that the study proposed to identify factors which may be important in family functioning, and in providing services to families of children with special needs. Parents were also told that their participation would be anonymous and confidential, that results hopefully would assist in providing help to families who are having difficulties, or families whose children have only recently been diagnosed. Children were not directly assessed by the researcher, although they were included to some extent through descriptive information and parent interview data. Consent for the use of child information was included on the parent consent form (see Appendix A).

Parents were advised of their right to withdraw at any time. This issue was addressed in the introduction letter (see Appendix A), and was clearly stated during the initial meeting and in the consent form. Following informed written consent, general demographic information and diagnostic history information were gathered. The Vineland Adaptive Behavior Scales was then administered as a structured interview in order to evaluate parents' perceptions of their child's level of functioning. Finally, a series of self-report questionnaires was given to parents to evaluate the other variables. Questionnaires were completed at their own leisure within their homes, and were later personally collected by the

researcher. No time limit was placed on completing the questionnaire, and parent response times varied from a few days to a month. Due to limited reading abilities, one parent sought assistance in reading the questionnaire.

A recording system was used so that questionnaires were identified only by number. The number codes were used throughout data collection, analysis, and interpretation. Data were analyzed on a group basis only, and identifying information was kept separate and confidential.

### Instruments

Self-report measures were used to assess the variables of coping strategies and social supports, and the parental attributes of self-esteem, locus of control, and beliefs. A measure of the pile-up dimension was also included in order to consider any additional stressors due to normal life events. The questionnaire included the Coping Health Inventory for Parents (McCubbin et al., 1983), Social Support Inventory (Cooke, Rossman, McCubbin, & Patterson, 1982), Adult Culture-Free Self-Esteem Inventory (Battle, 1992), Adult Irrational Ideas Inventory (Davies & Zingle, 1970), Rotter Internal-External Locus of Control Scale (Rotter, 1966), and the Family Stressors Index (McCubbin, 1991). Family functioning was evaluated by the Family Assessment Measure (Skinner,

Steinhauer, & Santa Barbara, 1983). The Interview Edition of the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984)) were also used as a structured interview to collect information from parents regarding their child's level of functioning.

### Coping Strategies

In order to evaluate parents' views of coping resources in their lives with special needs children, the Coping Health Inventory for Parents (CHIP) was included among the measures. The CHIP (McCubbin et al., 1983) is a self-report measure consisting of 80 items regarding those resources which parents have found to be most helpful. Each item has a rating scale from 1 to 4, ranging from a rating of "not helpful" to "very helpful." Three subscales examine different coping resources across the areas of family life, outlook, supports, sense of well-being, relationships with other parents, and communication with professionals. More specifically, the first subscale, Coping I (Integration, Cooperation, and Communication), is defined as "...maintaining family integration, cooperation, and an optimistic definition of the situation." (McCubbin et al., 1983, p.368). Coping II (Support, Esteem, and Stability) is defined as "...maintaining social support, self-esteem, and psychological stability.", and Coping

III (Medical Consultation and Communication) is defined as "...understanding the medical situation through communication with other parents and consultation with the medical staff." (McCubbin et al., 1983, p. 368).

As the CHIP initially was designed for families of children with chronic illnesses, this measure was based on responses from 100 families having a child with Cystic Fibrosis, and was further administered to 308 families of children with chronic illnesses in the United States in order to provide normative data. Criterion measures included the Family Environment Scale (FES) by Moos (1974), and indicators of the child's health status. Internal reliability for the CHIP has been identified as .79 for scales I and II, and .71 for scale III. Test-retest reliability was not reported. Factor analysis and discriminant analysis has reportedly provided evidence of construct validity (McCubbin et al., 1983).

### Social Supports

The Social Support Inventory (SSI) was included in the questionnaire as a measure of social supports experienced by parents in this study. The SSI (Cooke et al., 1982) attempts to determine sources of social support across five general areas by sampling 11 possible resources. The five general types of social support include emotional, esteem, network, appraisal,

and altruistic. In responding to the SSI, individuals rate each of the sources on a three point scale for a total of 81 items. These sources include spouse/partner, children, other relatives, close friends, co-workers, church/synagogue, community or neighborhood groups, professionals or service providers, special groups, books/television, and an "other" category for parents to complete at their choice. Norms are not available for the SSI, and construct validity has been reported based on past research (Cooke et al., 1982). Test-retest reliability has been determined to be .81 (Cooke et al., 1982).

### Parental Self-Esteem

Battle's Culture Free Self-Esteem Inventory (CFSEI-AD, 2nd edition, 1992) was used as a measure of parents' self-esteem. The instrument consists of 40 self-report items, with 16 items on the General scale, 8 items on the Personal scale, 8 Social scale items, and finally, 8 Lie scale items to measure defensiveness (Battle, 1992). Battle described General self-esteem as "...the individual's overall perception of self-worth..." (p. 3), Personal self-esteem as one's "...most intimate perception of self-worth..." (p. 3), and Social self-esteem as "...the individual's perceptions of the quality of relationships with peers..." (p. 3). Content validity was established by basing all items on various aspects of a construct definition of self-

esteem. Self-esteem was defined by Battle (1990) as "...the perception the individual possesses of his or her own worth..." with recognition that self-esteem gradually develops and matures to a relatively static construct (p. 3). Internal consistency of the instrument has been demonstrated through factor analysis, and test-retest reliability based on 127 undergraduate students as .81. Concurrent validity (Battle, 1988) has been reported compared with scores on other measures such as the Stanley Coopersmith Self-Esteem Inventory (1967), the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), and the Minnesota Multiphasic Personality Inventory (Hathaway & McKinley, 1951).

### Parental Beliefs

The Adult Irrational Ideas Inventory (AI-II: Davies & Zingle, 1970) was used to assess parents' beliefs in relation to those irrational ideas first identified by Ellis (1962). The AI-II was developed on the basis of Ellis' 11 irrational ideas, and items were drawn from the original Irrational Ideas Inventory (I-I) designed for adolescents by Zingle (1965). The AI-II consists of 60 items rating beliefs on a Likert scale (ranging from strongly agree to strongly disagree). Past research identified the I-I as a valid measure of irrationality (Davies,

1970; Zingle, 1965), and the AI-II was further validated through administration to 300 adults. Content validity and construct validity of the AI-II were documented through positive correlations with the I-I, and through administration to different clinical and "normal" groups (Davies, 1970) Test-retest reliability of the AI-II has been shown to be .77, with a range of .74 to .78 across the irrational ideas represented by the items (Davies, 1970).

#### Parental Locus of Control

Parents' locus of control was evaluated by administration of the self-report Rotter's Internal-External Locus of Control Scale (Rotter, 1966). This scale consists of 35 items with 29 forced-choice items tapping locus of control, and 6 "filler" items. Internal consistency in the range of .67 to .79 has been demonstrated by item and factor analysis, and the scale has reportedly been predictive of group differences (Rotter, 1966). Evidence of construct validity and discriminant validity has also been presented by Rotter (1966). Test-retest reliability has been shown to be between .49 and .83. Norms were provided based on administration of the measure to 575 male and 605 female undergraduate students (Rotter, 1966).



### Pile-Up Measure

The Family Stressors Index (FSI; McCubbin, 1991) was administered as a pile-up measure in order to determine the impact of any normal stressors which may have occurred within the life of the family over the past year. This self-report inventory includes ten questions about changes or events which the family may have experienced, and which may contribute to the overall level of family stress and functioning. Items require a yes or no response, with a higher score indicating a greater number of stressors. The FSI was designed as a pile-up measure based on the Family Inventory of Life Events (FILE) developed by McCubbin, Patterson, and Wilson (1979). In relation to the FILE, the validity coefficient of the FSI is .60 (McCubbin, 1991). Norms were based on 1000 families participating in a survey across the United States. As items for the FSI were drawn from the FILE, psychometric properties of the FILE are relevant, including overall reliability of .81 and .30 to .73 for the subscales. Construct, concurrent, and predictive validity for the FILE has been well documented (McCubbin, Patterson, & Wilson, 1980).

### Family Functioning

In order to provide an indicator of family functioning across a wide range of areas, the Family Assessment Measure

III (FAM III) was included in the questionnaire. The FAM III is a self-report instrument based on the McMaster Model of Family Functioning (Skinner et al., 1983), and was designed to measure the family's efforts to re-stabilize following a crisis situation. The test was developed based on the responses of 372 families seen in health and social service settings across Canada. The FAM III provides an overall score as well as scores for seven subscales including Task Accomplishments, Role Performance, Communication, Affective Expression, Affective Involvement, Control, and Values and Norms. Social Desirability and Defensiveness scales are additional components of the FAM III. For the original FAM, internal consistency was .93, and reliability was determined to be .95 for the total score, and .60 to .87 for the subscales. Construct, concurrent, predictive, and clinical validities have also been documented (Skinner et al., 1983).

### Child Functioning

Although the child's level of functioning was not directly assessed in this study, the parents' perceptions of their child's skills were measured through a structured interview using the Vineland Adaptive Behavior Scales (Survey Edition: Sparrow et al., 1984). This instrument was developed as a revision of the Vineland Social Maturity Scale (Doll, 1965) in order to "...assess

the personal and social sufficiency of individuals..." (Sparrow et al., 1984, p. 1). Recognizing that "...adaptive behavior is age-related..." and that "...adaptive behavior is defined by the expectations or standards of other people..." (Sparrow et al., 1984, p. 6), Sparrow et al. (1984) developed 297 items to assess adaptive behavior across four domains for individuals between the ages of birth to 18 years, 11 months. In addition to an overall Adaptive Behavior Composite, the Vineland examines the domains of Communication, Daily Living Skills, Socialization, and Motor Skills. Questions are asked of parents regarding their child's typical performance across these areas, and items are scored based on specific criteria outlined in the manual. Norms were based on a representative North American sample of caregivers for 3000 individuals with and without disabilities across 30 age groups. Individuals with disabilities included both ambulatory and non-ambulatory people with the diagnosis of mental retardation, as well as those having visual or hearing impairments. Internal consistency reliability has been documented as .70 to .95 for the subscales (Domains), and .89 to .98 for the overall Adaptive Behavior Composite score. Test-retest reliability is reportedly in the .80 to .90 range (Sparrow et al., 1984).

### Data Analysis

The data were collected personally by this researcher through structured interviews with the parents, and through collection of completed questionnaires. Questionnaires were examined upon collection for any missing data, and any discrepancies or unclear responses (i.e., two choices marked on individual items) were clarified at that time. Each of the instruments in the questionnaire was scored by the examiner, and results were anonymously tabulated for each parent participating in the study.

Initially, demographic data about the child, family and parents were evaluated in order to describe the sample. This initial analysis examined both the families of children with autism and the families of children with cerebral palsy, and combined both groups for an overall perspective. Means, standard deviations and scatterplots were computed in order to describe demographic data and results of parental questionnaires and examine the results in order to rule out any curvilinear relationships which might distort correlations.

Secondly, where possible, the results of parental questionnaires for both groups and the total sample were compared to normative data. This analysis was calculated by hand using t-tests for those instruments where normative data were available.

Third, the data were then analyzed to address each of the five research questions identified at the beginning of the research, and to assess pile-up of normal life stressors. These analyses included correlational procedures, separate analyses of variance, multiple regression analyses, and structural equation modeling in order to examine relationships between the independent variables, mediating variables, and family functioning for each of the two groups of parents, and for the total number of parents completing questionnaires. In response to the first of the research questions, Pearson product-moment correlations and multiple regression analyses were used to assess the role of social supports and coping strategies in predicting family functioning. In the second question, Pearson product-moment correlations were conducted for overall scores and subscale scores in order to examine the relationships among the variables of locus of control, self-esteem, and irrational beliefs. To address the third research question, the predictive value of parental locus of control, self-esteem and irrational beliefs as factors in family functioning was examined through correlational analyses and multiple regression analysis. In response to the fourth research question, predictive relationships among all of the parent variables and family functioning were evaluated through multiple regression analyses and structural equation

modelling using the program LISREL (Joreskog & Sorbom, 1988). LISREL essentially evaluated the overall model of independent and mediating variable in predicting family functioning. Parental views of coping strategies and social supports, and each of the parent attributes of locus of control, self-esteem and irrational beliefs were thereby tested for their ability to predict family adaptation. Finally, in response to the fifth research question, independent and mediating variables were compared for both groups of parents of children with autism and parents of children with cerebral palsy. This analysis consisted of using scatterplots to view the two groups of data and conducting analysis of variance in order to compare means across the independent, mediating, and dependent variables.

Group differences between mothers and fathers were also considered throughout these analyses, with subsequent combination for overall analysis. Additional post-hoc analyses further examined the relationship of the independent, mediating, and dependent variables to various child and family data such as parent education and occupation, gender of the child, chronological age of the child, age at diagnosis, and the child's level of adaptive functioning.

### Internal and External Validity

In order to discuss the generalizability of the results of this research, issues of internal and external validity were addressed. Internal validity identifies the extent to which a research design controls for possible explanations of variation found in the dependent variable. External validity refers to the generalizability of the findings to other subjects within the population, other measures of differences, and other research or clinical situations (Smith & Glass, 1987). As the independent variable was not experimentally manipulated in this research, it was especially important to ensure that threats to internal and external validity were minimized. Possible threats are discussed in the following sections in each of the areas of sample selection, measurement, and analysis.

#### Sample Selection

A primary research concern relevant to the validity and reliability of the results was the issue of random sampling. Through the nature of this study, some difficulties were identified regarding sampling as parents volunteered for participation in the research. The nature of their participation was therefore possibly biased first by their membership in a parent association regarding their child's disability, and second, by their choice to respond to the request for volunteers. While

it is important to consider that these parents may have differed across the variables examined in the study, this factor was considered unavoidable in the context of such parent research. Rather, this bias was considered in research design, analysis, and interpretation of results.

A second concern regarding the issue of random sampling was evident as Smith and Glass (1987) identified that measures should be independent of one another. In addition to the potential interrelationship of parental attributes such as locus of control, self-esteem, and irrational beliefs within the responses of each individual parent, there may have been confounding effects in those families where both parents responded to questionnaires. While they responded separately to questionnaires, parents in two-parent families were both present for the structured interview regarding their child's adaptive functioning. Other confounding effects of two parents within families responding to items regarding their own beliefs and views of family functioning may have also existed, and could not be isolated within the design and measures used.

### Measurement

Another source of concern regarding internal and external validity related to error of measurement. While the instruments used are widely recognized measures in the field,



the inherent problems of measuring personal constructs such as locus of control, self-esteem, and irrational beliefs were particularly clear. Additional concerns existed about the measurement of child functioning based on parent-report, and tools used to evaluate parental perceptions of coping strategies, social supports, and family functioning. Although such concerns were recognized, the general acceptance of these instruments in the field and examination of test validity and reliability discussed earlier in this chapter were believed to minimize measurement effects.

### Analysis

In statistical analysis of the data, procedures and tests were chosen in an attempt to increase the generalizability of results and recognize the limitations of the research. These statistics included computation of correlation coefficients to examine any relationships among the variables, t-tests to compare the findings to normative data, and separate analyses of variance to compare means and groups across the variables.

As numerous correlations were computed on the data, the increased probability of Type I errors and limitations of correlational research were considered. These limitations included the inability to manipulate the independent variable, problems with randomization, and the caution of correctly

interpreting correlational results (Smith and Glass, 1987). Since a primary limitation of correlational research is the inability to make inferences regarding causality, this research focused on identifying such relationships to better understand parent experiences. While of interest, the causality of these relationships between independent and dependent variables in dealing with individual parents and families is difficult to assess and was not attempted within this research design. Such attributes do not ethically or realistically allow for experimental manipulation, and this researcher recognizes the potential for change and development in these personal attributes during one's early history. Aside from the issue of causal inferences, attempts to minimize the possibility of spurious correlations were also made by using scatterplots of the data to ensure the absence of curvilinear relationships which might distort Pearson product-moment correlations. These scatterplots as well as box plots were also examined for out-lyer influences due to extreme scores, to ensure that these did not bias the results.

In order to compare the participants of this research with others in the population, t-tests were used to compare results of questionnaires with normative data where such information was available. Separate analyses of variance were also conducted to compare groups across the independent,

mediating, and dependent variables. The power of t-tests depends to a large extent on the assumptions of independent measurement associated with the issue of random sampling, normal distribution of scores within the population, and normal variances within the two populations compared (Smith & Glass, 1987). While this research indicated some threat to the first two of these assumptions, particularly regarding independent measurement, attempts were made to minimize the potential for Type I and Type II errors by considering the non-directionality of the procedures and sample size.

In the case of analysis of variance, one of the primary assumptions required that the populations from which samples were drawn were normally distributed for the dependent variable. The data from this research were examined through the use of frequency distributions to rule out any significant skew to the results. The second assumption of homoscedasticity further required that two or more population variances were equal. As discussed further in the Chapter IV, within-group variances were not greatly different and therefore indicated little concern about the second assumption for analysis of variance. The third assumption of analysis of variance further indicated the need for random sampling, and while this is often a problem in family research, this concern was addressed and considered in the interpretation of results.

In conclusion, Smith and Glass (1987) stated that violations of the first two assumptions have little effect on the validity of conclusions reached and described the ANOVA as a "robust" test in that results are likely correct probabilities even when populations are not exactly normal.

Due to concerns about the number of correlations conducted and the difficulty of meeting assumptions of statistical tests with the sample and data collected, however, attempts were made to increase the power of the tests in detecting significant differences. As the probability of error in falsely rejecting the null hypothesis (Type I) is established by the level of significance adapted in interpreting results, the size of alpha was set at a significance level of  $p \leq .01$  with significance at the  $p \leq .05$  viewed as possible trends.

### Limitations

As described above, several limitations were considered in interpreting the results of this research, and in making generalizations to the rest of the population. These limitations included a limited sample with potential bias due to selection of parent association members and voluntary participation, and measurement concerns. The use of self-report measures to assess parent variables, family functioning, and children's adaptive functioning presented some bias as no external

measures of these factors were taken. However, as the goal of this study was focused on parental perceptions and experience, the personal report of parents was viewed as the best means of obtaining information. Certainly, parent reports regarding their children's level of functioning and diagnosis may differ from professional assessment. However, it was felt that parent perceptions of these factors were important and provided critical information about their experience with a child with a disability. As discussed earlier, a pile-up measure was included in the questionnaire in order to address the issue of additional contributing stressors in the life of the family.

In consideration of the limitations, then, this research focused on increasing practical understanding of parental experience, identifying factors for further study, and considering implications for provision of services.

#### Delimitations

Lockey, Spirduso, and Silverman (1987) stated that "...delimitations describe the populations to which generalizations may be safely made..." (p. 28). While some of the biases related to sample selection and voluntary participation in this research were considered unavoidable, these concerns have been an ongoing problem in the area of family research (Reddon, 1989; Redington, 1992). The

majority of parents in this sample were members of parent associations, were from two-parent families, were mothers, and were living in urban or suburban areas. Generalizations of the overall results to similar populations were therefore reasonable. In evaluating the results of this research, consideration was also given to the children's chronological age range. As some researchers (Singer & Irvin, 1989) have identified, stressors and family functioning may change over the lifespan of the child and family. Therefore, generalizations of the data were considered applicable only to children of preschool and school age.

## CHAPTER IV

### Results

#### Introduction

In this chapter, the results of the study are described by initially identifying information about the participants of the research, detailing the results for the two groups studied with comparison to normative populations, and presenting the results of analyses focused on each of the five research questions discussed earlier. Finally, in the conclusion of this chapter, the results of post hoc analyses are addressed through a presentation of additional findings. In interpreting results, the size of alpha was set at a significance level of  $p \leq .01$  with  $p < .05$  viewed as possible trends.

#### Participants

##### Families

Families of children with autism or cerebral palsy were contacted through parent associations throughout Alberta and Saskatchewan. Of those families choosing to participate in the study, fifty of the participating families were from Alberta, and seven were from Saskatchewan. Seventy-five percent of the total sample were living in urban or suburban locales, 17 %

were living in small towns, and 8 % were living in rural settings. In total, 57 families completed participation in the research, including eight single-parent families, and 49 two-parent families. In 11 of the two-parent families, both parents responded to the questionnaire. In the remaining 38 two-parent families, only one parent in the home completed the questionnaire. Of these 38 parents, one parent was a father and 37 were mothers. Of the families with only the mother responding to the questionnaire, two were long-term foster care parents and one was an adoptive parent who had cared for the children during their early development. Table 14 in Appendix B depicts information about the participating families.

Of the total number of 57 families, family size averaged one to two children. Ten of these families had more than one child with special needs, and seven of these families had more than one child with the identified diagnosis. As discussed earlier, parents from these families were requested to focus on the child perceived as having more features of the specific disability.

### Children

Of the 57 families completing participation in this research, 32 of the identified children had the diagnosis of



autism. Twenty-five of the identified children had the diagnosis of cerebral palsy, due to a variety of factors which were not reported here in order to maintain confidentiality. A number of the children with cerebral palsy had secondary or concurrent disabilities, including visual and hearing impairment. Diagnoses were reported by the parents and, though not confirmed with external sources by this researcher, were made by physicians, psychologists, or teams of professionals.

Children participating in this research ranged in age from 22 months to 11 years, with a mean age of 6 years, 3 months. An analysis of variance compared the mean ages of children diagnosed as autistic and children with cerebral palsy, and found no significant difference in mean child age between the two groups (see Table 15 in Appendix B). Based on parent-report for the total group, the mean age of diagnosis of these children was 27 months. Children with cerebral palsy were generally diagnosed at an earlier age than children with autism. Indeed, an analysis of variance indicated a significant difference between groups for age at diagnosis. The mean age of diagnosis for children with autism was 40.10 months, and the mean age of diagnosis for children with cerebral palsy was 11.35 months. This difference yielded an F value of 58.68, significant at  $p < .01$ . Of the 57 children in total, 44 were male

and 13 were female. More specifically, of the 25 children with cerebral palsy, 14 were male and 11 were female. Thirty of the children with autism were male, and 2 were females.

Although the children were not directly assessed by this researcher, parental responses to the Vineland Adaptive Behavior Scales were used to provide some evaluation of their child's functional abilities. Based on parent report, the total group of identified children were well below normal limits across all of the scales of the Vineland. Table 1 shows the means and standard deviations for the children's scores across both groups. Means and standard deviations for standard scores on the Vineland indicated that the total group was at least two standard deviations below the normative mean across the Communication, Daily Living Skills, Socialization, and Motor Skills Domains, as well as for the Adaptive Behavior Composite (Mean standard score 48.88, Standard Deviation 18.13). The mean age equivalent for the child's Adaptive Behavior Composite (overall level of adaptive functioning) was 27 months for both of the two groups of children, and for the combined group total. A comparison of standard scores across the domains showed no significant difference between the two groups of children. While there was no significant difference between the children with autism and the children with cerebral palsy in terms of their overall level of adaptive

functioning, some differences were indicated in an analysis of specific subscales of the Vineland (see Table 16 in Appendix B).

Table 1

Child's Level of Adaptive Functioning on the Vineland Adaptive

Behavior Scales: Interview Edition, Survey Form (Standard Scores)

- Group Means(Standard Deviations) and Comparison of Means  
for Domains

	Autism	Cerebral Palsy	F	probability
Communication	56.3(23.0)	59.2(27.6)	.1855	N.S.
Daily Living Skills	44.7(18.8)	44.3(24.1)	.0052	N.S
Socialization	54.4( 8.7)	63.9(21.7)	5.0948	p<05
Motor Skills	60.5(18.2)	41.1(22.1)	13.2000	p<001
Adaptive Behavior				
Composite	48.2(14.6)	49.8(22.2)	.1135	N.S.

N.S. Not Significant

In a comparison of the two groups across the Vineland domains of Communication, Daily Living Skills, Socialization, and Motor Skills, differences were most evident in the areas of Socialization and Motor Skills. While not significant at the

desired  $p \leq .01$  level, the difference on the Socialization Domain suggested that children diagnosed as autistic scored lower compared to children with cerebral palsy. On the Motor Domain, a significant difference ( $F=13.20, p < .01$ ) was evident in comparing the standard scores of children diagnosed as autistic and children with cerebral palsy. In line with their diagnoses, children diagnosed as autistic were significantly higher functioning across both the gross motor ( $F=38.14, p < .01$ ) and fine motor ( $F=8.61, p < .01$ ) subdomains. Both groups, however, were below normal limits for their age on the Motor Domain with a mean age equivalent of 36 months for children diagnosed as autistic, and a mean age equivalent of 16 months for children with cerebral palsy.

Other comparisons of children's abilities on the Vineland were not statistically significant at the desired level. However, one comparison of the two groups on the Personal subdomain of the Daily Living Skills domain was approaching significance ( $F=5.37, p < .025$ ) and suggested that children diagnosed as autistic were slightly higher functioning in terms of personal care skills compared to children with cerebral palsy.

### Parents

Demographic data were also collected for the parents of the 57 families participating in the study. The mean age of

mothers in the total group was 35 years, and fathers had a mean age of 36 years. An analysis of variance indicated no significant difference in fathers' or mothers' mean age for the two groups. Information was also gathered regarding the educational and occupational levels of mothers and fathers in order to provide some indication of the socio-economic composition of the sample (see Table 2). Of the total number of parents, most reported a level of education at the technical or community college level. Information about occupation indicated somewhat more variability between mothers and fathers, with the majority of mothers working as a caregiver or in labour occupations, and the largest percentage of fathers working in a skilled trade.

Table 2

Parent Education and Occupation Level

<u>Education</u>	<u>Mothers</u>	<u>Fathers</u>
< grade 12	4%	8%
Grade 12 or equivalent	27%	12%
Technical/Community College	37%	38%
University	30%	30%
Graduate Degree	2%	12%

(Table 2 continued)

<u>Occupation</u>	<u>Mothers</u>	<u>Fathers</u>
Unemployed	0%	4%
Caregiver/Labourer	68%	12%
Skilled Trade	21%	44%
Semi-professional/Mid-management	9%	16%
Professional/Management	2%	24%

#### Comparison of Results to Normative Data

Normative data were available on five of the instruments used in the parent questionnaires. These included the Coping Health Inventory for Parents, the Rotter Internal-External Locus of Control Scale, the Culture-Fair Self-Esteem Inventory, the Family Stressors Index, and the Family Assessment Measure. Initially, means and standard deviations were calculated for parents of children diagnosed with autism and parents of children with cerebral palsy (see Table 3).

Table 3

Mean Scores (Standard Deviations) for Parents of Children with Cerebral Palsy (CP) and Parents of Children with Autism (A) Across Variables

<u>Measure</u>	<u>A</u>	<u>CP</u>	<u>prob.</u>
Coping Health Inventory for Parents			
(raw scores)			
-Integration, Cooperation, & Communication	34.97(8.29)	38.37(9.70)	N.S.
-Support, Esteem, & Stability	32.00(7.87)	31.75(9.89)	N.S.
-Medical Consultation & Communication	15.00(5.10)	15.87(4.25)	N.S.
Social Support Inventory(raw score)	108.22(14.72)	102.09(17.97)	N.S.
(Table 3 continued)			
Culture-Fair Self-Esteem			
Inventory (T scores)	51.64(9.09)	52.81(7.98)	N.S.
Adult Irrational Ideas			
Inventory (raw scores)	154.58(24.21)	163.75(20.96)	N.S.
Rotter Internal-External Locus			
of Control Scale (raw scores)	8.97(3.60)	10.34(3.85)	N.S.
Family Assessment Measure			
(Standard Scores)	50.61(8.67)	51.69(9.52)	N.S.
<u>Family Stress Index (raw score)</u>	<u>12.81(7.92)</u>	<u>12.27(8.65)</u>	<u>N.S.</u>

As subsequent separate analyses of variance indicated no significant difference between groups across the variables, the groups were combined in t-test analyses in order to compare the total group of parents with normative results reported for the population (see Table 4).

Table 4

Comparison of Results to Normative Data

(Mothers n = 55 are indicated by bold-face type

Fathers n = 13 are indicated by normal type, Total n = 68)

Measure	Normative Data Mean (S. D.)	Total Group Mean (S.D.)	t
<b>Coping Health Inventory</b>			
for Parents (raw score)			
-Integration, Cooperation, and Communication	<b>40 (15.0)</b>	<b>36.75 (9.14)</b>	<b>-2.64*</b>
	36 (20.0)	35.85 (9.10)	-0.06
-Support, Esteem, and Stability	<b>28 (12.0)</b>	<b>31.93 (8.38)</b>	<b>3.48**</b>
	25 (15.0)	31.69 (10.84)	2.22*



(Table 4 continued)

-Medical Consultation			
and Communication	15 (7.0)	16(4.55)	1.64
	12 (8.0)	12.92 (4.73)	0.70
Culture-Fair Self-Esteem			
Inventory (T score)	50 (10)	52.36 (8.22)	2.13*
	50 (10)	51.46 (10.14)	0.52
Rotter Internal-External			
Locus of Control			
(raw score)	8.42 (4.06)	9.56 (3.74)	2.28*
	8.15 (3.88)	9.85 (3.98)	1.55
Family Assessment			
Measure- Composite			
(Standard Score)	50 (10)	50.91 (9.34)	0.72
	50 (10)	52.00 (7.84)	0.92
Family Stress Index			
(raw score)	11 (6.0)	12.30 (8.69)	1.11
	11 (6.0)	13.65 (6.00)	1.60

\*\* p < .01 significance level \* p < .05 significance level

### Coping Health Inventory for Parents (CHIP)

Results for the sample of parents were compared with normative data for each of the three scales of the CHIP. On the Support, Esteem, and Stability scale, mothers' scores in the

sample were significantly higher than mothers within the normative population. On the Medical Consultation and Communication scale of the CHIP, parents within the sample did not report significantly different results from parents within the normative population.

#### Culture-Fair Self-Esteem Inventory

No significant results at the  $p < .01$  level were apparent in comparing parents of the combined sample with adults in the normative population on this overall self-esteem measure. The subscales of the Culture-Fair Inventory were also analyzed in comparing results with normative data, with no evidence of significant differences across the areas of General self-esteem, Social self-esteem, Personal self-esteem, or Defensiveness.

#### Rotter Internal-External Locus of Control Scale

On this self-report measure of locus of control, no significant differences at the  $p < .01$  level were apparent in comparing subjects to normative data. Mothers' and fathers' locus of control scores in this research were therefore not significantly different from adults in the normative population on this instrument.

### Family Assessment Measure (FAM III)

In comparing the overall scores on the FAM III for the total group of parents, no significant differences were apparent between the research sample and the normative population. However, an analysis of subscales from the FAM III indicated some differences of note (see Table 17 in Appendix B). Specifically, significant results were evident on the Social Desirability scale, with parents in the sample demonstrating less concern about social desirability compared to parents in the normative population. Mothers in the sample also demonstrated significantly lower Denial scores compared to mothers in the normative population (see Table 17 in Appendix B).

### Family Stressors Index (FSI)

On this pile-up measure of family stressors, mothers and fathers within the sample did not report significantly more stress from normal life events compared to the normative population. As this measure was used to indicate pile-up stress associated with normal life events, it was important to note that the parents in this study did not report experiencing more stress due to general life events than adults in the population.

### Research Questions

In this section, statistical results are presented with respect to each of the five research questions. For each question, descriptive statistics for the sample distribution are detailed, followed by relevant analyses.

#### Question 1.

Is healthy family functioning positively predicted by the availability of social supports and coping strategies?

#### Social Supports

On the Social Support Inventory (SSI), parents' responses were tabulated for the total group of both fathers and mothers. On Part A of the SSI, both fathers and mothers identified a mean of 9 of a possible 11 sources of support. On Part B of the SSI, total scores showed little difference between mothers and fathers in terms of overall social support. When the means for each of the separate sources were examined, it was apparent that both mothers and fathers identified their spouse, child, relatives, and friends as their four primary sources of support. In a rank-ordering of all of the means for the sources of support on the SSI (see Table 5), some differences were evident between mothers and fathers in the sample. Mothers ranked spiritual faith higher as a source of support compared

to fathers, and fathers ranked co-workers much higher as a support compared to mothers. Of interest, mothers and fathers appeared to equally value professionals or service providers and special groups as sources of support. In considering the results on the SSI for the two diagnostic groups in the sample, an analysis of variance comparing means indicated little difference in perceived social support between parents of autistic children and parents of children with cerebral palsy (see Table 3).

Table 5

Ranking of Sources of Support for the Total Group of Parents

	<u>Fathers</u>	<u>Mothers</u>
1.	spouse	spouse
2.	child	child
3.	relatives	friends
4.	friends	relatives
5.	co-workers	spiritual faith
6.	professionals	professionals
7.	special groups	special groups
8.	spiritual faith	neighbors
9.	neighbors	church
10.	church	books/television
11.	<u>books/television</u>	<u>co-workers</u>

### Coping Strategies

Parents' responses on the three scales of the Coping Health Inventory for Parents (CHIP) were tabulated and compared in order to describe the sample (see Table 3). As discussed earlier in a comparison of these results with normative data, parent responses indicated helpfulness across all three scales. When scores for fathers and mothers across the scales were transformed into standard scores for comparison within the sample, both scored highest on the Integration, Cooperation and Communication scale. This result indicated the highest degree of helpfulness from behaviors which improved relationships within the family and which fostered optimism about living with a child with a disability. Secondly, parents' scores on the Medical Consultation and Communication scale indicated a moderate degree of helpfulness from behaviors which encouraged positive relationships with professionals and other parents of children with disabilities. In comparison, they ranked items on the Support, Esteem and Stability scale as the lowest of the three scales. This last scale examines the helpfulness of behaviors which assist in their relationships with others and in strategies or activities which help to build and maintain self-esteem. An analysis of variance comparing the means for the two

diagnostic groups indicated no significant differences across the scales of the CHIP between parents of autistic children and parents of children with cerebral palsy.

#### Social Supports, Coping Strategies, and Family Functioning

In order to investigate any relationships between social supports, coping strategies, and family functioning, Pearson product-moment correlations were first calculated for the composite score from the Social Support Inventory (SSI)-Part B, scores for each of the scales on the Coping Health Inventory for Parents (CHIP), and the total score from the Family Assessment Measure (FAM III). A significant correlation was evident between high social support and high family functioning for the total group of parents in the sample ( $r=.47, p<.01$ ). In comparing the CHIP scales with FAM III results, significant correlations were indicated between high scores on the Integration, Cooperation and Communication scale and high family functioning ( $r=.35, p<.01$ ) and between high scores on the Medical Consultation and Communication scale and high family functioning ( $r=.37, p<.01$ ). No significant relationship was evident between scores on the Support, Esteem and Stability scale of the CHIP and scores on the measure of family functioning.

Secondly, a multiple regression analysis was performed to separately investigate the predictive value of social supports and coping strategies in family functioning. Of the independent variables in this analysis, the total score from the SSI-Part B accounted for most of the variance in total scores on the FAM III ( $F=18.87, p<.01$ ). While previous correlational analysis indicated significant relationships between some coping strategies and family functioning, parents' reported level of social support was the better predictor of family functioning.

#### Question 2.

Are parental locus of control, self-esteem, and irrational beliefs correlated with each other, in that there may be a relationship between higher self-esteem, internal locus of control, and lower report of irrational beliefs, or between lower self-esteem, external locus of control, and higher report of irrational beliefs?

#### Locus of Control

Parent responses to the Rotter's Internal-External Locus of Control Scale were tabulated for comparison within the sample and for comparison with normative data. Means and standard deviations were calculated for mothers and fathers, and for parents of children with autism and parents of children



with cerebral palsy (see Table 3 and 4). On this locus of control scale, a high score indicates a higher level of external locus of control. For the total group, fathers' responses indicated a mean score of 9.85 with a standard deviation of 3.98. Mothers' responses produced a mean score of 9.56 with a standard deviation of 3.74. No significant difference was evident between means for mothers and fathers within the sample. An analysis of variance compared the means of parents scores for the two groups of children with disabilities, with no evidence of a significant difference in locus of control between parents of autistic children and parents of children with cerebral palsy.

### Self-Esteem

Overall and subscale results from the Culture-Fair Self-Esteem Inventory were calculated for parents, and T-scores with a mean of 50 and a standard deviation of 10 were obtained using norms available in the manual (Battle, 1992). Based on scores for the Lie subscale, no concerns were evident regarding defensiveness for either the mothers or fathers within the sample (see Table 17 in Appendix B). The mean T-scores for fathers' overall self-esteem was 51.46 with a standard deviation of 10.14, and for mothers was 52.36 with a standard deviation of 8.22. Across the subscales, the total group of parents in the sample showed the highest level of

self-esteem in the Social domain, and the lowest level of self-esteem in the Personal domain. An analysis of variance showed no evidence of significant differences in overall self-esteem on this measure between parents of autistic children and parents of children with cerebral palsy.

### Irrational Beliefs

In tabulating results of the Adult Irrational Ideas Inventory for parents in the sample, it was noted that a low score indicated a lower level of irrational beliefs with a lowest possible score of 60. Results indicated a mean score of 162.77 for fathers with a standard deviation of 29.46, and a mean score of 157.98 for mothers with a standard deviation of 21.47. T-tests were calculated manually in order to compare these results with other studies using the Adult Irrational Ideas Inventory. The results in this research for each of the two groups of parents and the combined group were not significantly different from a group of teachers in rural Alberta (Anderson, 1985; Zingle & Anderson, 1990), representative samples of adults in the Edmonton area (Fox & Davies, 1971), or from groups of college students in research in the United States (Martin, Dolliver, & Irvin, 1977). An analysis of variance also showed no evidence of a significant difference between the

mean scores for parents of autistic children and parents of children with cerebral palsy.

#### Locus of Control, Self-Esteem, and Irrational Beliefs

Pearson product-moment correlations were calculated in order to examine any relationships among parents' scores on the Rotter's Internal-External Locus of Control Scale, Culture-Fair Self-Esteem Inventory, and Adult Irrational Ideas Inventory (see Table 6). For the total group of parents responding, a high level of external locus of control was significantly correlated with a low level of overall self-esteem. An external locus of control was similarly significantly related to a high level of irrational beliefs on these measures. A high level of irrational beliefs was in turn significantly correlated with a lower level of overall self-esteem.

Table 6

Interrelationships Between Parent Variables for the Total Group

(n = 68)

Variable	2	3
1. Locus of Control	38*	-.53*
2. Self-esteem	-----	-.56*
3. Irrational Beliefs	-----	-----

\* p<01

When Pearson product-moment correlations were calculated for mothers and fathers separately, interrelationships among these parent variables were most evident among the mothers in the sample (see Table 7).

Table 7

Interrelationships Between Parent Variables for Mothers and Fathers

Variable	2	3
Mothers (n=55)		
1. Locus of Control	.44*	-.60*
2. Self-esteem	-----	-.53*
3. Irrational Beliefs	-----	-----
Fathers (n=13)		
1. Locus of Control	N.S.	N.S.
2. Self-esteem	-----	-.66*
3. Irrational Beliefs	-----	-----

\* p<.01  
N.S. Not Significant

A high level of external locus of control in the mother's group was significantly correlated with a lower level of overall self-esteem, and with a higher level of irrational beliefs. Among mothers, a higher level of irrational beliefs was also significantly correlated with a lower level of overall self-

esteem. In the group of fathers, the only significant correlation was evident between a higher level of irrational beliefs and a lower level of overall self-esteem.

Correlational analysis was also conducted for each of the subscales of the Culture-Fair Self-esteem Inventory in order to consider any relationships with the Rotter's Internal-External Locus of Control Scale and the Adult Irrational Ideas Inventory. In close agreement with results for the overall self-esteem score, lower scores on each of the subscales of General self-esteem, Social self-esteem, and Personal self-esteem were significantly correlated with a higher level of irrational beliefs and a higher level of external locus of control (see Table 17 in Appendix B).

### Question 3.

Do the internal parental attributes of locus of control, self-esteem and irrational beliefs account for some of the variance in family adaptation to a child with a disability?

In order to address the above research question, correlations and predictive relationships were examined among the variables of locus of control, self-esteem, irrational beliefs, and family functioning. Overall scores from the Rotter Internal-External Locus of Control Scale, the Culture-Fair Self-

Esteem Inventory, the Adult Irrational Ideas Inventory, and the Family Assessment Measure were used in these analyses.

In the first phase of analyses, Pearson product-moment correlations were calculated for the total group to examine any significant relationships between parental attributes and family functioning (see Table 8). These results indicated significant relationships between the variables of locus of control, self-esteem, and irrational beliefs, and the variable of family functioning on the measures used.

Table 8

Correlations Between Measures of Parental Variables and Family Functioning

	Family Assessment Measure	probability
Social Support	.47	p<.001
Coping Health Inventory for Parents		
-Integration, Cooperation, & Communication	.35	p<.01
-Support, Esteem, & Stability	.19	N.S.
-Medical Consultation & Communication	.37	p<.025
Adult Irrational Ideas Inventory	-.52	p<.001

(Table 8 continued)

Rotter Internal-External

Locus of Control Scale	-.43	p<.001
Culture-Fair Self-Esteem Inventory	.51	p<.001

N.S. Not Significant

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Secondly, multiple regression analyses were conducted to investigate the predictive value of these relationships. A multiple regression analysis (see Table 9) indicated that of the three parental attributes tested, irrational beliefs and self-esteem accounted for most of the variance in family functioning (see Table 18 in Appendix B).

Table 9

Irrational beliefs and Self-esteem as Predictors of Family Functioning

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	F	probability
Irrational beliefs (AI-II)	23.97	p<.0001
Self-esteem (CFSEI-AD)	17.88	p<.0001

---



Question 4.

How much of the variance in family functioning among families with a child with a disability is accounted for by the variables of coping strategies, social supports, self-esteem, irrational beliefs and locus of control?

Initially, a multiple regression analysis of the variables of coping strategies, social supports, self-esteem, irrational beliefs, locus of control, and family functioning was conducted (see Table 18 in Appendix B). Of the parent variables, irrational beliefs, coping strategies related to Medical Consultation and Communication, and self-esteem accounted for most of the variance in family functioning (see Table 10).

Table 10

Irrational Beliefs, Coping Strategies (Medical Consultation & Communication), and Self-Esteem as Predictors of Family Functioning

<u>Variable</u>	<u>F</u>	<u>probability</u>
Irrational beliefs (AI-II)	23.97	p<0001
Coping strategies related to Medical Consultation & Communication (CHIP)	21.58	p<0001
Self-esteem (CFSEI-AD)	17.88	p<0001

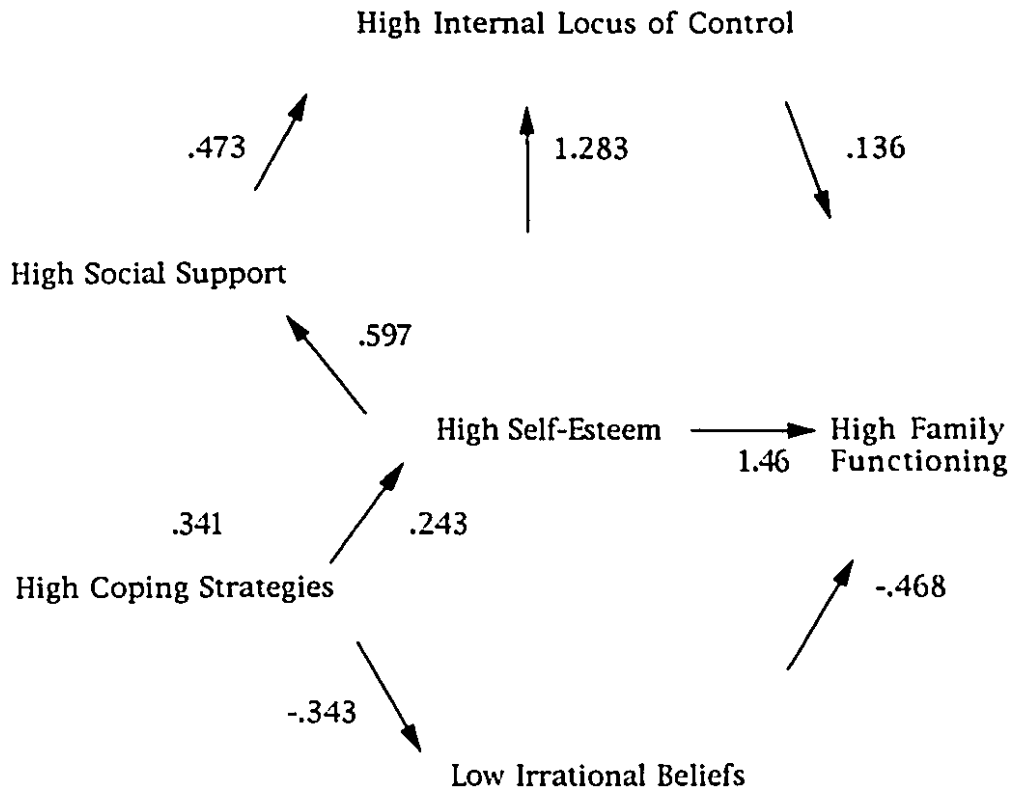
In the process of multiple regression analyses of coping strategies, social supports, self-esteem, irrational beliefs and locus of control in relationship to family functioning, some of the data for mothers were examined by a separate multiple regression due to the comparatively large proportion of mothers within the total sample (see Table 19 in Appendix B). The first variable to contribute to the largest amount of variance in family functioning among mothers was self-esteem . Coping strategies related to Medical Consultation and Communication were also significant predictors of family functioning among mothers, as was locus of control. These results provided further evidence of the relationship between the parental attribute variables and family functioning, as well as the role of coping strategies (see Table 11).

Table 11

Mother's Self-Esteem, Irrational Beliefs, and Locus of Control as Predictors of Family Functioning

<u>Variable</u>	<u>F</u>	<u>probability</u>
Mother's self-esteem	17.00	$p \leq 0001$
Mother's coping strategies (Medical Consultation & Communication)	16.52	$p < 0001$
<u>Mother's irrational beliefs</u>	<u>13.85</u>	<u><math>p &lt; 0001</math></u>

Finally, structural equation modeling using the program LISREL (Joreskog & Sorbom, 1988) was employed to test the overall model of predictive relationships among the independent variables (social support and coping strategies), mediating variables (locus of control, self-esteem, and irrational beliefs), and dependent variable (family functioning). This structural equation modeling method was chosen over path analysis due to the complexity of the model in order to examine the mediating effects of parental attributes. Due to little difference between groups of parents of autistic children and parents of children with cerebral palsy across these variables, the groups were combined for this analysis. The following model accounted for approximately 88% of the variance, and indicated that the model fit the data relatively well (Chi Square = 19.65,  $p=.416$ ) with an adjusted goodness of fit of .877 (see Figure 1). In the diagram of the model, relationships are indicated by arrows and their associated path coefficients. Similar to regression coefficients between z scores, the higher the path coefficient, the stronger the relationship between variables. While some of the path coefficients included in Figure 1 were not significant on their own, they were retained as part of the overall model.



**Figure 1.** Model of relationships between parent variables and family functioning tested by structural equation modelling.

In this model, relationships were indicated between social support and locus of control, self-esteem and social support, coping strategies and self-esteem, and coping strategies and irrational beliefs (see Figure 1). Coping strategies were also predictive of other coping strategies, in that scores on each of the scales of the CHIP were inter-related. Of the mediating variables, self-esteem was a strong predictor

of locus of control, and all three of the parental attributes of locus of control, self-esteem, and irrational beliefs were predictive of family functioning. The resulting model from this analysis was also quite consistent with the pattern of relationships described in McCubbin and Patterson's Double ABCX model (1983) as resources (bB) such as coping strategies and social supports were mediated by parent appraisals (cC) in predicting the outcome (xX). Although other analyses in this study indicated a significant relationship between social support and family functioning, this relationship was not as evident in this model possibly due to the comparatively weaker relationship between locus of control and family functioning, or due to error in measurement. It is also possible that the power of social support was not as evident in this analysis because the mediating variables of locus of control, self-esteem, and irrational beliefs accounted for much of the variance in family functioning, or because of some common variance with self-esteem and irrational beliefs.

#### Question 5.

Do these internal attributes of parents play a greater role as predictors and variables in adaptation in the case of families with a child diagnosed with autism as opposed to cerebral palsy?

Results for each of the instruments in the parent questionnaires were compared for the two groups of parents of autistic children and parents of children with cerebral palsy. Initially, box plots were visually inspected and revealed little difference between these two groups across the variables as means and standard deviations were in close agreement. Subsequent separate analyses of variance were conducted in order to compare group means across all variables (see Table 20 in Appendix B). No significant differences were evident in comparisons of pile-up stresses on the Family Stressors Index, social support on the composite score of the Social Support Inventory-Part B, coping strategies across the three subscales of the Coping Health Inventory for Parents, locus of control on the Rotter Internal-External Locus of Control Scale, overall self-esteem on the Culture-Fair Self-Esteem Inventory, irrational beliefs on the Adult Irrational Ideas Inventory, or family functioning on the Family Assessment Measure.

### Post Hoc Analyses

In addition to the above analyses testing the relationships among results for the total group, comparisons with normative data, and comparisons between parents of children diagnosed as autistic and parents of children with

cerebral palsy, subsequent post hoc analyses revealed some findings worthy of discussion. These analyses examined information about parent education and occupation in relation to other variables, gender of child, child chronological age and age at diagnosis, and information about child adaptive functioning in relation to other variables.

#### Education and Occupation of Parents

Pearson product-moment correlations were calculated to examine any relationships between educational or occupational information about parents and other variables. Among fathers, a higher educational level was correlated with a higher level of education for mothers ( $r=.31$ ), a higher level of overall family functioning as reported by fathers ( $r=.55$ ) and by mothers ( $r=.36$ ), and a lower level of irrational beliefs reported by fathers ( $r=.65$ ). A strong positive correlation also existed between fathers' education and occupational level. Among mothers in the sample, a higher level of education was correlated with a higher level of pile-up stressors reported by fathers ( $r=.81$ ), a higher level of family functioning reported by mothers ( $r=.34$ ), and a higher level of perceived social support ( $r=.26$ ). Mothers' views of family functioning were also positively correlated with the fathers' occupational level ( $r=.45$ ), as were mothers' coping strategies ( $r=.30$ ) and a lower

level of irrational beliefs reported by mothers ( $r=.28$ ). The occupational level of mothers in the sample correlated only with mothers' coping strategies related to Support, Esteem and Stability as measured by a scale on the CHIP ( $r=.30$ ).

### Gender of Child

In order to examine any differences in results across variables between parents of male children and parents of female children, separate analyses of variance were conducted to compare means for each of the parent variables and family functioning (see Table 12). No significant differences were evident in social support, coping strategies, locus of control, self-esteem, irrational beliefs or family functioning when comparisons were made on the basis of child gender.

Table 12

### Comparison of Means of Male and Female Children (Combined Group) Across Parent Variables and Family Functioning

Analysis of Variance					
Measure		SS	MS	F	F prob.
Social Support	BG	678.64	678.64	2.55	.114 (N.S.)
	WG	17548.58	65.89		



(Table 12 continued)

## Coping Health

## Inventory for Parents

## -Integration,

## Cooperation,

& Communication	BG	0.17	0.17	0.00	.964 (N.S.)
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	WG	5516.47	83.58		
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## -Support, Esteem,

& Stability	BG	0.05	0.05	0.00	.980 (N.S.)
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	WG	5201.00	78.80		
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## -Medical Consultation

& Communication	BG	0.86	0.86	0.04	.845 (N.S.)
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	WG	1483.61	22.48		
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## Rotter Internal-

## External Locus of

Control Scale	BG	30.02	30.02	2.17	.146 (N.S.)
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	WG	914.04	13.85		
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## Culture-Fair Self-

Esteem Inventory	BG	40.90	40.90	0.56	.458 (N.S.)
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	WG	4849.61	73.48		
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## Adult Irrational

Ideas Inventory	BG	1413.34	1413.34	2.73	.103 (N.S.)
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	WG	34136.94	517.23		
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(Table 12 continued)

## Family Assessment

Measure	BG	215.85	215.85	2.72	.104 (N.S.)
	WG	5241.20	79.41		

df BG 1

WG 66

N. S. Not Significant

Total 67

Child Chronological Age and Age at Diagnosis

Pearson product-moment correlations were calculated in order to examine relationships between the chronological age of the child, the child's age at diagnosis, parent variables, and family functioning (see Table 13).

Table 13

Correlations Between Child Chronological Age, Child Age at Diagnosis, Parent Variables, and Family Functioning

Variables	Chronological Age	Age at Diagnosis
Social Support	-.08 (N.S.)	.02 (N.S.)



possible relationships with other variables. Within the Vineland domains of Communication, Socialization, Daily Living Skills, and Motor Skills, inter-correlations ranged from  $r=.54$  to  $r=.94$  ( $p<.05$ ). In comparing Vineland results with other variables, Pearson product-moment correlations indicated positive relationships between a higher level of children's communication skills and mothers coping strategies on the Support, Esteem and Stability scale of the CHIP ( $r=.31$ ), negative relationships between a higher level of children's daily living skills and a lower level of irrational beliefs reported by fathers ( $r=-.57$ ), and a positive relationship between a higher level of children's daily living skills and mothers' coping strategies on the Support, Esteem and Stability dimension ( $r=.33$ ). Children's scores on the Socialization domain of the Vineland were positively correlated with mothers' coping strategies ( $r=.28$ ), and with a lower level of irrational beliefs reported by the fathers in the sample ( $r=.56$ ). A higher Adaptive Behavior Composite score for children was correlated with a lower level of fathers' irrational beliefs, and with mothers' coping strategies related to Support, Esteem, and Stability ( $r=.33$ ). Correlational analyses for the total group of parents additionally indicated a significant positive relationships between children's scores on the Personal subdomain of the Daily Living Skills Domain and parental self-

esteem ( $r=.87$ ), and between children's scores on the Socialization Domain and parental self-esteem ( $r=.70$ ).

### Summary of Results

In addition to results describing the participants in the research, parent scores on instruments within the questionnaire were compared with normative data. Analyses were then conducted to investigate each of the five research questions, and were supplemented by post hoc analyses.

In comparing results to normative data, it was evident that parents in the sample reported no greater stress than families in the population on the measure used. No significant differences were evident in overall family functioning compared to normative data.

In response to the research questions, the results indicated a significant predictive relationship between social support, coping strategies, and family functioning. The data further demonstrated significant relationships between parental attributes, specifically correlating high overall self-esteem, internal locus of control, and a low level of irrational beliefs, for the sample with the instruments used. These parental attributes were also significant predictors of family functioning, and a proposed model of independent, mediating, and dependent variables accounted for approximately 88% of

the variance in family functioning. In a comparison of parents of children diagnosed as autistic and children with cerebral palsy across all variables, no significant differences were evident based on these results.

Finally, post hoc analyses examined possible relationships within the data which were not directly related to the research questions. These results indicated a relationship between some aspects of the children's level of adaptive functioning, mothers' views of coping strategies, fathers' level of irrational beliefs, and parents' self-esteem. Demographic information also suggested a relationship between socio-economic status as measured by parent occupation and education with family functioning as perceived by both fathers and mothers. In examining parent variables and family functioning, no significant relationships were evident with child gender, child chronological age, or child age at diagnosis. Additional correlations were discussed in the post hoc analysis, with caution regarding the risk of making causal inferences in correlational research.

## CHAPTER V

### Discussion

#### Introduction

The objectives of this study included an attempt to further understand the experience of families with children with disabilities, to contribute to knowledge in the field of developmental disabilities and family research, to provide more information for clinical use in intervening with individual families who may be having difficulties or who may be new to the diagnosis, and also in planning programs to achieve the "best fit" between services and families in order to assist in adjustment and family functioning. In the past four chapters of this dissertation, the background and rationale for this research were described, a review of the literature in the field was detailed, methods and procedures used in conducting this study were identified, and results were presented. In this concluding chapter, these results are discussed with specific attention to the initial research questions as well as implications for practical use and future research.

## Discussion of the Results

### Participants

#### Families

As discussed earlier, the method of sample selection used undoubtedly led to some bias in the type of families participating in this research. Parents were contacted through newsletters sent anonymously by parent groups and associations, and they voluntarily contacted the researcher for more information. The possibility that parents belonging to such groups and associations were different from those who do not, and the possibility that those who chose to volunteer and complete participation were different from those who did not, was considered in making generalizations from these results. Such differences among families might exist in terms of the variables studied, such as self-esteem, locus of control, irrational beliefs, social supports, and coping strategies, as these parental attributes in themselves may influence a parent's interest or willingness to participate in projects. Family functioning may have also been a factor in volunteering for the research. For example, parents who perceived their families as successful were possibly more willing to participate in the research. On the other hand, those having difficulty might have shown more interest in research as a means of



voicing their concerns and seeking assistance. Although the subjective impressions of the researcher indicated a wide range of families with varied reasons for participation in the study, these biases were considered throughout the discussion of results.

Additionally, demographic information about the families was collected with possible implications for interpretation of the results. Although families participated throughout both Alberta and Saskatchewan, from a variety of locales ranging from urban to rural settings, most were from Alberta, and 75% of the total sample was living in urban or suburban areas. This information was important given the difference in services available across these different locations, and possibly, differences in other supports. Most of the respondents were from two-parent homes, and most of the parents participating were mothers. Although little difference in results was evident based on these factors, these characteristics of the sample were considered in attempts at generalization.

Finally, the fact that a few of these families had more than one child with special needs and, in some cases, more than one child with the identified diagnosis, was addressed. Although these parents were encouraged to focus on the child perceived as having the greatest number of clinical features, their experience of dealing with two children with disabilities

is likely different from those having one child with a disability. While the group of families with more than one child with a disability was too small in this research to identify any differences, this factor was reported by parents to be an important consideration and is worthy of further study.

### Children

One of the significant differences noted in a comparison of children diagnosed as autistic and children with cerebral palsy was the age at diagnosis. Children with cerebral palsy were diagnosed significantly earlier than children diagnosed with autism. Apart from hypothetical differences addressed by research Question 5., these families may have also been different in that many of the parents of children with cerebral palsy in this study likely had a longer timespan of experience of having a child diagnosed with a disability. During interviews, parents of children diagnosed as autistic voluntarily expressed considerable frustration about the delay and uncertainty regarding diagnosis, and suggested that their experience might therefore be different from parents of children with other disabilities. It was therefore important to recognize the differences between these two groups in terms of age at diagnosis.

Although no significant difference in chronological age was evident between groups in a comparison of means, the age

range of the children was an essential factor in interpretation of results. In this research, identified children were between the ages of 22 months and 11 years. As researchers have identified in the past, parent experiences and stressors may change over the life cycle of the child and family (Singer & Irvin, 1989). In attempting to make generalizations to the populations of parents with children with diagnosed disabilities, then, a distinction was made on the basis of age as this research focused on the experience of parents with younger children.

The child's level of functioning was also evaluated by parental report, with no significant differences at the  $p < .01$  level evident between the groups of children diagnosed as autistic and children with cerebral palsy. Clearly, however, these children have different diagnoses with varying features. One would expect, then, that the similarity between the two groups was due in part to the instrument used. The Vineland is a parental report measure which describes the child's functioning across four general domains. Analysis of these domains indicated some differences, although these were not significant at the  $p < .01$  level. In comparison to children with cerebral palsy, children diagnosed as autistic tended to score lower on the Socialization domain, higher on the Motor Skills domain, and higher on the Personal Care subdomain. Given the

clinical features of autism (DeMyer, 1979), it was expected that children diagnosed as autistic might score lower on items tapping social interest and interactive skills. Similarly, the motor involvement inherent in cerebral palsy was consistent with these results, in that children with cerebral palsy tended to be weaker in motor skills and personal care. Despite the differences in diagnosis, though, no significant differences were evident between these groups on the Communication domain. Although their limited language skills might have been for different reasons associated with their diagnosis, both groups of children were similarly weak in communication skills.

### Parents

Demographic information indicated that most of the parents participating in this research reported education at the technical/community college level. Although the same percentage of mothers and fathers completed college or university, fathers had greater representations at the extremes of the scale. Compared to the group of mothers, the percentage of fathers who had not completed highschool was greater, as was the percentage of fathers reporting attainment of graduate university degrees. While the sample of fathers was perhaps more skewed than the sample of mothers in terms of

educational level, then, both groups demonstrated a range of education.

In collecting information about occupational level, a large majority of women in the group of mothers were working as full-time care-givers at home. Most of the fathers were employed in a skilled trade. This difference between groups was considered in that mothers' and fathers' experiences with their children may have been different based on the amount of time spent together, and in that the support systems of these two groups differed. Certainly, this characteristic of the sample was considered in making generalizations to the population with regard for the varying roles of mothers and fathers, and the different implications for socio-economic status. Although information about income was not directly collected in this research, these results primarily described middle-income families with one parent working outside of the home, and one parent working within the home.

#### Comparison of Results to Normative Data

For those instruments with normative data, comparisons were made with parent scores in order to describe the sample and delineate any apparent differences. No significant differences were evident between the sample of parents and normative data on measures of pile-up stressors or family

functioning. This finding suggested that families in this research project had not experienced any greater stresses due to other factors in the last year, and that these families generally reported a relatively normal level of family functioning. While this finding was contradictory to much of the literature in the field with a traditional emphasis on problems and pathology (Abbott & Meredith, 1986), it was consistent with more recent research describing some of the positive, normal experiences among families of children with disabilities (Reddon, 1989; Redington, 1992; Singer & Irvin, 1989). When subscales of the measure used to evaluate family functioning were examined, though, it was apparent that mothers and fathers in the sample were less concerned about social desirability in responding to questions about the family compared to norms, and mothers were less defensive than average compared to normative data.

Across some of the other variables, trends and differences were apparent in comparing results to normative data. Mothers in this project were significantly higher than the norms in coping strategies related to Support, Esteem, and Stability. Based on these results, mothers in the sample therefore reported finding more help from coping behaviors related to maintaining social support, self-esteem, and psychological stability.

Finally, on the measures of parental attributes, normative data were available in order to make comparisons of parental self-esteem and locus of control. On a measure of locus of control, there were no significant differences between the sample and the normative population.

On a measure of self-esteem, parents in this research were not significantly different from the normative population. Taylor (1983) discussed the importance of self-esteem as one of the essential factors in adjustment to specific life events, such as parenting a child with a disability. In describing relationships between self-esteem and gaining a feeling of mastery or control over stressors, Taylor (1983) further identified the importance of building self esteem: 1) attributing a cause, 2) gaining a feeling of mastery or control over the stressor or life events, and 3) increasing self-esteem. Of interest, then, is the role that beliefs about self-efficacy, personal control, and events in the world, may play in adjustment to specific life events. In addition to family adaptation and functioning, though, parental self-esteem has other implications for overall emotional functioning and personal satisfaction.

## Research Questions

### Question 1.

The first research question addressed whether family functioning was positively predicted by coping strategies and social supports. In the area of social supports, little difference was evident between mothers and fathers, and both parents identified that they found the most support from their spouse, child, relatives, and friends. Clearly, these most intimate relationships were the most important to parents in daily support. Perhaps due in part to occupational differences between mothers and fathers, fathers ranked co-workers as a stronger source of support than did mothers. With the majority of mothers in the sample working in the home full-time, the issue of co-workers may have had little importance for them. Instead, mothers in the sample ranked spiritual faith as a stronger source of support than did fathers. Both equally valued the help of professionals and special groups, although these supports were clearly less valued than more intimate relationships in the lives of parents.

In the area of coping strategies, those behaviors related to improving relationships within the family and fostering optimism were rated highest by parents overall. While other coping strategies related to communication with professionals and finding support and stability were also important, these



results indicated the greatest need for coping strategies which assist in developing Integration, Cooperation, and Communication. This finding differed somewhat from other research with the Coping Health Inventory for Parents and family functioning, as Reddon (1989) found that mothers were most concerned about coping strategies related to Medical Consultation and Communication.

In response to the research question, analyses indicated that both social support and coping strategies as measured by the instruments used were significantly related to family functioning. Results particularly indicated significant relationships between a high level of social support and a high level of family functioning, and between a high level of coping strategies and a high level of family functioning. These findings were in close agreement with much of the literature on the positive and significant role of coping strategies and social support in family adaptation (Reddon, 1989; Singer & Irvin, 1989; Summers et al., 1989). Of these two variables, however, social support accounted for most of the variance in family functioning in this research project, and appeared to be the best predictor.

Question 2.

This research question examined the inter-relationships of the variables of locus of control, self-esteem, and irrational beliefs. Results are discussed separately by variable, and in terms of relationships among these variables. Each of these parent variables was measured by self-report inventories, and normative data were available for comparison on two of these variables. In the areas of locus of control, no significant differences were evident. Across the subscales of the self-esteem measure, parents in the sample were highest in their perception of themselves in relationships with others, and weakest (though still well within normal limits) in their most personal appraisal of self-worth. On a measure of irrational beliefs, no significant differences were evident between mothers and fathers, or between parents of children diagnosed as autistic and children with cerebral palsy.

Analyses of the results of these self-report inventories across variables indicated significant relationships among locus of control, self-esteem, and irrational beliefs for parents in the sample. As hypothesized and as predicted by the literature (McPhail, 1969; Summers et al., 1989; Taylor, 1983), the results of this research indicated significant relationships among an internal locus of control, a lower level of irrational beliefs, and a higher level of self-esteem. The significant

relationships between self-esteem and the other two variables were also evident in an examination of each of the subscales of the self-esteem measure including both the social and personal aspects of self-worth. Although causal inferences about the direction of these relationships is not possible, the significant correlations among the variables was consistent with Taylor's (1983) emphasis on the roles of attributing cause, gaining a sense of mastery, and developing self-esteem, in adaptation.

### Question 3.

This third question further examined the variables of locus of control, self-esteem, and irrational beliefs as predictors of family functioning. Although causality could not be determined, correlations indicated significant relationships between a higher level of internal locus of control and higher family functioning, a lower level of irrational beliefs and higher family functioning, and a higher level of self-esteem and higher family functioning. Although the sample of parents did not report being significantly different from the normative population in terms of family functioning, their level of family functioning was closely associated with these personal variables. Of these three parental attributes, the measure of irrational beliefs appeared to be the strongest predictor of family functioning in this data. Although irrational beliefs

accounted for most of the variance, self-esteem was also a significant predictor of family functioning.

These findings were generally consistent with other research investigating the variables of locus of control, self-esteem, and beliefs, and with Bristol's (1987) hypothesis that these variables play a role in family adaptation. Other researchers have provided evidence about the importance of locus of control in family functioning (Affleck et al., 1982; Bulman & Wortman, 1977; Henderson & Vandenberg, 1992; Taylor, 1983). Self-esteem has also been an important predictor of family response in the literature (Antsey & Spence, 1986; Morgan et al., 1986), as have general findings about the role of positive parent beliefs in family adaptation (Frey et al., 1989; Tuttle, 1986). Examination of these attributes has further evidenced the importance of parent appraisals in adapting to a child with a disability (Dyson, 1991; Sloman & Konstantareas, 1990).

#### Question 4.

The fourth research question further examined the predictive relationships among parent variables and family functioning. Specifically, the question asked how much of the variance in family functioning among families with a child with a disability was accounted for by the variables of coping

strategies, social supports, self-esteem, irrational beliefs and locus of control.

Of all of the parent variables, initial regression analyses indicated that irrational beliefs, coping strategies related to Medical Consultation and Communication, and self-esteem accounted for most of the variance in family functioning. This result was consistent with past studies discussing the role of coping strategies in adaptation (Bristol, 1987; Singer & Irvin, 1989; Summers et al., 1989), and with research on self-esteem and belief systems (Antsey & Spence, 1986; Frey et al., 1989; Morgan et al., 1986; Tuttle, 1986). When mother data were analyzed separately, self-esteem was the greatest predictor of family functioning. These findings provided strong support for Taylor's (1983) discussion of the significant role that mastery and self-efficacy play in family functioning. Coping strategies related to Medical Consultation and Communication were also significant predictors of family functioning among mothers, as was locus of control. These results were in close agreement with other research on the positive role of coping strategies (Bristol, 1987) and locus of control (Affleck et al., 1982; Henderson & Vandenberg, 1992). Affleck et al. (1982) found that parents with an internal locus of control were better adjusted, and were more active in obtaining and participating in treatment. Henderson & Vandenberg (1992) similarly

found that locus of control was one of the most important factors in family adjustment among parents of children with autism.

Finally, a model was developed to test the predictive relationships among the independent variables (social support and coping strategies), mediating variables (locus of control, self-esteem, and irrational beliefs), and dependent variable (family functioning). The model presented (see Figure 1) depicted predictive relationships between social supports and coping strategies, parental attributes, and family functioning by accounting for approximately 88% of the variance. This finding provided strong support for Bristol's (1987) hypothesis that parent variables were significant mediating factors in family adaptation, and further agreed with literature on positive relationships between a high level of social support, high coping strategies, internal locus of control, high self-esteem, low irrational beliefs, and high family functioning (Singer & Irvin, 1989; Summers et al., 1989; Taylor, 1983).

Additionally, this model was quite consistent with McCubbin and Patterson's (1983) Double ABCX model of family response. These results indicated that personal resources (bB) such as coping strategies and social supports were mediated by parent appraisals (cC) such as self-esteem, irrational beliefs, and locus of control in predicting family functioning (xX). While these

models were complementary, though, the comparison with the Double ABCX model was tentative due to the relatively small sample size and limitations of this research.

#### Question 5.

Question 5. examined any group differences between parents of children diagnosed as autistic and parents of children with cerebral palsy. While this question focused on differences in the parental attributes of locus of control, irrational beliefs, and self-esteem, potential group differences were also investigated on the pile-up measure of family stress, social supports, coping strategies, and family functioning.

Across all of these independent, mediating, and dependent variables, there were no significant differences between the two groups of parents. This result was in contrast to other research which identified differences in family functioning for varying disabilities (Fisman & Wolf, 1991; Gillberg et al., 1992; Konstantareas & Homatidis, 1989, 1991). While problems with sampling and measurement might account for some of this inconsistency, other explanations may have contributed to the findings in this research. In considering child variables, it was possible that the similarity in mean chronological age and overall adaptive functioning between the two groups of children increased the commonality

of parents' experiences. The diagnoses chosen for study in this project may have also been a factor in the results, as both diagnoses present with their own challenges and have not commonly been compared in the literature. Parents of children with autism have typically been compared with parents of children with intellectual disabilities (Fisman & Wolf, 1991), rather than with children having physical or multiple disabilities. It should also be noted that this finding was in agreement with at least one other study indicating little difference in stress or well-being of families among comparisons of children with different disabilities (Donenberg & Baker, 1993). Finally, these results further suggested that family functioning was more related to social supports, coping strategies, and parental attributes than to the specific disability.

#### Post Hoc Analyses

Correlational analyses indicated results of note, particularly regarding parent occupation and education, gender of child, age of child and age at diagnosis, and child's level of functioning. Based on the results of this research, a higher level of education and occupation was associated with a higher level of family functioning, particularly for fathers. Given the risk of inferring causality, it was important to note only the



significance of this relationship. This finding was quite consistent with past research indicating higher stresses among parents from lower socio-economic groups (Breslau et al., 1982; Mahoney, 1992). Explanations for the result include consideration of the socio-economic benefits of a higher level of education and occupation, and possibly, greater access to services and supports. On the other hand, a more positive family environment may also be more supportive of upward mobility in terms of furthering one's education and vocational development. Indeed, fathers who reported a higher level of occupation indicated a significantly higher level of social support.

Gender of the child, chronological age of the child, and age at diagnosis were not significantly correlated with either parent variables or family functioning in this research. This finding contrasted with past research which indicated a relationship between family stress and age of the child (McGrath & Grant, 1993; Singer & Irvin, 1989).

With respect to the child's level of functioning, overall adaptive ability was not directly correlated with a higher level of family functioning. This finding contrasted with past research which indicated the most difficulty among families of children with the most severe degree of disability (Pahl & Quine, 1987), but was in agreement with recent research

indicating that family functioning was not correlated with the severity of the disability (Donenberg & Baker, 1993; Mahoney, 1992; Saddler et al., 1993). However, higher levels of child's adaptive functioning were related to a lower degree of irrational beliefs among fathers, and a higher level of coping strategies among mothers. Of the child variables, self-care and social skills presented as the two areas most closely related to coping and beliefs in the data. Although it is incorrect to presume causality in these relationships, these variables are clearly worthy of further study.

### Strengths of Families

Overall, the results of this research indicated several positive findings regarding families of children with disabilities. The families in this study did not demonstrate a significant difference in family functioning compared to normative populations, and indicated that families had not experienced any greater pile-up of normal life stressors over the past year. This result was in close agreement with similar studies of stress and family functioning among parents of children with disabilities (Reddon, 1989; Redington, 1992). Parents in this sample reported finding social support from their spouses, children, friends, and relatives, with some support from spiritual faith and co-workers. While parents

reported finding less support from professionals, this result was viewed positively in that families seemed to view themselves as capable and somewhat independent of professional support. On a measure of coping strategies, parents in this study scored higher than parents in the normative population on behaviors related to preserving supports, self-esteem, and stability. Additionally, no strong, significant differences were found between parents in the sample and representative populations on measures of locus of control, self-esteem, and irrational beliefs. Clearly, the parents in this research demonstrated many of the same personal resources as other adults in the population, and reported normal family functioning. This finding supported past research and discussion of the normal aspects of parenting a child with a disability (Turnbull, 1985; Turnbull et al., 1988), and the positive experiences of these families (Singer & Irvin, 1989; Summers et al., 1989).

#### Implications for Clinical Practice and Service Delivery

Given the above strengths of families in this research, parents presented with many resources beneficial to finding and using services, as well as attributes helpful to further building personal satisfaction and family functioning. Normal levels of internal locus of control, self-esteem, and irrational

beliefs may better allow parents the opportunity to seek and benefit from social networks, which in turn assist in family adaptation (Bristol, 1987). Similarly, parents with an internal locus of control, high self-esteem, and low irrational beliefs, may be aided in the process of seeking information from professionals and other parents, exploring local services, and choosing to participate in available programs. Such parents may also be most helpful to their children and to other families by becoming effective advocates for better services.

#### Age at Diagnosis

One of the issues raised by the data was the significant difference in age at diagnosis between the two groups of children. Children with cerebral palsy were diagnosed at a significantly younger age than children diagnosed as autistic. While no significant group differences were evident on other variables, parents in both groups expressed considerable frustration regarding diagnosis during our contacts. Although some delay in diagnosis may be unavoidable given the nature of these disabilities, parents expressed a strong desire for as much information as early as possible.

### Differing Needs of Mothers and Fathers

Other results indicated that parents may have differing needs for services. While both mothers and fathers valued assistance in coping strategies to strengthen relationships within the family and foster optimism, mothers particularly valued coping strategies in the area of support, self-esteem, and feelings of stability. Groups for mothers of children with disabilities might therefore focus on enhancing relationships with others outside of the family, and developing feelings of overall self-worth as well as their self-image regarding their role as a mother. Communication, role responsibilities, and feelings of personal accomplishment or control might also be considered in dealing with parents and families. These issues are important to consider in ensuring that all family members have the same information about the child's disability and program in order to assist in role performance and communication.

### Social Support

Of the variables studied in this research, social support was identified as an important aspect of family functioning. Assistance to families, particularly new families, would therefore be most helpful in building and maintaining social supports. This might be accomplished through increased

networking among parents of children with disabilities, and through other services such as respite and financial assistance which would increase the possibility of social interaction. As parents in this study particularly valued support from spouses and children, marital and family issues would be important to address in working with families. Given that support from friends and relatives was also very highly ranked by parents, this might be fostered through involving friends and relatives in services. Informally, this could include allowing parents to invite the participation of friends and family in social outings at school or through parent associations. More formally, it may be helpful to offer informational seminars on disabilities to the close friends and relatives of families of children with disabilities. During this researcher's contacts with families in the study, parents occasionally spoke of the difficulty in explaining their child's disability to those closest to them and the role that this difficulty sometimes played in access to support.

### Parental Attributes

The results also demonstrated significant relationships between parental attributes and family functioning. All three variables of locus of control, self-esteem, and irrational beliefs were correlated, and were predictive of family functioning on

the measures used. These results were supportive of comments by Summers et al. (1989) asserting the need for parents to establish some sense of causality, to feel a sense of control and mastery, and to experience feelings of accomplishment and positive comparisons with others in order to build self-esteem. Given these relationships, efforts to build even one of these areas may be helpful overall to parents and families. For example, early diagnosis with provision of all information regarding the disability may assist in determining some sense of causality. In terms of service delivery, Hobbs et al. (1984) discussed the risk of traditional "helping" professionals in terms of personal control, accomplishment, and self-esteem. By trying to help families without their direct input or involvement, service providers may unintentionally foster dependency or "helplessness" leading to decreased self-esteem and possibly withdrawal from supports and services (Hobbs et al., 1984). Instead, Summers et al. (1989) proposed a more consumer-driven service delivery whereby professionals attempt to understand parents' efforts to determine a cause and diagnosis, provide as much information as possible in clear terms, identify progress in the child as it specifically relates to actions of the family, and help families to focus on more positive aspects of their child's development through feedback and support groups with other parents. Doernberg (1982)

further reported that parents felt intimidated, unheard, or dismissed by professionals. If such concerns exist about professionals, the need for feelings of personal control, accomplishment, and self-efficacy among parents appears especially important in increasing access to information and services.

#### Perspectives for Service Provision

As there were no significant differences between parents of children diagnosed as autistic and parents of children with cerebral palsy in this study, the nature of the diagnosis may not be as significant as commonly thought. Services might therefore be provided with less attention to the specific diagnosis and instead be designed to respond more to specific family and parent needs. Consideration of parent differences in terms of locus of control, self-esteem, beliefs, coping strategies, and social supports, may be helpful in matching families and services. Hypothetically, while parents with an external locus of control may prefer center-based treatment for their child, it would be important to involve these parents in decision-making and program implementation as much as possible in order to help develop their personal feelings of accomplishment, control, and efficacy in one area of their lives.



Other authors have recognized the need for more parent-focused services (Hawkins & Singer, 1989; Hobbs et al., 1984; Summers et al., 1989). Hawkins and Singer (1989) proposed a program of stress management for parents of children with special needs, with specific attention to skills training in self-monitoring, relaxation, coping self-statements, and modeling. They suggested teaching coping styles in order to alter events preceding stressful situations, manage reactions to stressors, and develop social supports. Additionally, Hawkins and Singer (1989) described cognitive modification techniques to improve responses to better understand and respond to stressful situations. Hobbs et al. (1984) also proposed a project to increase parental involvement, and Summers et al. (1989) further identified the needs for respite in order to decrease stress and increase the use of coping strategies, social support groups, feelings of mastery and control, education for parents in behavior modification to increase feelings of mastery and control, informed participation in decision-making, and counselling to teach problem-solving and communication. More recently, McClellan (1990) studied the results of training in stress management and teaching strategies conducted as part of the Family Intervention Project (Kysela, McDonald, Reddon, & Gobeil-Dwyer, 1988), and found some support for intervention.

Finally, results of post hoc analyses suggested the need for more concrete help in terms of financial assistance to maximize access to services, and increased services for children with disabilities in order to improve children's overall achievement and level of functioning, and in turn, possibly assist in family adaptation.

#### Suggestions for Future Research

Based on the results and limitations of this study, several areas were indicated as worthy of further investigation in future research.

Although age at diagnosis was not significantly correlated with parent variables or family functioning in this research, it is proposed that this factor be further explored in future research. Comparing groups of parents whose children were diagnosed at different ages within the same diagnosis (i.e., autism) would be of interest, although the child's level of functioning and severity of clinical features would need to be addressed as confounding factors.

Due to the difficulties of sample selection in this field, sufficient numbers of respondents did not allow for comparisons of one- versus two-parent homes, or consideration of differences in those families having more than one child with the identified diagnosis. Such information would be

helpful in further understanding the experience of parents, and more importantly, in provision of appropriate services to individual families.

While a measure of family functioning was used to evaluate parents' perceptions of their families in this study, further qualitative research to examine themes specific to family stress regarding their child with a disability, and family adaptation to the disability, would be helpful.

Ideally, sample selection in future research would include a wider range of families and parents. While it is difficult to reach parents who may be having more problems, attempts might be made through professionals in the field, crisis services, and parent support groups within parent associations.

Specific relationships between parental attributes such as locus of control, self-esteem, and irrational beliefs, and actual use of services might also be explored. While this research demonstrated a relationship between these variables and family functioning, it would be helpful to better identify the nature of services which best fit personal attributes of parents.

Finally, while this research has attempted to focus on the experience of parents, it would also be helpful to consider the role of attributions in the work of helping professionals. Harry (1992) and Brinker (1992) both identified the need for early intervention workers to examine their own assumptions,

beliefs, and definition of family as well as disabilities, in order to provide the best service to families.

### Concluding Remarks

The results of this research indicated that there was no significant difference in overall family functioning between the parents of children diagnosed as autistic, parents of children with cerebral palsy, or parents in the normative population. This finding was in contrast to much of the traditional literature, but was supportive of more recent trends recognizing the positive and normal aspects of parenting a child with a disability (Summers et al., 1989). The results also established the role of coping strategies, social supports, and parental attributions in accounting for some of the variance among families in terms of their overall level of functioning. Throughout this research, five specific questions addressed the role of coping strategies and social supports, as well as parental locus of control, irrational beliefs, and self-esteem, in predicting family functioning. These relationships were demonstrated, with no significant differences between parents of children diagnosed as autistic, and children with cerebral palsy.

This study further demonstrated the need for additional research in this area, both qualitative and quantitative, in order to better understand and meet the needs of parents.

Efforts to respond to problems in sample selection and measurement in this field would also be helpful. Although this research was fortunate to gather information from higher functioning families in order to identify those variables which assist in adaptation, it is also important to explore these same variables among families who report a lower level of functioning. Finally, this research has hopefully demonstrated the need for practical use of results in order to improve service delivery to parents, and to add other dimensions to new and existing programs.

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APPENDIX A

Letter of Intent  
Consent Form

## Letter of Intent

Dear Parents:

In order to give the best service to families of children with special needs, researchers and clinic workers have tried to find ways to assist families. We would like to find out more about how to get the best match between families and services, and have a specific interest in learning more about those family characteristics which help with family functioning. We would like to work with two specific groups of families. These groups include families who have a child diagnosed as autistic, and families who have a child diagnosed as having cerebral palsy. If your family falls in either of these two groups, we would like to talk to you about our research project.

If you decide that you would like to know more about the project, we would be very happy to meet with you in person, at your convenience. If you then decide to take part, we can meet again to have a short interview and ask you to fill out a series of questionnaires. The interview and questionnaires should take approximately 2 hours. All information will be kept completely confidential, and your results will be numbered and treated in a large group to keep details private. If you decide to take part, it is also important to know that you would be free to withdraw from the project at any time. When the study is finished, you will receive a letter about the results, and we would be very happy to talk with you should you have any questions or comments.

Thank you for taking the time to read this letter, and for considering our project. We feel that this research is very important in helping other families of children with special



needs. We sincerely hope that you will consider taking part. If you would like more information or have any questions, please call Lorna Hall at 474-0341 or Dr. Gerry Kysela at 492-5026. We look forward to talking with you in the future.

Sincerely,

Lorna Hall M.A.Sc.  
Graduate Student (474-0341)  
University of Alberta

Gerard Kysela Ph.D.  
Professor (492-5026)  
University of Alberta

## Consent Form

Having been informed of the purpose and procedures involved in the Hall Research Project, I, \_\_\_\_\_, am willing to participate. I understand that I have the right to withdraw from the project at any time, and that all information about myself and my child will be treated with complete confidentiality and anonymity.

Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

Lorna Hall M.A.Sc.  
Graduate Student (474-0341)

Gerard Kysela Ph.D.  
Professor (492-5026)

**APPENDIX B**

**Additional Tables of Results**

Table 14

Summary Table of ParticipantsNumber of Parents and Families Across Different Categories

Category	Autism	Cerebral Palsy	Total
Families Participating	32	25	57
Parents Responding	36	32	68
Mothers Responding	31	24	55
Fathers Responding	5	8	13
Families in Alberta	31	19	50
Families in Saskatchewan	1	6	7
Both Parents Responding	4	7	11
Mother Only Responding	27	17	44
Father Only Responding	1	1	2
Single-parent Families	6	2	8
Two-parent Families	26	23	49
Foster/Adoptive Parents	1	2	3

Table 15

Comparison of Child's Mean Age at Diagnosis Between Children with Cerebral Palsy and Children Diagnosed as Autistic

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Analysis of Variance

<u>Source</u>	<u>df</u>	<u>SS</u>	<u>MS</u>	<u>F</u>	<u>probability</u>
Between groups	1	11592.61	11592.61	58.68	p<.001
Within groups	55	10866.21	197.57		

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Table 16

Child's Level of Adaptive Functioning on the Vineland Adaptive Behavior Scales: Interview Edition, Survey Form (Age Equivalents in Months)- Group Means(Standard Deviations) and Comparison of Means for Domains and Subdomains

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Domains

<u>Subdomains</u>	<u>Autism</u>	<u>Cerebral Palsy</u>	<u>F</u>	<u>probability</u>
Communication	32.2(25.5)	32.0(28.7)	.0005	N.S.
Receptive	30.0(23.2)	34.8(29.9)	.4798	N.S.
Expressive	28.8(23.6)	31.4(30.0)	.1257	N.S.
Written	40.5(29.8)	36.1(27.2)	.3260	N.S.
Daily Living Skills	30.9(17.7)	24.1(17.9)	2.0400	N.S.
Personal	32.7(20.3)	21.4(14.8)	5.3726	p<.025

(Table 16 continued)

Domestic	32.2(17.6)	28.6(17.2)	.5823	N.S.
Community	27.0(18.3)	22.9(20.2)	.6395	N.S.
Socialization	20.6(14.4)	27.8(21.3)	2.3244	N.S.
Interpersonal	19.2(13.8)	27.8(25.1)	2.7200	N.S.
Play	19.6(14.4)	28.1(20.6)	3.3513	N.S.
Coping Skills	22.9(17.4)	28.4(23.5)	1.0293	N.S.
Motor Skills	36.9(13.7)	16.2(15.4)	29.0354	p<.001
Gross Motor	34.4(15.6)	12.4(9.7)	38.1398	p<.001
Fine Motor	39.8(17.9)	23.5(24.2)	8.61	p<.01
Adaptive Behavior				
Composite	27.4(14.9)	27.1(22.1)	.0035	N.S.

N.S. Not Significant

Table 17

Comparison of Results to Normative Data on Subscales of the Culture-Fair  
Self-Esteem Inventory and Family Assessment Measure

(Mothers n = 55, Fathers n = 13, Total n = 68)

Measure	Normative Data Mean (S. D.)	Total Group Mean (S. D.)	t
<b>Culture-Fair Self-Esteem</b>			
<b>Inventory (T scores)</b>			
General Self-Esteem	50 (10)	51.22 (8.00)	1.13
	50 (10)	51.39 (10.90)	0.46
Social Self-Esteem	50 (10)	50.53 (7.10)	0.55
	50 (10)	47.31 (11.25)	-0.86
Personal Self-Esteem	50 (10)	52.36 (10.2)	1.71
	50 (10)	53.39 (7.4)	1.65
Lie Subscale	50 (10)	49.02 (7.0)	-1.04
	50 (10)	48.15 (7.0)	-0.95

(Table 17 continued)

## Family Assessment

## Measure (Standard Scores)

Task Accomplishment	50 (10)	51.09 (11.4)	0.71
	50 (10)	50.30 (13.5)	0.08
Role Performance	50 (10)	54.33 (13.0)	2.47*
	50 (10)	51.00 (4.7)	0.77
Communication	50 (10)	51.76 (9.9)	1.32
	50 (10)	54.46 (6.7)	2.40*
Affective Expression	50 (10)	50.96 (10.2)	0.70
	50 (10)	53.62 (9.0)	1.45
Affective Involvement	50 (10)	49.16 (9.8)	-0.64
	50 (10)	51.23 (10.9)	0.41
Control	50 (10)	49.90 (10.4)	-0.07
	50 (10)	50.62 (10.1)	0.22
Values and Norms	50 (10)	49.15 (10.3)	-0.61
	50 (10)	51.80 (9.3)	0.20
Social Desirability	50 (10)	45.26 (8.2)	-4.30**
	50 (10)	45.77 (4.1)	-3.71* *
Denial	50 (10)	44.3 (10.6)	-3.99**
	50 (10)	47.61 (4.9)	-1.76

\*\*  $p \leq .01$  significance level\*  $p < .05$  significance level



Table 18

Multiple RegressionParent Variables and Family Functioning

<u>Variables in the equation</u>	<u>B</u>	<u>SE B</u>	<u>Beta</u>	<u>T</u>	<u>Sig T</u>
Coping strategies (CHIP)					
Medical Consult. & Commun.	-.663	.177	-.346	-3.74	.0004
Self-esteem (CFSEI-AD)	-.307	.118	-.290	-2.59	.0119
<u>Irrational beliefs (AI-II)</u>	<u>.138</u>	<u>.044</u>	<u>.352</u>	<u>3.14</u>	<u>.0025</u>
<u>Variables not in the equation</u>	<u>B</u>	<u>SE B</u>	<u>Beta</u>	<u>T</u>	<u>Sig T</u>
Social Support (SSI)	-.133	-.138	.587	-1.11	.2724
Coping strategies (CHIP)					
Integration, Cooperation					
& Communication	-.086	-.086	.545	-.68	.4977
Coping strategies (CHIP)					
Support, Esteem & Stability	-.140	-.175	.669	-1.41	.1641
Locus of Control (Rotter)	.140	.160	.572	1.29	.2025

Table 19

Multiple RegressionMother Variables and Family Functioning

<u>Variables in the equation</u>	<u>B</u>	<u>SE B</u>	<u>Beta</u>	<u>T</u>	<u>Sig T</u>
Coping strategies (CHIP)					
Medical Consult. & Commun.	-.785	.214	-.382	-3.67	.0006
Locus of Control (Rotter)	.683	.289	.273	2.36	.0220
Self-esteem (CFSEI-AD)	-.389	.131	-.342	-2.95	.0047
<u>Variables not in the equation</u>	<u>B</u>	<u>SE B</u>	<u>Beta</u>	<u>T</u>	<u>Sig T</u>
Social Support (SSI)	-.247	-.267	.643	-1.96	.0551
Coping strategies (CHIP)					
Integration, Cooperation & Communication					
	.002	.002	.534	.02	.9884
Coping strategies (CHIP)					
Support, Esteem & Stability	-.155	-.199	.803	-1.44	.1574
Irrational Beliefs (Rotter)	.182	.183	.558	1.32	.1937

Table 20

Comparison of Means between Groups of Children with Cerebral Palsy and Children with Autism Across the Variables of Social Support, Coping Strategies, Locus of Control, Self-Esteem, Irrational Beliefs, and Family Functioning

Analysis of Variance					
Measure		SS	MS	F	F probability
Social Support	BG	636.28	636.28	2.39	.127 (N.S.)
	WG	17590.94	266.53		
Coping Health					
Inventory for Parents					
-Integration,					
Cooperation,					
& Communication	BG	196.16	196.16	2.43	.124 (N.S.)
	WG	5320.47	80.61		
-Support, Esteem,					
& Stability	BG	1.06	1.06	.01	.908 (N.S.)
	WG	5200.00	78.79		
-Medical Consultation					
& Communication	BG	12.97	12.97	.58	.448 (N.S.)
	WG	1471.50	22.30		

(Table 20 continued)

Rotter Internal-					
External Locus of					
Control Scale	BG	31.87	31.87	2.31	.134 (N.S.)
	WG	912.19	13.82		
Culture-Fair Self-					
Esteem Inventory	BG	23.33	23.33	.32	.576 (N.S.)
	WG	4867.18	73.75		
Adult Irrational					
Ideas Inventory	BG	1423.53	1423.53	2.75	.102 (N.S.)
	WG	34126.75	517.07		
Family Assessment					
Measure	BG	19.63	19.63	.24	.627 (N.S.)
	WG	5437.43	82.39		

df BG 1

WG 66

N. S. Not Significant

Total 67