

EXAMINING THE EFFECTS OF RAISING AUTISTIC CHILDREN  
ON FAMILY FUNCTIONING:  
USING THE DOUBLE ABCX-MODEL

by

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## ABSTRACT

Using the Double ABCX Model as a framework, an investigation of the effects of raising autistic children on family functioning was the focus of this research. The sample population (N=39) was based on voluntary participation from members of support groups and agencies that focused on families with autistic members, such as, the Autism Society of British Columbia (ASBC), the Autism Calgary Association, and Child Development Centers across the province. The sample was composed of primary caregivers of children, 7 years old or younger and who had recently been diagnosed with autism. The caregiver was asked to complete a questionnaire that took approximately 30 minutes. The questionnaire was composed of three measures, Family Inventory of Life Events and Changes (FILE), Coping Health Inventory for Parents (CHIP), and Family Adaptability and Cohesion Evaluation Scales II (FACES II). The use of these scales examined the pile-up, coping, and functioning in families faced with raising a child who was autistic.

Initial regression analysis showed no relationship between a family's pile-up and their coping mechanisms. A relationship between coping and family functioning did emerge however. In subsequent regression analyses using the measurement instruments subscales, correlations between certain types of pile-up and different coping mechanisms did appear. Certain subscales of coping continued to be highly correlated with family functioning, as well as, its two subscales adaptation and cohesion. Finally, a relationship also appeared between four of pile-up's subscales and family functioning.

This study found that the family's coping mechanisms had the most impact on how they adapted and maintained a sense of cohesion in light of raising their child with autism.

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When I began my endeavor to obtain my Master of Arts degree I was unsure of what I wanted to study. One day in January, during my first year in the program, I woke up with the notion of autism in my head. From this point on doors opened and experiences came to me in an uncanny fashion. I met people that would forever change my perceptions and knowledge of autism. I would like to take this opportunity to thank some of these very influential people.

First and foremost, I would like to thank two people who influenced my perspective and outlook on autism. Leonora Gregory gave me a gift of insight into the autistic person's experience. She taught me to "see" the individual first followed by the autism. Joan Storlund demonstrated the importance of family and told me never to discount what the family is going through, because their experience is just as important as the individual with autism's.

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## **CHAPTER 1**

### **INTRODUCTION**

Since the 1940's, when Leo Kanner and Hans Asperger first described the syndrome that we know today as "Autism," much has changed in terms of medical understanding and research focus. Professionals have moved away from blaming the parents for their child's illness, as well as, focusing on the "pathology" of the syndrome and are now examining stress and coping in terms of families living with children who have developmental disabilities. Every individual and, in turn, every family experiences stress and strain at some point in their life course. When a child who has been diagnosed with autism is added to the equation, how does this affect the family's perceived stress, coping mechanisms, and functioning?

Families report a wide range of behavioral and emotional responses to their child's diagnosis of autism. Some families view this event as catastrophic and see the child as the source of major change and adjustment within the family system (Trute, 1987; Patterson & McCubbin, 1983). Other families perceive the diagnosis as less threatening and meet it with accommodations and minor family adjustments. Still other families remark that the diagnosis of their autistic child has been an enriching experience (Bristol & Schopler, 1983) and has served to actually strengthen the marital relationship (Kazak & Marvin, 1984). It is important to recognize the continuum along which these families lie. Families may range from the highly negative emotional and behavioral responses such as feelings of loss and chronic sorrow to the highly positive responses of perceived marital strength and enrichment of family life (Trute, 1987). Families and parents will find themselves at many different points along this continuum and may even hold varying degrees of both the positive and negative emotional and behavioral responses at the same time (Trute, 1987).

A study conducted by Trute (1987) at the University of Manitoba concluded that “two parent families, with a steady source of income and few children in the household were the ones that were at advantage for adjustment” (pp. 19-20). Does this mean that families who do not have this ideal life; single parent families, families on social assistance, or families with numerous children; are doomed to a life of maladjustment with their autistic child? The extent to which these three factors play a role in family adjustment will be explored later. However, researchers have stated that raising a child with autism does have a “particularly pervasive stressful effect, directly and indirectly affecting many aspects of family life” (Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robbins, & Plienis, 1992, pp. 206). Divorce rates for families raising disabled children have been reported to be as high as triple the national average (Bristol & Schopler, 1983). Raising an autistic child may have more serious implications for the mother because of her increased childrearing demands, as well as, her role of continual crisis manager (Konstantareas, Homatidis, & Plowright, 1992). This may explain reports that claim one third of mothers raising disabled children suffer from depression (Bristol & Schopler, 1983; Cantwell & Baker, 1984). Research on fathers of disabled children reveal that they suffer increased emotional and financial strains, while siblings exhibit emotional and behavioral disorders (Bristol & Schopler, 1983).

The purpose of this study is to explore, using the Double ABCX Model, the impact of raising a child with autism on the family’s coping abilities and functioning. A detailed analysis of the Double ABCX Model and how it relates to families raising an autistic child will be explored. Throughout the subsequent section, important concepts such as coping, stressor, adaptability, crisis, and cohesion will be defined.

This research has important implications for researchers, parents, families, practitioners, educators, and policy makers. Implications for these groups will be discussed later in this paper.

The Double ABCX Model has been used in numerous studies focusing on families with disabled members, chronically ill members, as well as, families experiencing stress from bereavement, alcoholism, war induced separation and unemployment. McCubbin (1988) used this model to study the relationship between family characteristics and the health of a child who had myelomeningocele. Prader-Willi syndrome, cerebral palsy, and cystic fibrosis are other examples of disabilities studied using the Double ABCX Model. However, the model has yet to be applied to the study of families with an autistic child.

The variables associated with the Double ABCX Model lend themselves well to the issues faced by families with autistic children. Families with autistic children are dealing with a crisis situation, a pile-up of stressors, demands on resources, and a situation that elicits coping strategies in order for adaptation and cohesion to occur.

Before examining these issues and formulating hypotheses, a review of the literature is discussed. It will be useful to attempt to define autism, its epidemiology and etiology. A look at some of the issues faced by families raising autistic children will lead into the literature on stress and coping and finally into a review of the Double ABCX Model.

## CHAPTER 2

### REVIEW OF LITERATURE

#### Autism

##### A definition of autism.

The definition of *autism* is not a simple one; a one or two sentence description is not available. Autism is categorized in the DSM-IV under developmental disorders, specifically: Pervasive Developmental Disorders (PDD). The term pervasive developmental disorders was chosen because it focuses on the severe and extensive developmental deficits present in children with these disorders (Gillberg, 1990). Typically, authors define autism by delving into the characteristics or behaviors seen in autistic children. Konstantareas created a chart describing the characteristics of autism, it looks like this:

Figure 1. Characteristics of Autism  
(Konstantareas, 1981, pp. 6)

Anxiety Attacks  
Unusual Perceptual Experiences  
Tantrums – Self-injury  
Inability to Develop Social Relations  
Stereotyped Repetitive Play Activities  
Tendency for Uneven Rates of Development  
Infancy Onset  
Cessation / Non-communicative Speech after Development

Capability for Rote Memory  
Hyperactivity – Short Attention Span  
Insistence on Sameness  
Lack of Imagination  
Delay in Language Development  
Reversal of Pronouns  
Echolalia  
Normal Physical Appearance

Some of the other commonly attributed characteristics of autism are: inappropriate laughing and giggling, a lack of caution, stand-offishness, insensitivity to pain, extreme distress for no apparent reason, aversion to cuddling, sustained odd play, difficulty playing with other children, acting as if he/she is deaf, avoidance of eye contact, rocking and whirling, indicating needs by gestures, strong resistance to learning, walking on tip toes, and spinning objects-including self.

When looking at the characteristics associated with the phenomenon of autism, it would be naïve to assume that a child would be affected by each characteristic and with equal strength (Webster, Konstantareas, Oxman, & Mack, 1980). With varying combinations of the type and severity of the disorder, each individual child can run the gamut of the characteristic behaviors (Webster et al., 1980). When examining the above behaviors, an attentive reader will offer the insight that every child at some point in their development will experience one or two of these characteristics. For example, it is very common for children to develop the use of pronouns and later regress to pronominal reversal, particularly reversing “you” for “I.” However, when the behaviors are used as a means for diagnosis, such characteristics are persistent beyond what is expected in relation to the child’s mental age (Rutter, 1976).

#### The epidemiology of autism.

When studying the epidemiology of autism, one must be cautious of the time of publication and the place where the study was conducted. There is a tremendous amount of literature from the 1960’s through to the present day. Some of the older literature is still valid today, however, much of our understanding and knowledge regarding autism has changed considerably since the days of Kanner. Most of the research on autism conducted in the 1970’s and 1980’s was done in the United States (specifically Wisconsin), England, and Denmark (Paluszny, 1979). Variations in study results could be due to sampling differences or differences

in the researcher's methodology. However, all studies did confirm, and I think we would agree today, that autism is a rare syndrome. Estimates predict that autism affects three or four individuals out of ten thousand (Ritvo, Freeman, Pingree, et al., 1989; Steffenburg & Gillberg, 1986).

Wing (1973) stated that one third to one half of all autistic children have some other severe condition affecting the central nervous system, such as epilepsy or cerebral palsy. Other syndromes or conditions also commonly seen in children with autism are Down syndrome, Hurler syndrome, Dandy-Walker syndrome, meningitis with secondary hydrocephalus, congenital rubella, schilder's disease, hypsarrhythmia, or congenital lues (Knobloch, 1976). Researchers have found the affliction rate to occur four or five times more frequently among boys than girls (Ritvo, Freeman, Pingree, et al., 1989; Steffenburg & Gillberg, 1986, Werry, 1979).

Today, there appears to be no clear association between birth order and autism. This is in contrast to Paluszny's (1979) controversial birth order studies that claimed a higher incidence rate of autism among first-born males. Another controversial area of study is that of socioeconomic status. When Kanner began his research in the 1940's, he found a high incidence of autism among those families with highly educated parents living in the upper social class (Paluszny, 1979). Other researchers have found varying results, perhaps due to the particular sampling methods used in the studies (Wing, 1980). Some claim no difference in socioeconomic status of parents whose children were autistic as compared to those parents who had children with psychotic problems (Paluszny, 1979). Yet others found an association between socioeconomic status and autism but the correlation was not as strong as Kanner first claimed. An epidemiological survey conducted by Ritvo et al. (1989) concluded that the prevalence of

autism in a family was not associated with parental education, occupation, racial origin, or religion.

### The etiology of autism.

There are three widely stated claims as to the cause of autism. In the early days of autistic research, it was believed that either “refrigerator parents” or parental psychopathology could cause this syndrome. These views have been dismissed on three bases. First, studies on children who were deprived of maternal care in old-fashioned institutions showed no symptoms of autism. Second, most parents of autistic children also have “normal” children; it is rare to see two autistic children in one family. Finally, parents of autistic children show no abnormal behavior as compared to the rest of society, they are no more mentally ill than any other person (Wing, 1973; McAdoo & DeMyer, 1978).

Physical causes have also been studied as a possible link to autism. A small number of cases have shown the onset of autism after certain illnesses, such as encephalitis (Wing, 1973). Once again, studies have shown that one third to one half of autistic children have some other handicap resulting from a malfunctioning brain or central nervous system (Wing, 1973). In Knobloch’s (1976) study of fifty autistic children, eighty percent were found to have had some complications during pregnancy or neonatal complications. Paranatal complications included low birth weight, bleeding, toxemia, neonatal convulsions, failure to initiate respiration, and/or the need for oxygen.

The final possible cause of autism is genetics. Researchers have been looking at family histories in search of some form of genetic pattern in the genograms. In a review of the genetic factors in autism and childhood schizophrenia, Smalley (1991) found no evidence for a genetic link in autism. Other researchers feel that while it is very possible that there is a significant hereditary influence in the etiology of the autistic syndrome, this hypothesis does have some

limitations. The most problematic results for this hypothesis are the low rates of autism among nontwin siblings (Ornitz in Rutter & Schopler, 1978). More recent research has led to an understanding in the role of genetics and its link to autism. Le Courteur and his associates (1996) describe a high concordance rate for autism among monozygotic twins, this finding indicates a strong genetic component.

For parents, the absence of a definitive explanation for the cause of their child's autism can be very difficult. In an attempt to cope with the feelings of guilt and uncertainty pertaining to their child's disability, many parents develop their own explanations for the disorder in an "attempt to achieve partial emotional closure" (Gray, 1995, pp. 109). When parents were asked open-ended questions concerning the cause of their child's autism they typically offered more than one possible cause, see Figure 2.

Figure 2. Causes of Autism According to Parents  
(Gray, 1995, pp. 109)

Causes	Frequency*
1. Birth trauma	15
2. Congenital damage	
Exposure to chemicals/radiation	7
Brain/chemical/central nervous system problem	8
Problems/illness during pregnancy	10
Drinking/drugs during pregnancy	4
Vaccination during pregnancy	1
3. Childhood illness	6
4. Heredity (various pathologies)	10
5. Psychological factors	4
6. Magical/religious explanations	3
7. Reaction to childhood vaccination	1
8. Hyperthyroidism	1
9. Inadequate post-birth care	1

\*Due to the fact that most parents gave more than one cause of autism, the total number of causes is greater than the total number of respondents.

According to Gray (1995), the most common explanation parents offered was birth trauma. This could include either a very long or a very brief labor, the use of forceps in delivery,



a breach birth, or a variety of other problems. Congenital damage offered many possible causes for the child's autism including: illness during pregnancy; non-specific problems relating to the fetus's brain, biochemical system, or central nervous system; and exposure to chemicals or radiation (Gray, 1995). Finally, heredity was a common explanation, however, a focus on the nature of the genetic effect was never specified (Gray, 1995).

The possibility still remains that defective genes or damage from radiation or other conditions during prenatal development may play a role in the etiologic picture (Carson & Butcher, 1992). However, it seems apparent at this point that the disorder we call autism involves both multiple kinds of deficit and multiple etiologic pathways (Goodman, 1989; Gillberg, 1990). Therefore, we should not expect to find large risk factors accounting for autistic outcomes (Carson & Butcher, 1992).

#### Families with autistic children.

To understand the special demands imposed on families with autistic children, it is important to remember that all parenting is sometimes stressful. Some of the problems parents experience are typical for all families with a disabled child; however, some problems are specific to autism. Briefly, we should discuss some of the more global stressors facing parents of a child with a disability.

Parents of children with disabilities undergo a process of dealing with feelings of guilt, isolation, shame, and despair in response to this crisis situation. This is due to the fact that when a family is expecting a child, they are not expecting a child with a disability. Therefore, the diagnosis comes as a blow, as they are not prepared. At this time, a readjustment of dreams, goals, and expectations for their child, as well as, for themselves occurs. This crisis is undoubtedly very intense, involving feelings of loss, fear, anger, loneliness, self-doubt, and depression (Glidden et al., 1993).

Disabled children may be dependent on their parents for a lifetime. This prospect is not only a daunting burden to bear but it also adds stress to the parents who worry about what will happen to the child when they die. Parents can sometimes receive badly needed support from relatives. However, some relatives may be less constructive in their actions and attitudes (Wing, 1972). They may feel that a disabled child brings shame to the whole family. These relatives may attempt to exclude the family and/or the child from outings, family affairs, or visits (Wing, 1972).

Another problem parents face is the educational system. Integration, inclusion, and special education are just some of the potential strains parents must deal with. For instance, the child must be labeled with a severe disability in order to gain special aids, such as, a special education assistant (SEA) or an individual education plan (IEP). Often parents find themselves fighting with the system in an attempt to gain the appropriate services their child needs; this is especially true for the families who have high functioning autistic children. Integration and inclusion into a regular classroom has its benefits and drawbacks for all individuals involved, including the teacher, the disabled student, the other students, and the parents of both parties.

One of the potential difficulties for siblings of a disabled child is the fact that parents inevitably spend extra time with the special needs child. This can be especially hard on the sibling if the two are of similar ages and are young (Wing, 1972). Older children may not have the same difficulties with lack of attention but they may feel that they cannot have their friends over to play. Parents must make a conscious effort to invite the friends over. When questions arise from the brother, sister, or from their friends regarding the child's disability, parents are best to answer these questions frankly, simply and in a calm, relaxed manner (Wing, 1972). This will take a lot of emotional maturity on the part of the parents but they must be careful not to become reactive to hard or sensitive questions.

Every family trying to raise a child with special needs faces the stressors discussed above. The autistic syndrome, however, brings some unique problems to the family and its functioning. For instance, if there are no additional disabilities affecting the child's appearance, autistic children are born looking "normal" (Wing, 1972). This is referred to as a hidden disability. This type of disability can be very challenging for both the parents and the child because society views the child as being "normal" and, therefore, places its "normal" expectations and standards on the child. When the child is not able to meet these expectations, society frowns upon the child and labels the parents "inadequate."

Autism is not usually diagnosed until the second or third year of the child's life and confirmed at four years of age. During this time behaviors may slowly begin to emerge. The parents may have a nagging sense that something is wrong but this anxiety is suppressed and denied (Wing, 1972). The parents seem to ride a teeter-totter in the sense that they are aware of a problem, especially when they compare their child to other children. Yet, they resist this awareness because they find reassuring signs of normalcy that reinforce their hope that their child is normal (Wing, 1973; Wing, 1972). Inevitably, the uncertainty becomes too much and professional help is sought. However, this long period between the onset of concern and final diagnosis means that parents of autistic children typically experience severe difficulties legitimizing the disability and coping with daily life (Gray, 1995).

The delay in diagnosis often leads to secondary behavior problems which may have been addressed at the start if the disability was evident from birth (Wing, 1972). Once again, because these children look "normal," when they show either the characteristic autistic behaviors or a secondary behavior problem, the general public tend to scrutinize rather than sympathize, as they would if the child appeared severely disabled (Wing, 1972; Wing, 1973). Jimmy's mother has an ideal story to support this point,

I was told off by a lady in the supermarket one day. You have to hold his hand, if you don't he'll grab something...he grabbed a tomato out of this lady's basket and before he got a chance to eat the thing I grabbed it away from him – but the tomato fell out of his hand and fell to the floor and I picked it up and put it back in the basket. She gave me the dirtiest look and looked at Jimmy and said “A fellow your age should know better.” And then looked at me as if I should be a parent who should teach him a few manners. (Mack & Webster, 1979 in Webster et al., 1980, pp.32-33).

Many parents are not prepared for having children let alone an autistic child. Autism is fairly rare and, therefore, the parents may feel that they are alone in this life with this child. In the past, when parents were blamed for their child's autism, they were discouraged from making contact with other parents of autistic children. This only served to further perpetuate the parents' sense of shame and guilt, as well as, continue their feelings of isolation. Some parents are not prepared to deal with the child's autistic symptoms and in an attempt to search for a solution, parents may bounce from one approach to another (Wing, 1980). They may never actually find a solution because not enough information is given to the parents, therefore, for each approach, not enough time is given for an effect to occur (Wing, 1972).

One characteristic of autism that causes the family great distress is the social withdrawal or aloofness of the child. Some autistic children display empty facial expressions, others are unable to look straight into a person's eyes, a child may pull away if he/she is touched, or may look at or “walk through” people as if they were not there (Wing, 1972). These characteristic qualities of autism cause parents to feel unwanted and unloved, which often increases their distress. However, as some autistic children age, they tend to grow out of some of these behaviors and may become more affectionate (Wing, 1972). Parents may rejoice at these milestones their child is accomplishing.

We have now examined some of the pertinent issues families face when raising a child with special needs. From a theoretical perspective, one pre-eminent theory or model has emerged

to assist in the examination of the stresses these families are dealing with. This model is called the Double ABCX Model and will be discussed in the following section.

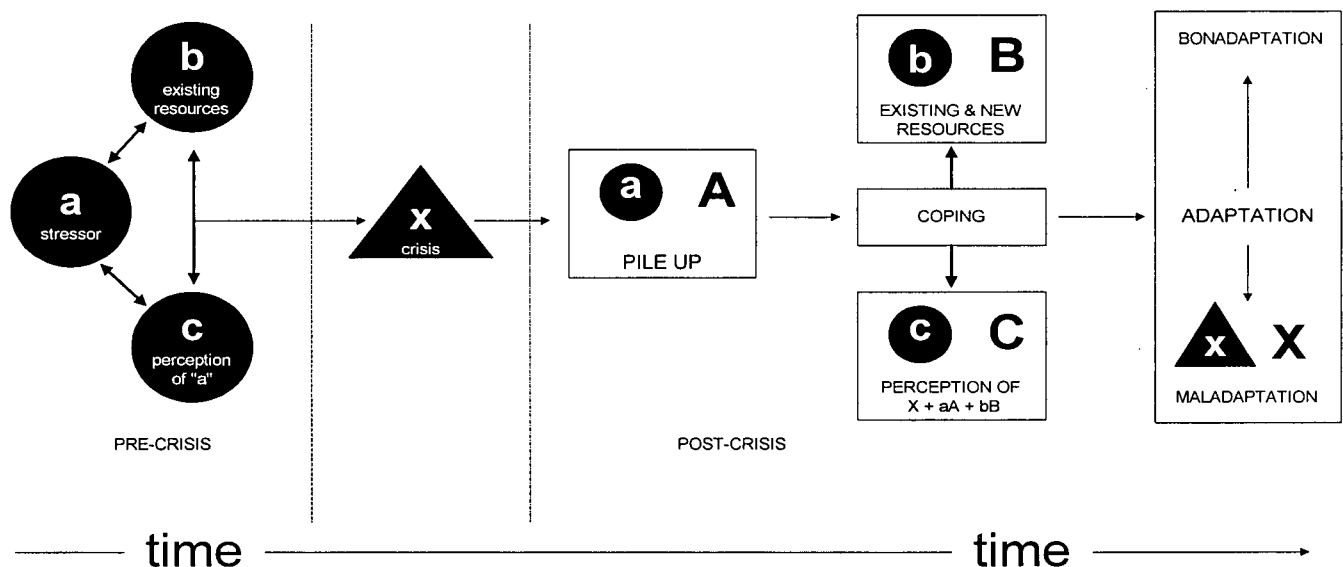
### The Double ABCX Model

Before examining the Double ABCX Model and how it pertains to families with autistic children, it would be informative to give a brief history of the model. Initially, family researchers were interested in identifying the variables that account for family adaptations and adjustments to stressful situations (McCubbin & Patterson, 1983). The earliest model available for measuring such variables was the Hill (1949) ABCX family crisis model. It stated:

*A (the stressor event) - interacting with B (the family's crisis meeting resources) - interacting with C (the definition the family makes of the event) - produce X (the crisis).*

This model was later used to guide a longitudinal study of 216 families who had a father or husband held captive or unaccounted for in the Vietnam War (McCubbin & Patterson, 1983; McCubbin & Patterson, 1982). Observations of these families led to the formulation of the Double ABCX Model which used Hill's original ABCX Model as a foundation and added to it a post-crisis component (McCubbin & Patterson, 1983). The Double ABCX Model is shown in Figure 3.

**Figure 3. The Double ABCX Model**  
(adapted and modified from McCubbin & Patterson, 1983, pp. 12)



For this research, it is the post-crisis section of the model that we are particularly interested in. However, before we can move into this post-crisis section we must identify the first set of variables in the pre-crisis stage.

Family demands: Stressor and hardships (*a* Factor).

In order to clarify the *a* factor, a definition of stressor and hardships must be supplied. A *stressor* is a life event or transition impacting upon the family unit which produces, or has the potential of producing, change in the family social system (McCubbin & Patterson, 1983; Burr, 1982). Such stressor events could include change in family boundaries, roles, values, goals, or interactions among family members (McCubbin & Patterson, 1983). *Hardships* in a family are defined as those demands on the family unit specifically associated with the stressor event (McCubbin & Patterson, 1983). An example of family hardships would be the increased work hours in an attempt to earn more money for the increased medical costs of raising a disabled child. In this study, the *a* factor is the child being diagnosed with autism.

Family capabilities: Resistance resources (*b* Factor).

The family's resources are described as the *b* factor in this model. These resources are the means used by the family in an attempt to resist a crisis, thus, preventing change in the family social system (McCubbin & Patterson, 1983). Hansen (1965) has described this same conceptual phenomenon as vulnerability and remarks on its continuity. Resources, in the case of a family with a child who has autism, may include family adaptability. *Adaptability* is described as the family system's ability to change its power structure, role relationships, and relationship rules in response to situational and developmental stress (Olson, Russell, & Sprenkle, 1983). Flexibility

in changing roles (mother stops working in order to care for a disabled child, father helps out around the home more) or mutual emotional support between the spouses are examples of this adaptability (Patterson & McCubbin, 1983). Hill (1958) summarized the *b* factor as “adequacy-inadequacy of family organization.”

Family definition: Focus on stressor (*c* Factor).

The *c* factor is the subjective interpretation or definition the family makes in response to the seriousness of the experienced stressor (McCubbin & Patterson, 1983; Trute, 1987). This subjective interpretation will be indicative of how the family perceives the stressor and how it affects them. As mentioned in the introduction, some families define a child’s diagnosis of autism as an opportunity to grow together and strengthen the marital bond (Patterson & McCubbin, 1983; Bristol & Schopler, 1983; Trute, 1987; Kazak & Marvin, 1984). Other families view such a diagnosis as catastrophic and a prelude to the family’s demise (McCubbin & Patterson, 1983; Patterson & McCubbin, 1983; Trute, 1987).

Family tension: Stress and distress.

Before moving on to the *x* factor of the ABCX Model, it is important to make the distinction between tension, stress, and distress. When a family is experiencing the *a* factor of stressor events and hardships, they are also developing tension within the family that must be managed (Antonovsky, 1979). If this tension is not managed, stress will emerge. Stress is distinctive from stressors in that family *stress* is defined as “a state which arises from an actual or perceived demand-capability imbalance in the family’s functioning and which is characterized by a multidimensional demand for adjustment or adaptive behavior” (McCubbin & Patterson,

1983, pp. 9). At the same time, family *distress* is defined as “an unpleasant or disorganized state which arises from an actual or perceived imbalance in family functioning and which is also characterized by a multidimensional demand for adjustment or adaptive behavior” (McCubbin & Patterson, 1983, pp. 9-10). Therefore, stress becomes distress when it is defined or subjectively interpreted by the family as unpleasant or undesirable (McCubbin & Patterson, 1983).

Family crisis: Demand for change (*x* Factor).

When we pool the above factors together; a) the stressor event and subsequent hardships, b) the family's resources to resist unwanted change, c) the family's subjective interpretation or definition of the stressor event, and d) the impact of the stress or distress, we create a foundation that gives the family the ability to prevent the stressor event from evolving into a crisis situation (McCubbin & Patterson, 1983). The *crisis* or *x* factor is defined as “a continuous variable denoting the amount of disruptiveness, disorganization, or incapacitatedness in the family social system” (McCubbin & Patterson, 1983, pp. 10). Unlike stress, which is the imbalance between demand and capability, crisis is the family's inability to restore stability and the pressure upon families to make changes in the family structure and patterns of interaction (McCubbin & Patterson, 1983). It may be said that stress may never reach crisis proportions if the family is able to use their resources and define the stressor event in such a way that systemic change is avoided and family stability is maintained (McCubbin & Patterson, 1983). For the research at hand, the stress of raising a child with autism will assume this *x* factor position. It is at this point that we begin to concentrate on the post-crisis components of the Double ABCX Model.

After close observation of the 216 families in crisis, due to the prolonged absence of husbands or fathers in the Vietnam War, four additional factors that aided these families in their adaptation over time were revealed. These additional factors were; a) the pile-up of additional



stressors and strains, b) family efforts to activate, acquire, and utilize new resources from both within the family and the community, c) modifications in the family definition of the situation with a different meaning attached to the family's predicament, and d) family coping strategies designed to bring about changes in family structure in an effort to achieve positive adaptation (McCubbin & Patterson, 1983).

#### Family demands: Pile-up (*aA* Factor).

During the life course families are continually faced with stressors and strains. Longitudinal data has shown that these stressors and strains have a tendency to pile-up, particularly following a crisis event such as a death in the family, a diagnosis of an illness or disability, or a natural disaster (McCubbin & Patterson, 1983). This pile-up of demands on the family is referred to as the *aA* factor in the Double ABCX Model. McCubbin and Patterson (1983) identify five categories of stressors and strains that have been attributed to this pile-up in a family's crisis situation.

#### (1) Stressors and its hardships

The initial diagnosis of autism will play a role in the pile-up of demands for the family. Along with the initial stressor, the family is also attempting to deal with the hardships associated with raising a child with autism. Patterson and McCubbin (1983) outline these possible hardships as including:

- *Strained family relations* as a consequence of formed coalitions between the primary caretaker and the child; overprotectiveness of the child which hinders the child's process of individuation; scapegoating either the child or the parent believed to be genetically responsible for passing on the disability; overt or covert

rejection of the child by one or both parents or by siblings; worry about what will happen to the child when the parents are no longer around to care for him or her; sibling resentment of the additional caregiving time given to the autistic child; and an overall increase in intrafamily tension and conflict.

- *Modification in family activities and goals* such as less likelihood of both parents pursuing a career; research is now linking a genetic factor to autism and this creates a great deal of uncertainty for the parents when deciding whether or not to have more children.
- *The burden of increased tasks and time commitments* such as extra appointments to see specialists, therapists, doctors, teachers, or SEA's due to the child's need for speech therapy or behavior modification. Such appointments may also be related to the secondary illnesses often associated with autism such as cerebral palsy or attention deficit hyperactivity disorder.
- *Increased financial burden* related to one parent having to quit their job in order to care for their autistic child. Special medical consultations, medications, therapy, respite care, and in some cases institutionalization also drain the family's finances.
- *Social isolation* can be common for families raising autistic children because of the parents' fear of the child's reactions or temper tantrums in public. Parents may also have a hard time finding adequate childcare. O'Moore (1978) found that mothers of children with autism showed higher levels of stress in activities that involved social contact, such as shopping or going on family trips, this will undoubtedly result in a lack of social interactions.

- *Medical concerns* pertaining to understanding, clarifying, and verifying diagnostic and medical information.
- *Differences in school experiences* are very relevant for today's child with autism because of inclusion or mainstreaming. The child's school experience, as well as the parent's, will include many meetings with principals, teachers, teaching assistants, and resource teachers all in an attempt to give the child the best education available. Some families opt for home schooling, which involves a large time commitment and openness to available resources.
- *Grieving* is a process that all parents of disabled or ill children may go through. It is a life long process of dealing with feelings of loss, guilt, pain, and sorrow. Frustrations, as well as sadness, arise when a child does not complete certain developmental milestones in an "on time" manner. Parents may also grieve for their child's physical, intellectual, or emotional delays or feel anxiety regarding the restricted life opportunities that lie ahead.

## (2) Normative transitions

Human beings are continually growing and developing throughout their lifetime and because of this growth, both individuals and the family system experience normative transitions or changes. Such changes in an individual include the increased need for independence around adolescence or the desire to pursue a career by the primary caretaker. At the family level, transitions may include adolescent turmoils and tribulations, the death or birth of a family member, or launching of the children (McCubbin & Patterson, 1983). Bristol and Schopler (1983) explain that when the autistic child reaches adolescence, the permanency of the child's disability becomes apparent and any hopes for normalcy give way to concerns about the future

when the parents are no longer around to care for or support the child. Whether these transitions are perceived as either positive or negative, they further the pile-up because they demand change within the family system.

### (3) Prior strains

Much like normative transitions, prior strains also add to the pile-up of demands experienced by the family. Prior strains emerge insidiously in the family rather than at a specific point in time (McCubbin & Patterson, 1983). Examples could include unresolved strains involving the relationship with in-laws, or prior stressors pertaining to parent, spouse, student, or employee roles. It has been suggested that the birth of a disabled child may not have a direct influence on the marriage but rather serves to exacerbate what is already a troubled marital relationship (Trute, 1989).

### (4) Consequences of family efforts to cope

This is an important element in the pile-up of stressors in the family system. Often the father will work longer hours (or take on extra jobs) in an effort to meet the increasing financial burden of not only raising a family with one income, but also raising a family with a disabled child. In some instances fathers take on this extra workload in order to avoid the child either because they are in denial or because they cannot yet accept the child's disability. In either case, the extra workload often isolates the father from the family and places the burden of the childcare role onto the mother (McCubbin & Patterson, 1983). Mothers are often found to be the advocates for their child in the medical, educational, or legal realms. As the mother changes her roles, strengthens her authority and independence, and increases her self-esteem intrafamily strain and tension may emerge.

##### (5) Intra-family and social ambiguity

The pile-up of demands these families are facing leads to changes in the family system, which cause uncertainty or ambiguity regarding the future. The family may experience ambiguity pertaining to its structure (McCubbin & Patterson, 1983). For instance, will the child with autism always be a central or intertwined member of the family or will he or she move away from home and live independently. Parents may wonder if they will ever be able to resume their career as a professional. Families may experience ambiguity in the social setting when looking for help to manage their stress of raising a child with autism. For instance, the disabled community has come a long way in raising awareness of people with special needs. However, people with autism lack any physical or overt characteristics or signs of a disability. Society, therefore, *sees* them as normal children with behavior problems due to poor parenting.

##### Family adaptive resources (bB Factor).

A family's set of adaptive resources are the psychological, social, interpersonal, and material characteristics that a family uses in order to meet certain demands and needs (Patterson & McCubbin, 1983). These characteristics are used by individual family members, the family as a unit, and by the community (McCubbin & Patterson, 1983; Patterson & McCubbin, 1983). When exposed to a crisis situation, like the stresses and strains of raising an autistic child, the family's adaptive resources take the form of (1) existing resources and (2) expanded or new resources.

##### (1) Existing resources

The family's existing resources are already part of the established repertoire used by the family to reduce their vulnerability to crisis (Patterson & McCubbin, 1983). At the individual

level, these already existing resources may include: management of the home, engaging in hobbies, recreation, or work, and the ability to meet the needs of and nurture the children (McCubbin & Patterson, 1983). A family's existing resource repertoire may draw on the family's sense of togetherness (cohesion), role flexibility, mutual values, and communication (McCubbin & Patterson, 1983). Successful families who have autistic adolescents describe themselves as "close-knit," "able to roll with the punches," and able to adjust as the child's needs change (Bristol & Schopler, 1983). Furthermore, families with adequate finances and good physical health are better able to deal with additional stressors (Bristol & Schopler, 1983). Community resources are also important and include friendships and religious participation (McCubbin & Patterson, 1983).

## (2) Expanded resources

The second type of resources families rely on are the *B* in the *bB* factor: expanded resources. These resources may be new to the family's repertoire or may be strengthened and developed existing resources that emerge from pile-up or from dealing with the crisis situation (McCubbin & Patterson, 1983). For instance, the individual family member may attempt to learn everything about autism by reading books, watching movies and documentaries, and by speaking to professionals. Knowledge is power and with this knowledge the primary caretaker will find an increase in self-esteem and a sense of control over one's own life (Bristol & Schopler, 1983). At the family level, a reallocation of roles and responsibilities will help the family deal with the crisis situation (McCubbin & Patterson, 1983). For example, the primary caregiver may allocate additional chores around the home to other children; the eldest child may take on a part time job in order to increase the family income; or extended kin may be called upon for support and childcare. An extremely important component to the family's ability to deal with a crisis is the

community or social support they seek and receive. In much of the literature regarding crisis and families, Cobb (1976) has been noted as saying, "social support has been defined as information that a family (a) is cared for and loved, (b) is esteemed and valued, and (c) belongs to a network of mutual obligation and understanding." Parents should be encouraged to join support groups, such as the Autism Society of British Columbia (ASBC), in order to network with other parents with similar children, experiences, concerns, and stressors. Other examples of formal community support include: medical and dental care, churches and synagogues, respite care, and alternative living arrangements (Bristol & Schopler, 1983).

#### Family definition and meaning (cC Factor).

There are two perceptions taking place in the cC factor of the Double ABCX Model. The first *c* indicates the family's definition of the initial stressor believed to cause the crisis: the diagnosis of autism (Patterson & McCubbin, 1983). At this point the family may perceive such a diagnosis as shameful, catastrophic, overwhelming, or in contrast, adapt a positive view of acceptance, optimism, faith and courage (Patterson & McCubbin, 1983). The second *C* represents the family's definition of the entire crisis situation. This includes the initial stressor, as well as, the added stressors, strains and hardships, both the old and new family resources, and finally ways to cope that will hopefully bring the family system back into equilibrium (McCubbin & Patterson, 1983). This subjective redefinition of the crisis situation allows the family to "(a) clarify the issues, hardships, and tasks so as to render them more manageable and responsive to problem solving efforts; (b) decrease the intensity of the emotional burdens associated with the crisis situation; and (c) encourage the family unit to carry on with its fundamental tasks of promoting member social and emotional development" (McCubbin & Patterson, 1983, pp. 16).

The *cC* factor is a critical component in a family's coping process because as the family redefines the situation as a "challenge," an "opportunity for growth," or endows the crisis with meaning, such as "believing it was the Lord's will," this appears to facilitate the family's coping and eventual adaptation (Patterson & McCubbin, 1983).

#### Family adaptive coping.

The coping process is both behavioral and cognitive. Resources, perceptions, and behavioral responses interact as families attempt to regain balance in the family's functioning (McCubbin & Patterson, 1983). There are two distinct types of coping strategies employed by families: (1) *instrumental coping strategies* which attempt to change the stressful situation and (2) *palliative or intrapsychic coping strategies* which involve attempts to minimize, tolerate, or ignore the stress of raising an autistic child (Bristol & Schopler, 1983). One or both of these coping strategies may be used to help the family's coping efforts by "(a) eliminating and/or avoiding stressors and strains; (b) managing the hardships of the situation; (c) maintaining the family system's integrity and morale; (d) acquiring and developing resources to meet demands; and (e) implementing structural changes in the family system to accommodate the new demands" (McCubbin & Patterson, 1983, pp. 16-17).

#### Family adaptation (functioning) balancing (*xX* Factor).

In the original ABCX Model (1958), the *x* factor, or the crisis experienced by the family due to a stressor, has been viewed as the dependent variable (McCubbin & Patterson, 1983). This crisis variable is believed to be continuous and symbolizes the continuum of disruptiveness, incapacitatedness, or disorganization experienced by the family (McCubbin & Patterson, 1983).



In the Double ABCX Model, the *X* variable, or post-crisis adjustment, focuses on reducing or eliminating the disruptiveness experienced by the family and attempts to restore the family's equilibrium (McCubbin & Patterson, 1983; McCubbin & Patterson, 1982). However, it should be noted that disruptions in family routines often help to maintain intrafamily relationships and stimulate desirable changes within the family (McCubbin & Patterson, 1983; Hansen & Johnson, 1979).

There are three elements pertinent to family adjustment, these include (a) the individual family member, (b) the family unit, and (c) the community which is comprised of both the individual family members and the family system (McCubbin & Patterson, 1983). Demands and capabilities influence each of these elements. Through family adaptation, a balance is sought to meet the demands of one unit (i.e. the family member) using the capabilities of another (i.e. the community) (McCubbin & Patterson, 1983); thus, bringing two levels of family interaction into a "fit" (McCubbin & Patterson, 1982).

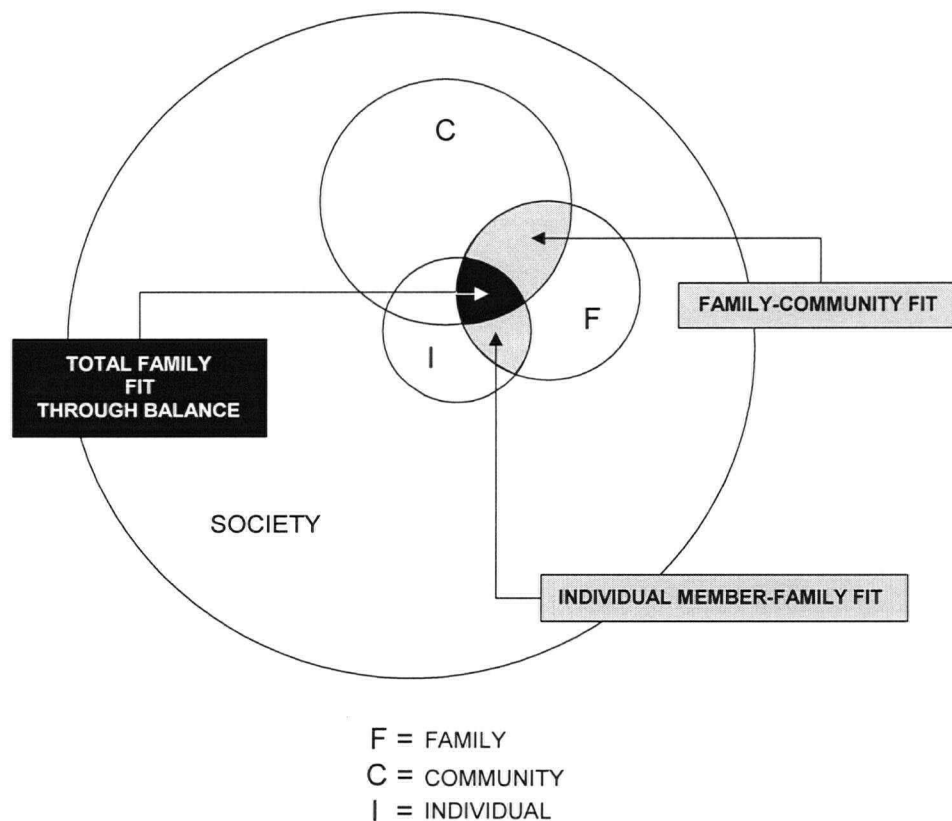
The first level of balance is the member to family fit, in which, equilibrium is sought between the individual family members and the family system (McCubbin & Patterson, 1983). It is hypothesized that family stress emerges when there is a demand-capability imbalance. For instance, imbalance would occur in a family with an autistic child if the family was incapable of changing roles, values, or beliefs to meet the needs of the autistic member (i.e. rigid families are low in adaptability according to the Circumplex Model). Conversely, if the family provides no structure for the autistic child (i.e. a chaotic family system) this will also prove to be detrimental to the child.

The second level of balance is family to community fit. Here a balance is sought between the family unit and the community. It has been observed that a balance between two social institutions, family and work for instance, compete for the involvement and commitment of the

family members, thus, creating an imbalance (McCubbin & Patterson, 1983). For example, when the primary caregiver expresses a desire to return to her career, but the family is unwilling to change roles and responsibilities, this will add stress, pressure, and guilt onto the mother or wife. This family must work together in order to reestablish and achieve a demand-capability balance between the work demands and the family needs (McCubbin & Patterson, 1983).

According to Melson (1980), “family adaptation is achieved when the *discrepancy* between the demands on the family unit...and the resources...are at the absolute minimum” (McCubbin & Patterson, 1982, pp. 39). Figure 4 depicts the two levels of fit between the individual family member and the family unit and between the family unit and the community.

**Figure 4.** Two Levels of “Fit” Between Family and Members, Family and Community (McCubbin & Patterson, 1982, pp. 40)



Certainly an interaction between the family member and the social environment exists, however, this level of "fit" is not pertinent to the discussion at hand, which is "family" adaptability.

A distinction between family adaptation and family adjustment should be made. "*Adjustment* is a short-term response by a family, which changes the situation momentarily, but is not intended to have any long-term consequences. *Adaptation*, however, implies a change in the family system, which evolves over a longer period of time and is intended to have long term consequences involving changes in family roles, rules, patterns of interaction, and perceptions" (McCubbin & Patterson, 1982, pp. 39, italics added).

When families are attempting to achieve adaptation, they soon become aware that there is no "perfect" fit involving a total balance between the family demands and capabilities (McCubbin & Patterson, 1983). Instead, successful adaptation or functioning will be achieved when a realization is made that they will adapt to the crisis situation to the best of their abilities and circumstances at that time. Antonovsky (1979) has described the term *coherence* as being "the pervasive, enduring, though dynamic feeling of confidence that internal and external environments are predictable and there is a high probability that things will work out as well as can reasonably be expected" (McCubbin & Patterson, 1983, pp. 19). Also involved in the concept of coherence, is the family's ability to balance "control" and "trust" in their life circumstances (McCubbin & Patterson, 1983). This means that the family must be able to differentiate when they should take control of the situation from when they should trust the powers of others to deal with the situation (McCubbin & Patterson, 1983). When families achieve this balance between trust and control, they are on their way to coherence which will naturally move them towards bonadaptation, even when all of the demands are not fully met using all of their available resources (McCubbin & Patterson, 1983).

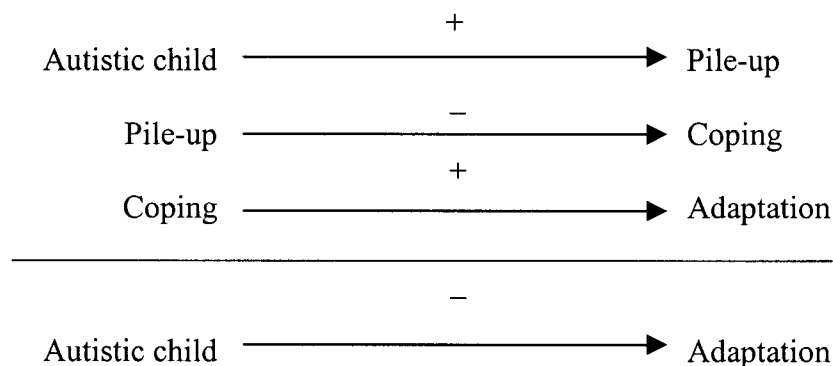
The final outcome of a family's struggle with a crisis situation is reflected in their attempts to achieve "fit" between the member-to-family and the family-to-community levels and this is measured in their level of adaptation. Family adaptation or functioning is a continuum along which *bonadaptation* and *maladaptation* are found. At the positive end of the family adaptation continuum, one will find bonadaptation which is characterized by (a) the maintenance or strengthening of family integrity; (b) the continued development of the individual member and the family unit; and (c) the maintenance of family independence and its sense of control over environmental influences (McCubbin & Patterson, 1983). At the negative end of the continuum, maladaptation is found, and is characterized by (a) the deterioration of family integrity; (b) the curtailment or deterioration in the personal health and development of the individual member or the well-being of the family unit; or (c) the loss or decline of family independence and autonomy (McCubbin & Patterson, 1983).

## CHAPTER 3

### ORIENTATION AND PURPOSE

#### Overview of Assumptions

Now that the conceptual components underlying this research have been explored, we can move on to the research problem and hypotheses that have emerged from a review of the literature and application of the Double ABCX Model to families with autistic children. Following the flow of the Double ABCX Model, we presume the family has already gone through the pre-crisis stage; the diagnosis of autism, the demands on resources, the family definition; and has emerged with the reality of having to raise this child. This reality is the  $x$  factor or crisis stage. I predict that the presence of the autistic child will effect the pile-up of demands on the family in a positive direction (i.e. the pile-up will increase). This increased pile-up will in turn effect the coping of the family (i.e. development of new or improved resources and a change in perception of the crisis, pile-up, and resources). Finally, the family's coping will effect the adaptation of the family system. Deductively, one can then say that the presence of an autistic child will effect the family's adaptation. This stream of logic looks like this:



This research will examine how families raising autistic children perceive their pile-up of demands, coping abilities, and adaptation and cohesion in response to the presence of this child.

In an effort to avert any confusion, a definition of each of these variables may be useful. To date, there has been no formal definition of pile-up in the literature, however, we can derive a working definition from the numerous articles in which pile-up is discussed. *Pile-up* refers to the demands or changes placed upon a single family member or the family system from experienced stressors and strains in response to a crisis. Recall, stressors are discrete life events that produce, or have the potential of producing, change in the family social system. Strains, on the other hand, emerge insidiously as felt tension in response to stressor events and effect the level of family functioning.

According to Patterson and McCubbin (1983), "*coping* is the central process describing families' efforts to adapt and achieve a new level of organization or balance in their system. Coping emerges out of the pile-up of demands on the family and involves an interaction of resources, perception, and behavioral responses" (pp. 28). Coping has both cognitive and behavioral components and may involve either active (i.e. instrumental coping) or passive (i.e. palliative coping) means of attaining the desired balance in family functioning.

In response to the family's pile-up and coping experiences, the family's functioning or adaptation will be the dependent variable in this research. Family functioning is determined by adaptability and cohesion in the family system. *Family Adaptability* is defined as "the ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress" (Olson et al., 1983, pp. 70). *Family Cohesion* is defined as "the emotional bonding that family members have toward one another" (Olson et al., 1983, pp. 70).

### Assumptions and Hypotheses

Once again, following the natural flow of the Double ABCX Model, the first hypothesis deals with the child diagnosed with autism or the perceived crisis situation. Because this hypothesis is not going to be tested, it may be prudent to call it an assumption instead. This assumption is global and encompasses all components of the model; further hypotheses will be more focused. The first assumption states that the presence of an autistic child in the family system will effect all components of the family's functioning (i.e. pile-up, resources, perceptions, and adaptation). This may be due to the increase in medical or professional care, the mandatory departure from the paid work force in order to care for the child, one parent blaming the other for "causing" the disability (i.e. a genetic link), or a host of other possible causes. This increase in pile-up will effect the family's coping strategies, and in turn, their adaptation towards balanced family functioning.

The severity of autism may be inconsequential because the family will be in crisis from the diagnosis alone. Research results pertaining to the level of disability and its effects on family functioning are contradictory and inconclusive. For instance, Factor, Perry, and Freeman (1990) hypothesized that users of respite care would have more severely disabled children. Their results, however, concluded that families who used respite care had significantly higher levels of "parent and family problems", "pessimism" and "child characteristics" (Factor et al., 1990). They went on to say that there was a "range of functioning within both the user groups and the nonuser groups, indicating that severity of child's handicap is not the only important factor to consider" (Factor et al., 1990, pp. 144).

Bristol and Schopler (1983) cite a study (Bristol, 1979) that found "easier," less dependent autistic children and adequate services enabled families to cope more successfully than families with autistic children who had difficult personality characteristics. Such

characteristics include management problems, degree of dependency, need for assistance in self-help skills, lack of activities, and decreased prospects of independent living (Bristol & Schopler, 1983). Contrary to Bristol and Schopler's opinion, Trute (1989) concluded "the child's sex, level of disability, and temperament attributes did not appear to be directly related to family adjustment. One could not say that families with less disabled children, with easier temperament, tended to do better" (pp. 13).

#### Hypothesis 1

**High pile-up of demands will be negatively related to coping in families raising an autistic child.**

The first hypothesis deals with the family's pile-up of demands, the *aA* factor of this model. These demands include stressors, hardships, and prior strains. These life changes the family is experiencing, upset the homeostasis, or balance the family has established, therefore, creating a need for readjustment (McCubbin et al., 1996). Excessive changes tax a person's ability to readjust thereby creating stress. Through exploring the pile-up of these stressors, hardships, and strains an explanation may be provided as to why some families are more vulnerable to a single stressor or lack the resiliency to recover from a crisis situation (McCubbin et al., 1996). If a family's resources to cope are already overtaxed, they may be unable to make additional adjustments in light of further stressors (McCubbin et al., 1996).

#### Hypothesis 2

**Families with less coping mechanisms will have a more difficult time adapting to their autistic child.**

This hypothesis centers on the family's coping abilities. The family's adaptation is dependent upon their coping, and their coping is dependent upon their resources and how they perceive the diagnosis of autism. The *C* factor in the Double ABCX Model is critical because it

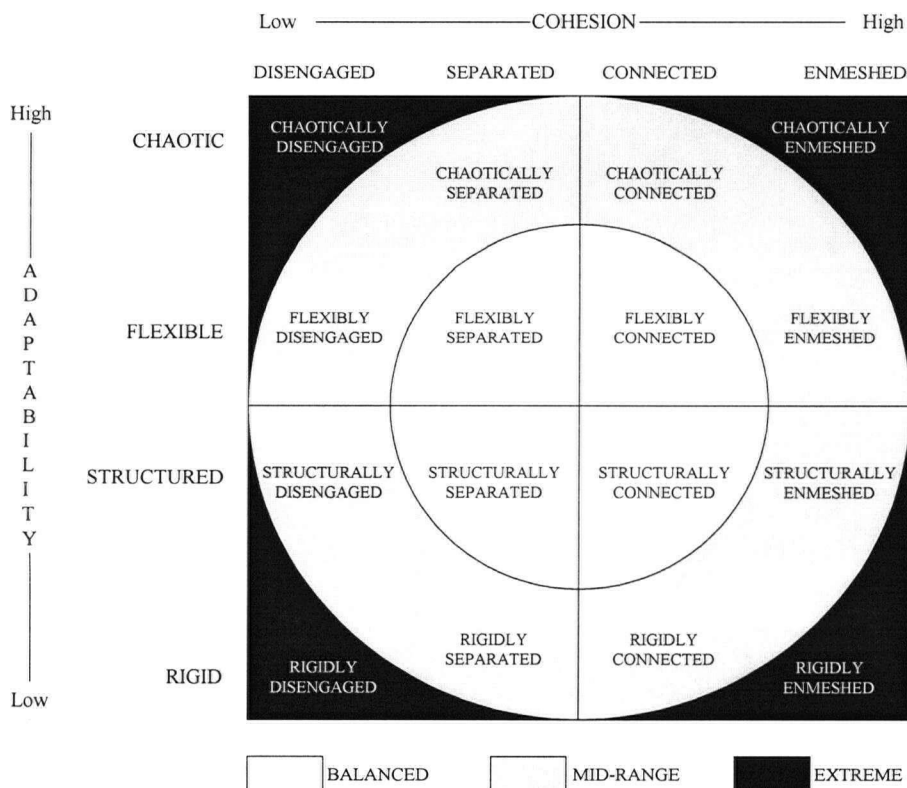


is subjective in its interpretation, or as Trute (1987) states, it involves “cognitive appraisal.” The interpretation of the seriousness of a life event will lead to the scope of coping strategies a family will initiate in response to the event (Trute, 1987; McCubbin & Patterson, 1983). Personality characteristics, knowledge about autism, and previous experience in dealing with change and meeting crises will most likely effect the individual responses.

The last hypothesis looks at the *X* factor in the Double ABCX Model, that is to say, the family’s adaptation. Many concepts emerge at this point because we use Olson’s Circumplex Model to explore the family’s functioning, adaptation, and cohesion. A brief explanation of the Circumplex Model will help form the basis for the final hypothesis.

In the mid 1970’s David Olson reviewed the literature of Robert Angell who had come to be known for his pioneering work on cohesion, adaptability, and family functioning. From this literature Olson developed the Circumplex Model, see Figure 5.

Figure 5. Olson’s Circumplex Model  
(Thomas & Olson, 1993, pp. 161)



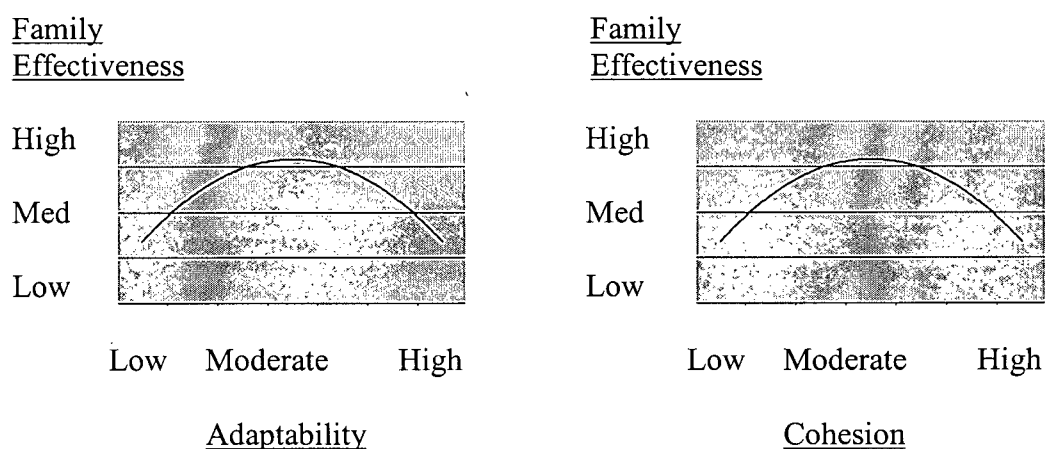
This model is a two-dimensional figure with the variables cohesion and adaptability along each axis. *Family Cohesion* is defined as “the emotional bonding that family members have toward one another and the degree of individual autonomy they experience” (Olson & McCubbin, 1982, pp. 49). Families high in cohesion are said to be connected or enmeshed. This means that an individual has a sense of “we-ness,” loyalty to the family, and the welfare of the group is more important than the good of the individual (Burr, Day, & Bahr, 1988). Enmeshed families have diffused internal boundaries with little interpersonal distance (Burr et al., 1988). They are intertwined to the point that there is little room for individuality. On the opposite end of the spectrum, families who are low in cohesion are described as separated or disengaged. These families are individualistic, and the interests and needs of a single person come before the needs and desires of the group. These families have internal boundaries that are very rigid with little integration or connectedness (Burr et al., 1988). Those families who are extremely disengaged are like “isolated individuals who are living together” (Burr et al., 1988, pp. 244).

*Family Adaptability* is defined as “the ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress” (Olson & McCubbin, 1982, pp. 51). Adaptability has also been described as a family’s *flexibility* (Olson, Lavee, McCubbin, 1988). Once again, the continuum has been divided into four categories ranging from high adaptability to low adaptability. Families who are highly adaptable are chaotic and can be characterized as being so flexible that little predictability, organization, or pattern exists in the family’s functioning (Burr et al., 1988). Those groups in the mid-range of adaptability are defined as being either flexible or structured. The lowest extreme is said to be rigid and, thus, resistant to change, clinging to established patterns, and in opposition to new things (Burr et al., 1988).

When the four levels of cohesion and the four levels of adaptability are combined in this two-dimensional diagram, a system of sixteen conditions emerges. These sixteen different types of marital and family conditions can be grouped into four balanced types, four extreme types, and eight mid-range types of family functioning. This original model was based on the idea that “the two variables of adaptability and cohesion are related to family effectiveness in a quadratic and fairly symmetrical way” (Burr et al., 1988, pp. 244).

According to Olson, there is a positive relationship between these variables up to a certain point, after which the relationship becomes negatively correlated. This is shown in Figure 6.

Figure 6. Family Effectiveness’s Relationship with Adaptability and Cohesion  
in Olson’s Initial Model  
(Burr et al., 1988, pp. 246)

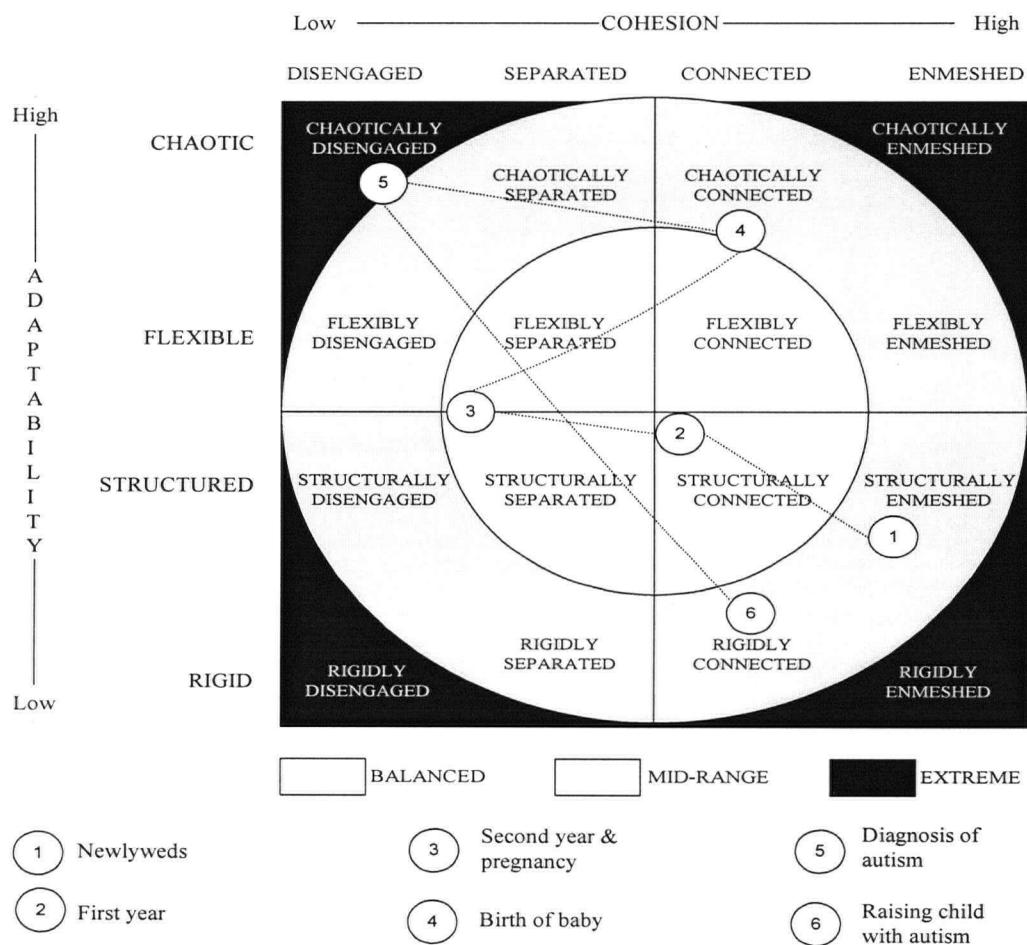


As a family increases its adaptability or cohesion from low to moderate levels, there is also an increase family effectiveness, thus, creating a positive relationship between the two variables. However, when a family increases its adaptability or cohesion from moderate levels to high levels, the family effectiveness decreases, meaning a negative relationship is formed between the variables. One can conclude that the greatest probability of effectiveness is when families have reached a moderate level of both adaptability and cohesion (Burr et al., 1988). This

means that families who fall in the inner four conditions in Figure 5 are the most effective at coping with family stressors.

However, this statement needs to be qualified because it could also be argued that in order for a family to function effectively when raising an autistic child, it may need to be in one of the middle or outer quadrants of this model (Olson, 1995a). Families may move throughout this model as they pass through different life stages and this should be viewed as being “normal” for this family, see Figure 7. In fact, it may be necessary for the family to vacillate in order to function effectively with the family stressors.

Figure 7. Movement through the Circumplex Model Due to Life Stage Changes



For example, when a couple is first married they may find themselves fitting under the “structurally enmeshed” category of the Circumplex Model. They are structured because they are

still trying to work out their roles in the marriage and they are enmeshed because they are in love and spend most of their time together.

As the couple reaches their first anniversary the honeymoon stage is over and the couple moves into a more balanced area of cohesion. The two are now “structurally connected.” Their adaptability has increased somewhat and their cohesion has balanced out.

During the second year of marriage the couple becomes pregnant, now they fall under the “flexibly separated” portion of the continuum. Their adaptability has continued to increase over the years and they are now more flexible in their power structures, roles and rules in the relationship. The husband may become very involved in his career and the wife may become very involved in her work and the pregnancy, thus, leaving the couple more separated on the cohesion continuum.

When the dyad becomes a triad, at best, they may be described as “chaotically connected.” The birth of the child changes everything and now the couple is faced with midnight feedings, diaper changing, lack of money, and a vanishing social life. However, the couple is too busy to realize how chaotic their lives have become and the addition of this new person proves to be a bonding experience and brings the couple closer together.

A few months after the child is born the parents may begin to suspect that something is not right with this child. The baby does not like to be held, never makes eye contact with the mother or father, and is a fussy eater. A few years go by, the child is now three and a half years old, and the parents have just received the news that their child is autistic. This couple may find themselves “chaotically disengaged” at this point. Their lives now consist of appointments with doctors, speech pathologists, behavior therapists, occupational therapists, as well as, wait lists to contend with and support group meetings to attend. Everything is up in the air and the parents have to fight every step of the way for programs and treatment for their child, their life is nothing

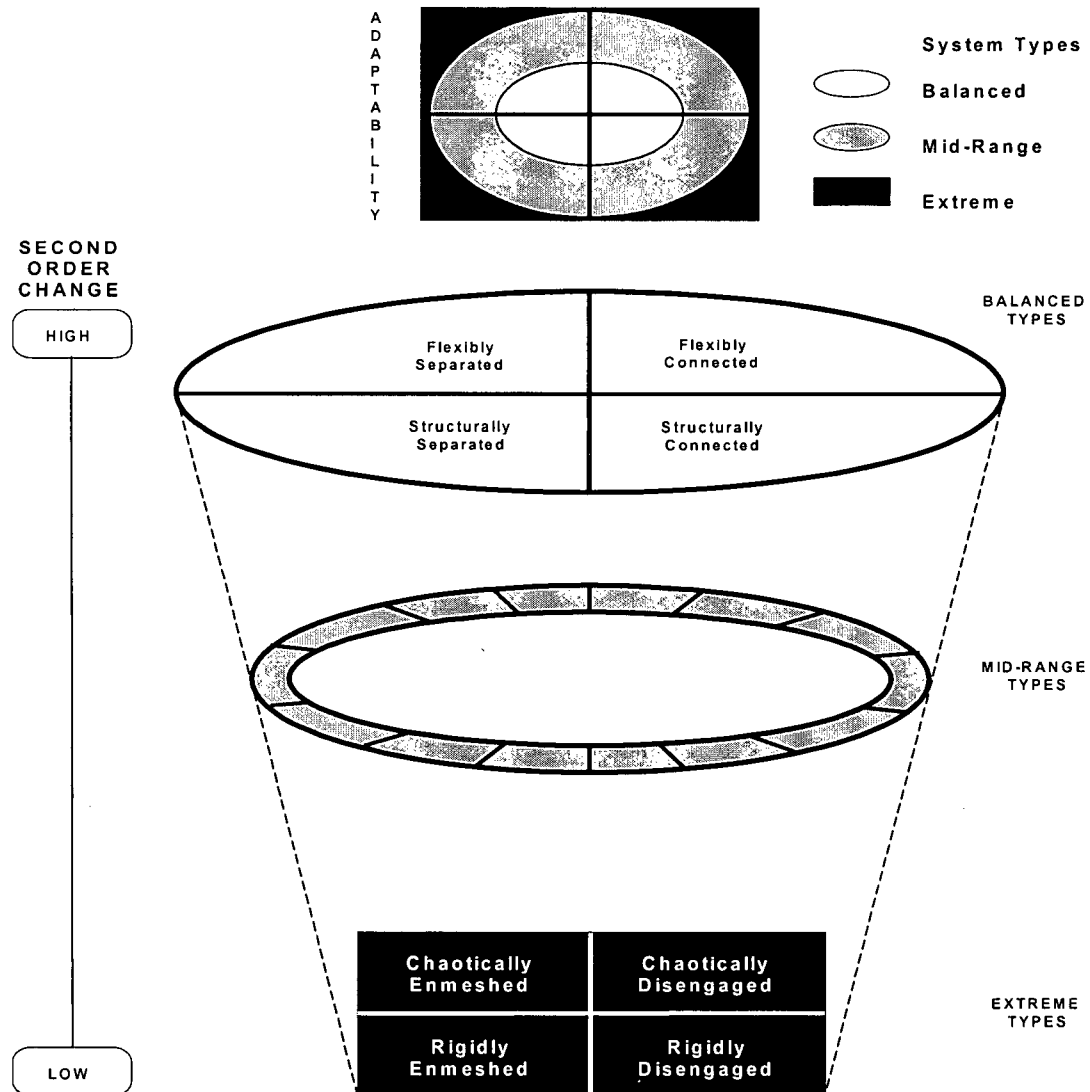
less than chaotic. The diagnosis places a tremendous strain on the family. The father is having a difficult time coping with the news and as a result may take on additional responsibilities at work which keeps him away from home longer. When he is at home, he spends his time outside in his workshop or mowing the lawn. The mother is feeling the burden of having to raise this child on her own. She is tired, stressed, and without the emotional support she needs from her husband. Their relationship is disengaged at this point in their lives.

A few more years pass and the couple is now raising their child with autism. They are beginning to receive help from some of the wait lists they have been on, for instance, a speech pathologist has been assigned to them, they now have a social worker on their side, and they are receiving a few hours of respite care per week. The couple has worked hard to develop a routine for themselves and their child. Doctors and therapists are seen on certain days of each week, support group meetings are scheduled weekly, the child eats at certain times and naps at a regular time everyday. The couple is rigid in their adaptability at this point but they find themselves connected as a couple. The father has come to terms with the diagnosis; they find emotional support from each other and are working as a team in the raising of their child.

As one can see from this example, it may be necessary for an individual or a couple to move along certain axes or in and out of different quadrants as they cope with life's up and downs.

Recently, a three-dimensional Circumplex Model has been developed in an attempt to improve the measurement and utility of the model. This 3-D version of Olson's model elevates the Balanced family types to the highest level, followed by the Mid-Range types, and on the lowest level the four Extreme types of family functioning (Olson, 1991), see Figure 8.

Figure 8. The Three-Dimensional Circumplex Model  
(Olson, 1993, pp. 110)



As well as attempting to improve the measurement and utility of the model, the 3-D design also enables one to incorporate first and second order change more effectively than the original Circumplex Model (Olson, 1993). First-order change is that which occurs *within* a family system (Olson, 1993). The basic family system does not change, rather a change in “degree” takes place along the flexibility dimension (Olson, 1993). Second-order change is change of the system itself from one system type to another type of system (Olson, 1993). This

second-order change can occur in times of normative stress, such as the birth of a child, or nonnormative change, such as the diagnosis of a chronic illness or disability.

First-order change is curvilinear, as demonstrated in Figure 6, which means that too much or too little change is problematic. However, second-order change is linear, as demonstrated in Figure 8, with higher change in the balanced systems and the lowest level of change in the extreme systems (Olson, 1993).

This three-dimensional Circumplex Model illustrates the “dynamic similarity of the types within the Balanced, Midrange, and Extreme types” (Olson, 1993, pp. 110). One can now see that the four Balanced types of functioning are more similar to one another dynamically than they are to any of the Extreme types of functioning (Olson, 1993). The notion of dynamic similarity within Balanced or Extreme types is often lost when looking at these dimensions in the Circumplex Model’s original two-dimensional or 4 X 4 design (Olson, 1993). These improvements to the original Circumplex Model is the reason why the 3-D version is used to interpret the data collected in this research.

This brings us to the final hypothesis.

### Hypothesis 3

**The family’s functioning (adaptability and cohesion) will be predicted by their level of pile-up and their ability to cope with the demands of raising an autistic child.**

It has been hypothesized that “balanced families who have moderate levels of both cohesion and adaptability will function more adequately over the life cycle and be better able to adapt to both normative and situational stressors” (Olson, McCubbin, & associates, 1983 in McCubbin, 1988, pp. 204). A balanced or moderate level of cohesion in a family system allows members to develop an individual autonomy while still maintaining a sense of emotional bonding between the individuals (McCubbin, 1988). A balanced or moderate level of



adaptability in a family system signifies the member's ability to change their structure, rules, and roles in response to challenges faced by the family and its members (McCubbin, 1988). Trute's (1989) study found that families with disabled children had lower levels of consensus than did control groups. He explained this may be due to the ongoing demands of child-care and increased decision making in regard to the care and management of the disabled child. However, even though these parents tended to disagree over everyday issues more frequently, their levels of cohesion were actually higher than the families without a disabled child. Trute (1989) concluded that a key element in overall family functioning is the level of couple cohesion.

## CHAPTER 4

### METHODOLOGY

#### Participant Requirements

The purpose of this study is to examine the effects of raising an autistic child on family functioning. There were four criteria the families had to meet in order to participate in this study, they are as follows: (1) the parent must be fluent in English, (2) the family must have two adults living in the household, (3) the child must be diagnosed with autism, and (4) the child must be seven years old or younger.

The parent that completed the questionnaire had to be fluent in English for several reasons. Firstly, the participant had to be able to understand the questionnaire in order to complete it, as no translator was provided. Secondly, by excluding ESL (English as a Second Language) families, or families where English was not spoken fluently, it was hoped that this would help control for variations in FACES II scores that may be due to cultural and structural differences in family organization and functioning.

The family had to have two adults living in the household in order to participate in this study. These individuals did not need to be married; common law, cohabitating, or homosexual couples were acceptable, however, single parent families were excluded from this study. When conducting a study of this nature, one must make a distinction between single and two parent families. Since pile-up and coping mechanisms were being examined, it was believed that a single parent family may have increased pile-up not due to the child but rather due to a separation or divorce and, therefore, we would be studying confounding factors. Single parent families would function differently from two parent families and because of this they had to be excluded from the study.

The study was limited to families whose children had been diagnosed with autism and not those classified as Aspergers. Children with Asperger's syndrome are very different from autistic children, for example, Asperger children are verbal, whereas, autistic children are either non-verbal or exhibit severely delayed speech. The differences between these two syndromes are substantial enough to warrant a distinction, and therefore, criteria for participation.

Finally, the sample population was to include autistic children ranging in age from 2 to 7 years old. Two is the minimum age requirement because under the age of two these children cannot yet be diagnosed with this syndrome. Autistic children are typically diagnosed between the ages of two and three and confirmed at age four. The cut off age for this study was seven years old. In the original thesis proposal, six was going to be the cut off point, however, it was suggested that the age be increased to seven in order to add another group of possible families into the study. By increasing the age, this changes some of the resources available to families, as well as, increases the variability among the group. However, this age group is still young enough, that the diagnosis probably did not occur too long ago and it was hoped that questioning families with recently diagnosed children would increase the likelihood that the family would still be in a crisis. If families with older autistic children were sampled, it is possible that these families would have had more time to develop coping strategies and may be through the crisis stage.

### Recruitment of Participants

Initially it was planned that an announcement would be circulated in the Autism Society of British Columbia's (ASBC) newsletter informing members of this study, the sampling criteria, and the contact number of the investigator. This sole means of recruitment proved to be insufficient and other means of "getting the word out" needed to be explored. Bulletins and

brochures were made and distributed to Dunbar Community Center, Pacific Riding for the Disabled, Child Development Centers across the province, Sunny Hill Hospital, Ministries for Children and Families across the province, the Neurological Center, and support groups and agencies, such as, Autism Societies in BC and Alberta, Gateway, Loral House, and Families for Early Autism Treatment (FEAT). In some cases, questionnaires were also sent out to these agencies for distribution by the support workers. The following groups also accepted a submission into their newsletters regarding this study, four months in the ASBC's paper, the Autism Society Central Alberta (Red Deer), the Family Support Institute (BCAL), BC Therapeutic Riding Association, and the Autism Calgary Association. On one occasion the researcher attended a support group meeting held by the ASBC for parents of autistic children and questionnaires were handed out after parents were informed of the current study.

#### Data Collection Procedure

The bulletins and brochures that were distributed contained the researcher's home phone number and email address. A couple of mothers contacted the researcher through email, however, the majority made contact through the telephone. At this point, a questionnaire along with a self addressed stamped envelop was sent to the family. Once the parent most knowledgeable (PMK) completed the questionnaire, they returned it by mail in the envelop that was provided.

As mentioned above, questionnaires were also sent out to some agencies and their staff distributed them to members that met the research criteria. In one case, the researcher met the family in their home and entertained the child while the mother completed the questionnaire.

### Response Rate

A total of 137 questionnaires were sent out to families, Autism Societies, Child Development Centres, and other agencies that specialized in autism. Fifteen families contacted the researcher over the phone or by email and 16 questionnaires were sent out to them. Of those 16 questionnaires, 11 were returned with some personal information (return address, attached letters or notes). One hundred and twenty-one questionnaires were sent to agencies such as the Society for the Treatment of Autism in Calgary, Gateway in Ladner, Autism Calgary Association, and the Autism Society of British Columbia. Of these 121 questionnaires, only 46 made it to the families of autistic children, 75 questionnaires remain in foyers, on social workers desks, or were returned to the researcher untouched. Despite this disappointing apathy among some of the support workers, of the 62 questionnaires that did get to parents and families, 39 were returned, a return rate of 63%.

### Measurements

The research at hand consisted of two independent variables, one dependent variable, and several control variables.

#### Independent Variable: Pile-Up

The first independent variable assessed the pile-up of life events these families have encountered. In order to measure this, the Family Inventory of Life Events and Changes (FILE) was used (McCubbin, Patterson, & Wilson, 1983). FILE is devised to measure the amount of both normative and nonnormative demands experienced by a family in the past. FILE is a 71 item self-report instrument that asks parents whether or not these events have occurred within the past year. FILE has broken these 71 items down into 9 subscales which assess the family's (1) intrafamily strains, (2) marital strains, (3) pregnancy and childbearing strains, (4) finance and

business strains, (5) work-family transitions and strains, (6) illness and family “care” strains, (7) losses, (8) transitions “in and out”, and (9) family legal violations. FILE’s internal reliability is .72 and test-retest reliability is .80 (McCubbin, 1988). Please see McCubbin, Thompson, and McCubbin (1996) for previously reported standardized weights for the items, validities, and reliabilities.

#### Independent Variable: Parental Coping

The second independent variable assessed parental coping using the Coping-Health Inventory for Parents (CHIP) (McCubbin, McCubbin, Nevin, & Cauble, 1981). CHIP was developed to “assess parents’ appraisal of their coping responses to the management of family life when they have a child member who is seriously and/or chronically ill” (McCubbin, Thompson, & McCubbin, 1996, pp. 407). As mentioned above in our discussion of the Double ABCX Model, coping involves the use of existing and the development of new resources, perceptions, and behaviors. This inventory is a self-report instrument, which consists of 45 items that ask parents how helpful each behavior is for their situation, and to rate each of the statements on a scale of 0-3 (0=not helpful, 1=minimally helpful, 2=moderately helpful, and 3=extremely helpful). For each statement, parents may also respond by indicating that they do not cope in a certain way because either they ‘chose not to’ or it was ‘not possible’. According to McCubbin et al. (1996), when scoring CHIP, these two choices (‘chose not to’ or ‘not possible’) are equivalent to 0 and therefore are coded as such.

Factor analysis on the 45 items found three coping patterns which accounted for 71.1% of the variance of the original correlation matrix (McCubbin et al., 1983; McCubbin, 1988). These three coping patterns are labeled (I) *Family Integration, Cooperation and an Optimistic Definition of the Situation*, (II) *Maintaining Social Support, Self-esteem and Psychological*

*Stability*, and (III) *Understanding the Health Care Situation Through Communication with Other Parents and Consultation with the Health Care Team* (McCubbin et al., 1981).

Coping Pattern I is composed of 19 behaviors that center around family life and relationships and the parent's perception of life with a disabled child (internal reliability = .79) (McCubbin et al., 1981; McCubbin, 1988). Coping Pattern II consists of 18 behavioral items that focus on the parents' efforts to maintain a sense of "well-being" through social activities and relationships that will enhance the individuals' sense of self-esteem and self-worth (McCubbin et al., 1981; McCubbin, 1988). This pattern also explores the strategies used to manage psychological tensions and pressures (internal reliability = .79) (McCubbin et al., 1981; McCubbin, 1988). Finally, Coping Pattern III involves eight behaviors that focus on parents and their relationship with their disabled child, the medical profession, and other parents with disabled children. Parents' attempts at gaining knowledge about the disability and mastery of home care treatment regimens are also examined (internal reliability = .71) (McCubbin et al., 1981; McCubbin, 1988). For additional reliability and validity assessments of CHIP, please see McCubbin, Thompson, & McCubbin (1996).

#### Dependent Variable: Family Functioning

The dependent variable in this research is family functioning. The final inventory that was administered measured family functioning through the family's adaptability and cohesion. This was done with David Olson's Family Adaptability and Cohesion Evaluation Scales (FACES). It is based upon the Circumplex Model and is a self-report inventory that measures the family's functioning in terms of cohesion and adaptability. There are several versions of this inventory ranging from FACES I to FACES IV. In this research, FACES II was used. This inventory consists of 30 one-sentence descriptions of family characteristics, 14 of which assess adaptability and 16 assess cohesion. Family members were asked to rate each item on a scale of

1-5 (1=almost never, 2=once in awhile, 3=sometimes, 4=frequently, and 5=almost always). With the new three dimensional model of the Circumplex Model, high scores on adaptability and cohesion represent more balanced family types and low scores represent extreme family types (Olson, 1991). Consequently, high scores on the adaptability dimension should now be interpreted as “very flexible” rather than “chaotic” (Olson, 1991). And high scores on the cohesion dimension should be viewed as “very connected” rather than “enmeshed” (Olson, 1991).

Currently, FACES II is recommended over FACES III due to its higher alpha reliability, a result from the increased items in FACES II (30-items) versus FACES III (20-items). Cronbach Alpha for the two versions is shown in Figure 9.

Figure 9. Alpha Reliability for FACES II versus FACES III  
(Olson, 1995b)

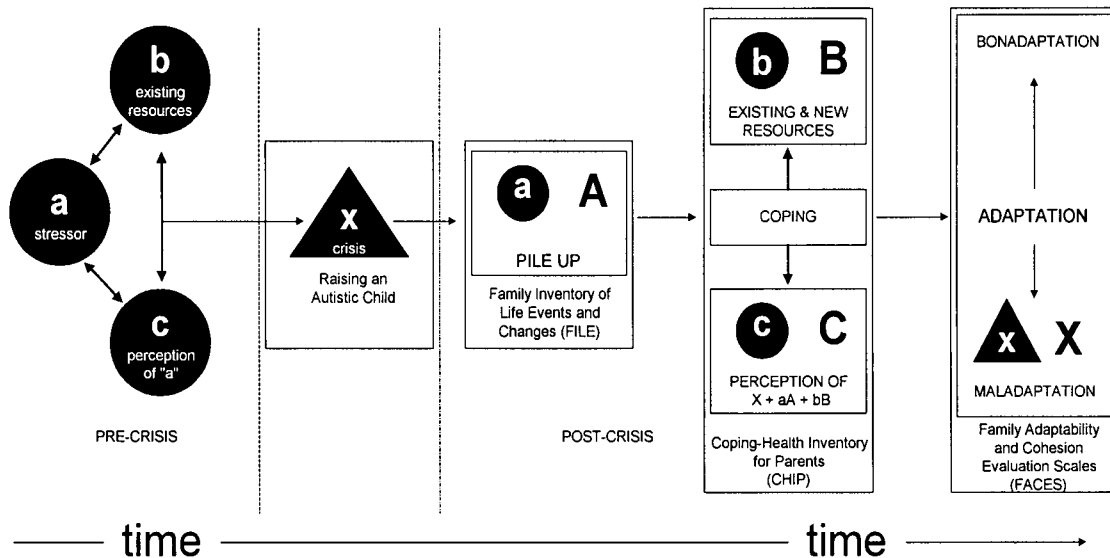
	<u>FACES II</u>	<u>FACES III</u>
Cohesion	.87	.77
Adaptability	.78	.62
Total Scale	.90	.68

Olson (1995b) also notes that the concurrent validity for FACES II is higher than for FACES III, especially where family adaptability is concerned. This means that when other measures are used to examine constructs similar to adaptability and cohesion, these instruments correlate higher with FACES II than with FACES III (Olson, 1995b). See Hampson, Hulgus, and Beavers (1991) for a full comparison between the Dallas Self-Report Family Inventory (SFI) and both FACES II and FACES III.

Now that we are familiar with the independent and dependent variables, perhaps it would be useful to have a visual representation of how these measures are associated with the Double ABCX Model. Figure 10 depicts the different factors in the model and the measurement instruments that will be used to measure each concept.



Figure 10. Double ABCX Model and the Instruments Used to Measure Each Factor



### Control Variables

There are several variables in this study which might confound the hypothesized effects. For example, time since onset is measured by asking (1) age of the autistic child on the day the questionnaire is completed, (2) at what age did the PMK perceive the child may have a problem, and (3) at what age was the child finally diagnosed with autism? By controlling for or determining the onset of autism, we are controlling for the pile-up experienced by the family. We are also controlling for the amount of time the families have had to develop resources and coping strategies to help deal with their child because this will inevitably effect their family functioning.

The parent most knowledgeable (PMK) was also asked if any other family member had a disability, what the respondents' relationship was to the autistic child, for example, their mother or father, and who looks after the child when the PMK is working or away.

By determining whether or not other family members had a disability, the researcher was able to control for previous experience. If the parents had previous experience either growing up with a family member who had a disability or raising another child with a disability this would

give them an advantage over families who were developing coping strategies and resources for the first time. The respondents' relationship to the child is important to ascertain because different relationships will bring different factors into the equation. For example, a mother may bring different resources to the raising of the child than a father would or a relative. It is also important to find out whose perspective these answers are coming from, who in the house hold is stressed out, who is doing most of the care giving, who is working. If the PMK is a nanny or relative, this could be linked to the family's socioeconomic status. If both parents are working, one may presume that they must be somewhat "comfortable" in order to afford a nanny. Conversely, if both parents are working and the PMK is a grandparent, one may infer family financial pressures, meaning the grandparent does the care giving in order to save the parents money on babysitting or daycare costs.

The PMK's socioeconomic status was measured along with their spouses' SES. The participants SES was measured through age, occupation, and education. The marital status of the PMK was questioned, as well as, the annual income of the household.

By controlling the family's socioeconomic status, we are attempting to control for the difference in resources the parents may have or be able to buy. For example, parents with a higher education may be better able to cope with an autistic child than families with lower levels of education. Furthermore, with higher education comes better jobs and better income. Families who have a high annual income may be able to afford alternative therapies, such as Lovaas' Applied Behavior Analysis, or they may be able to afford to buy respite care out of their own pockets. Families with lower annual incomes may find these coping alternatives further their pile-up of stressors.

The PMK was asked their marital status because this sample was limited to families with two adults living in the household. As mentioned before, the couple did not have to be married, however, single parent families were not being studied.

## CHAPTER 5

### RESULTS

#### Sample Description

Thirty-nine families participated in this study and were recruited from all over British Columbia and parts of Alberta. Thirty-five of the subjects had one autistic child in their home and four families had two autistic children under the age of 7 years. The children with autism ranged in age from 2 years, 9 months to 7 years, 8 months old with the average age being 5 years, 4 months and a standard deviation of 1 year, 2 months. The PMK was asked when the family first suspected something was wrong with their child and these ages ranged from as young as 2 months old up to 5 years, 2 months. The average age parents began to suspect their child was different was at 1 year, 8 months of age. The standard deviation was 10 months.

Many parents claim that too much time passes between when they first suspect something is wrong and when a diagnosis is finally confirmed. The age at which their child was diagnosed with autism was asked and the average age of diagnosis for this sample was 3 years, 4 months, the standard deviation was 13 months. The range of ages for a diagnoses was between 19 months and 7 years of age. This seems to confirm what many parents are saying about a huge time lag between perceiving a problem and getting some help.

These families had anywhere from one to six children in the home with the average number of children being 2.4 and a standard deviation of 1.14. Some of the parents in this sample commented on their reluctance to have additional children after their youngest was diagnosed with autism. This could be for fear of producing another child with autism or because their lives became extremely hectic. It is interesting that, in this sample, only 17 out of the 39 families (44%) tried again after they had a child with autism and 22 out of the 39 families (56%) had only the one child or the child with autism was their last.

The PMK was asked if any other family member had a disability and 64% answered “no” to this question. The remaining 14 families who did have other members with a disability stated that these disabilities included: multiple sclerosis, autism, Down’s syndrome, heart defects, alcoholism, Asperger’s syndrome, depression, attention deficit hyperactive disorder, developmental delays, and muscular dystrophy.

As suspected, the PMK was overwhelmingly the mother in this sample, however, three fathers did complete questionnaires. The average age of the PMK was between 26 and 35 years old. Thirty-six of the thirty-nine subjects were married, two were separated, and one was in a common law relationship. The annual household income for these families averaged between \$40,000 and \$49,999 per year.

The PMKs education ranged from as little as Grade 9 up to Bachelor and Masters degrees, nursing diplomas, and college diplomas. Thirteen percent of the PMKs had some level of high school (ranging from Grade 9 to Grade 12), thirty-seven percent had some form of post secondary education, twenty-six percent went on to obtain their BA, BSc, or B.Ed. degrees, eleven percent had nursing diplomas, and thirteen percent had their Masters degree.

Over half of the PMKs (54%) stayed at home with their autistic child. Their at-home routine often included the coordination of intensive intervention programs for their autistic child, as well as, their involvement in the community with organizations and committees that were centered around this disability.

### Description of Variables

#### Independent Variables: FILE and CHIP

This study utilized two independent variables. The first, FILE, measured the family’s pile-up of stresses and strains over the past 12 months. FILE consists of nine subscales that

measure such stresses as intrafamily strain, marital strains, losses, and financial strains. Please see Appendix A for the frequencies of each of the nine subscales. When these subscales are combined, the overall pile-up the family has experienced is revealed. The lower the score on FILE the less stress a family is experiencing. According to McCubbin and associates (1996) the normative stress levels for families in the preschool family stage are low at a score between 0-220, moderate between 221-839, and high at 840 plus, with a mean of 530. The results from this study had a mean of 569.67, with a standard deviation of 278.05. The median was 510.00, the mode was 467.00, the variance was 77310.54, and the standard error of the mean was 44.52. There was a range in scores of 1208.00. Once again, this variable appears to be normally distributed with a skewness of .704, standard error of skewness .378 and a kurtosis of .700, standard error of kurtosis .741. Cronach's alpha for the FILE instrument was .8085.

Results from this study found that only 5 out of the 39 families (13%) would be considered to have low stress levels in their family system, these scores ranged from as low as 79 up to 217. On the other hand, 29 of the 39 families (74%) fell under the moderately stressed criteria. These numbers ranged from 245 to 817. Finally, 13% or 5 out of the 39 participants found their families highly stressed out, ranging in scores from 851 up to 1287.

The CHIP measurement instrument "assess parents' appraisal of their coping responses to the management of family life when they have a child member who is seriously and/or chronically ill" (McCubbin, Thompson, & McCubbin, 1996, pp. 407). This instrument is divided into three subscales which look at (1) maintaining family integration, cooperation & an optimistic definition of the situation, (2) maintaining social support, self esteem & psychological stability, and (3) understanding the health care situation through communication with other parents & consultation with the health care team. Please see Appendix B for the frequencies of these three subscales.

Unlike FILE scores, the higher parents score on CHIP the better. Recall, parents were asked to rate items on a scale of perceived 'helpfulness,' high scores indicate high levels of 'helpfulness' and, therefore, high levels of coping. McCubbin has used this line of reasoning (helping = coping), in her 1988 study, and this research is following the precedent set by her. Scores may range anywhere from zero up to 135. The mean score for this sample was 77.64, with a standard deviation of 19.41. The median was 75.00, the mode was 55.00, the variance was 376.87, and the standard error of the mean was 3.11. In this sample, 21% of the families had low levels of coping strategies, 51% had moderate levels of coping, and 28% had high levels of coping strategies working for them. Again we saw a relatively normal distribution with a skewness of .125, standard error of skewness .378 and a kurtosis of -.574, standard error of kurtosis .741. There was a range of scores of 82.00, the lowest score was 36 and the highest score was 118. Cronbach's alpha was .8891.

#### Dependent Variable: FACES II

FACES II determines a family's level of functioning through their recorded adaptability and cohesion scores. Cronbach alpha, as reported in Figure 9, is .78 for adaptability and .87 for cohesion. Please see Appendix C for the frequencies of both adaptability and cohesion. Recall, adaptability is defined as "the ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress" (Olson & McCubbin, 1982, pp. 51). Adaptability scores can range from 15 to 70, this score determines which of the four subcategories (Rigid: 15-39, Structured: 40-45, Flexible: 46-54, and Very Flexible: 55-70) one will fall into. In this study, the mean adaptability score was 46.77 with a standard deviation of 7.84. In this sample, 17.9% of the families fell into the rigid category, 25.6% were structured, 38.5% were flexible, and 17.9% were categorized as being very flexible or chaotic.

Cohesion is defined as “the emotional bonding that family members have toward one another and the degree of individual autonomy they experience” (Olson & McCubbin, 1982, pp. 49). Cohesion scores can range from 15 to 80, once again determining which of the subcategories one will fall into (Disengaged: 15-50, Separated: 51-59, Connected: 60-70, and Very Connected: 71-80). The mean score on cohesion for this sample was 61.28, with a standard deviation of 11.40. Eighteen percent of the participants fell into the disengaged category, 15.4% were separated, 51.3% were connected, and 15.4% were very connected or enmeshed.

When these two scores are combined and divided by two, the “family type” emerges. Like adaptability and cohesion, there are four categories families may fall into, Extreme with a score of 1-2, Mid-Range being 3-4, Moderately Balanced at 5-6, and Balanced families are scored between 7-8. The mean family type score was 4.85 with a standard deviation of 1.66. Please see Appendix C for the frequencies of Family Type. From this study, 15.8% of the families were considered extreme, 25.6% were mid-range, 48.7% were moderately balanced, and 10.3% fell into the balanced category.

It is important to remember, that because of such a small sample size, it is very difficult to establish normality. However, all three of these measurements did have approximately normal distributions. The skewness for adaptability was -.218, with the standard error of skewness being .378. The kurtosis score for adaptability was -.525 and the standard error of kurtosis was .741. Cohesion was -.969 skewness and the standard error of skewness was .378. Kurtosis was .118 for cohesion, with a standard error of kurtosis coming in at .741. Finally, family type was skewed at -.312, with a standard error of skewness at .378 and it had a kurtosis of -.633 with a standard error of kurtosis at .741.



### Control Variables

In the sample description, many of the control variables have already been mentioned. At this time, the remaining variables must be discussed. As mentioned above, 54% of the PMKs stayed at home with their child. The remaining 46% held a variety of jobs that ranged from boarding kennel owner to community school co-ordinator, and registered nurse to teacher.

The PMK was also asked who looked after their child when they were at work or away from home. Sixty-four percent said that their spouse looked after the child when they were away. Many families had more than one babysitting alternative. Thirty-four percent stated school or preschool, 11% used a family day home, and 13% went to a licensed day care. Five percent had a nanny, 18% used grandparents, while 21% used a sitter. A respite worker provided 10% of the alternative sitting, and another 11% was provided by therapists. Finally, 10% of parents' alternative sitting was met by nieces, family friends, and siblings.

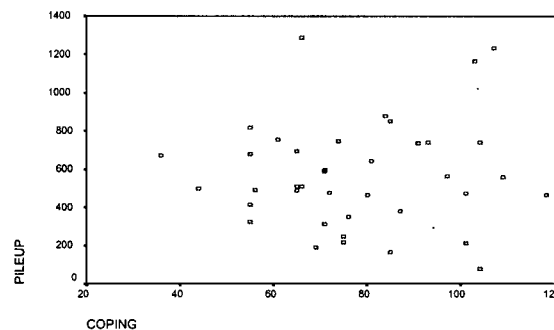
Although the PMKs age ranged from 26 to 35 years, their spouses' age averaged between 36 and 45 years. Much fewer, only 3%, of the spouses were not in the labor force as compared with 54% of the PMKs. Sixteen percent of spouses had some form of a skilled craft or trade, such as, a painter, landscaper, steel fabricator, or cabinet maker. Many spouses were employed and self-employed professionals, such as, teachers, professors, and lawyers. Other professions ranged from mail clerk to computer analyst and managers to sales representatives.

Finally, the spouses' education also ranged from Grade 9 up to an MD/PhD. Thirteen percent of spouses completed high school, 18% obtained their BA, BSc, or B.Ed., 13% had their Masters or CGA, and 5% had a doctorate. The remaining 42% of spouses had some form of post secondary training either with BCIT or college courses elsewhere.

## Hypothesis Testing

Hypothesis 1 stated that high pile-up of demands would be negatively related to coping in families raising an autistic child. A scatterplot was examined in an attempt to find possible curvilinear effects, see Figure 11. A bivariate correlation matrix was then constructed to test this hypothesis, see Table 1 on page 59. The results from these two tests showed that there was no relationship between pile-up and coping. The Pearson correlation coefficient was .059 with a significance of .361 (1-tailed),  $N = 39$ .

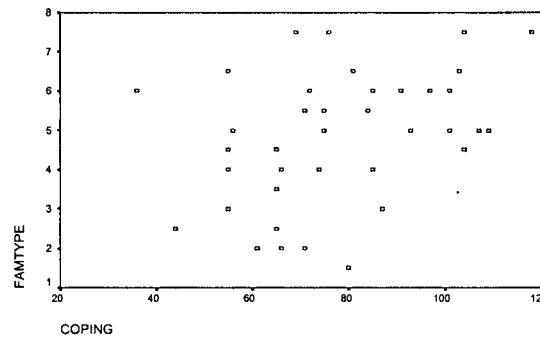
Figure 11. Scatterplot of Pile-up and Coping  $N=39$



The second hypothesis stated that families with less coping mechanisms would have a more difficult time adapting to their autistic child. Once again, a scatterplot and a bivariate correlation matrix were constructed to see if there was indeed a relationship between the two variables, CHIP and Family Type. Recall, adaptability and cohesion are measured using FACES II and are combined to yield the Family Type variable.

The scatterplot showed that there was a positive linear relationship between these two variables, see Figure 12.

Figure 12. Scatterplot of Coping and Family Type N=39



The correlation matrix also showed a relationship between Coping and Family Type. The original bivariate correlation matrix included the dependent variable, Family Type, the two independent variables, Pile-up and Coping, and all of the control variables discussed at the end of Chapter 4. From this correlation matrix, the number of children in the household was the only control variable that was found to be significantly related to Family Type. It should be noted that in subsequent analysis, the control variable, Number of Children, will be the only control variable entered into future equations because it is the only control variable that was found to be significantly related to the dependent variable. Table 1 shows a summary of these variables as related to Family Type.

Table 1. Correlation Coefficients

		FAMTYPE	COPING	PILEUP
FAMTYPE	Pearson Correlation	1.000	.371**	-.241
	Sig. (1-tailed)	.	.010	.070
	N	39	39	39
COPING	Pearson Correlation	.371**	1.000	.059
	Sig. (1-tailed)	.010	.	.361
	N	39	39	39
PILEUP	Pearson Correlation	-.241	.059	1.000
	Sig. (1-tailed)	.070	.361	.
	N	39	39	39
# of Children	Pearson Correlation	.428 <sup>t</sup>	.094	-.234
	Sig. (2-tailed)	.007	.568	.152
	N	39	39	39

\*\*p<0.01 (1-tailed).

<sup>t</sup>p<0.01 (2-tailed).

Using the coping and number of children variables, two multiple regression analyses were conducted, see Table 2. In model one, the independent variable, coping, was entered into the multiple regression equation with family type being the dependent variable. R square equaled .138, the adjusted R square was .115, and the Beta was .371 ( $p=.010$ ,  $N=39$ ). This means that 14% of the observed variability in family type was explained by the coping variable. Another way of stating this is one is able to accurately predict 14% of the family type scores using the coping variable.

Table 2. Models for Coping and Number of Children Regressed on Family Type

Variable	Betas	
	Model 1	Model 2
Coping	.371**	.334*
# of Children		.397**
R <sup>2</sup>	.138	.294

\*\* $p<.01$

\* $p<.05$

Beta is the standardized regression coefficient and in the first model Beta = .371 ( $p=.010$ ). The regression coefficient indicates how closely the points cluster around a straight line. Larger numbers suggest a stronger linear relationship between the two variables. The significance level indicates how many times out of one hundred the researcher could expect to find a number that large or larger by chance. Therefore, we can conclude that the Beta in model one shows that there is a linear relationship between coping and family type and one would expect to find a number this large or larger by chance in one out of one hundred cases.

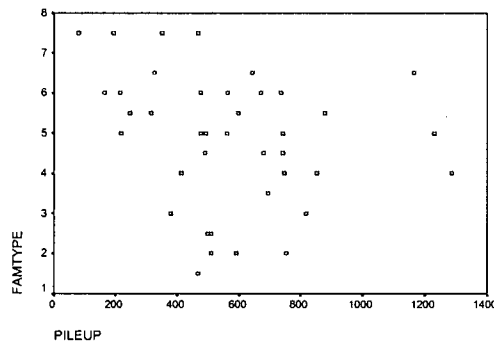
The second model incorporates the significant control variables into the equation, in this case number of children was the only significant control variable. Block one of the regression equation included number of children and family type as the dependent variable. The R square for number of children was .183, adjusted R square was .161 and the Beta was .428 ( $p=.007$ ,  $N=39$ ). Coping was entered into the equation in block two. With these two variables regressed

onto family type, 29% of the variance from family type was now explained by coping and the number of children in the household. The correlation coefficient was .542 and the adjusted R square was .255, and the Beta was now .397 ( $p=.008$ ) for number of children and .334 ( $p=.023$ ) for coping,  $N=39$ .

From this second model, we can conclude that our explanation of the variance in family type has increased 16% with number of children entered into the equation. The number of children in the household plays a large roll in determining the type of family in which one may fall. With this said, it is important to note that even though number of children has a significant impact on family type, when this variable is entered into the regression equation, the independent variable, coping, remains significant. This point is critical in that it suggests that coping is not spuriously related to family type, thus, making the possible relationship between coping and family type more plausible.

Hypothesis 3 stated the family's level of functioning (adaptability and cohesion) would be predicted by their level of pile-up and their ability to cope with the demands of raising an autistic child. Figure 12 shows the linear relationship between coping and family type. Figure 13 below, shows the negative linear relationship between pile-up and family functioning. Although this is not a strong linear relationship, in fact,  $r = -.241$  ( $p=.070$ ,  $N=39$ ), one is able to see that as the amount of pile-up increases in the household the family type decreases (recall, higher family type is indicative of better adaptation and cohesion within the family unit).

Figure 13. Scatterplot of Pile-up and Family Type N=39



### In Depth Examination of Subscales

The three hypotheses examined in this research are derived from the effect of two independent variables and one dependent variable. Each variable or scale is constructed from subscales, recall FILE is made up of nine subscales, CHIP has three, and Family Type is derived from two subscales. It is important to examine these subscales and their relationships because as we will see, frequently, these subscales mask data and critical information can be missed when only the larger instrument is examined.

The first hypothesis examined the relationship between pile-up and coping, the dependent variable was not part of this equation, it was concluded that there was no relationship between these two variables. However, when the subscales (SS) were examined, Marital Strains (FILE SS 2) and Maintaining Family Integration, Cooperation & an Optimistic Definition of the Situation (CHIP SS 1) were correlated ( $r = -.345$ ,  $p < .05$ ,  $N = 39$ ). This means that as a family's marital strains increase, their family integration, cooperation and positive outlook decreases. Pregnancy and Childbearing Strains (FILE SS 3) was correlated with Maintaining Social Support, Self Esteem & Psychological Stability (CHIP SS 2) ( $r = -.274$ ,  $p < .05$ ,  $N = 39$ ). This means that as a family experiences increased strains pertaining to pregnancy or childbearing (i.e. spouse had an unwanted or difficult pregnancy) their overall sense of social support, self-esteem and/or

psychological stability decreases. Table 3 shows a summary of the significant FILE and CHIP subscales correlated with each other.

Table 3. Correlation Matrix of Significant FILE and CHIP Subscales

	Integration, Cooperation, Optimism	Support, Esteem, Stability
Marital Strains Pearson Correlation	-.345*	-.086
Sig. (1-tailed)	.016	.302
N	39	39
Pregnancy & Childbearing Strains Pearson Correlation	.026	-.274*
Sig. (1-tailed)	.437	.046
N	39	39
Work-Family Transitions & Strains Pearson Correlation	.061	.345*
Sig. (1-tailed)	.355	.016
N	39	39

\* $p < .05$  (1-tailed).

The preceding significant correlations follow the general finding of increased pile-up leads to decreased coping, however, this is not the case in all dimensions. For instance, Work-Family Transitions and Strains (FILE SS 5) and Maintaining Social Support, Self Esteem & Psychological Stability (CHIP SS 2) were correlated at .345 ( $p < .05$ ,  $N=39$ ). Some of the most commonly answered items in Work-Family Transitions and Strains were a decrease in satisfaction with their job or career, a child member changed to a new school, a member started or returned to work, and a member was promoted at work or given more responsibilities. From this correlation, we can conclude that as the number of these items increase, thus, causing an increase in the family's pile-up, their sense of "social support, self-esteem, and psychological well-being" also increases.

It should be noted that by using the 9 FILE subscales and 3 CHIP subscales, 27 comparisons (at the .05 level) were conducted. If there was random sampling, one would expect to get at least one significant outcome by chance alone. However, the above analyses are not conducted from a random sample and, therefore, these results may be chance findings. One must

be cautious because although these findings may be by chance alone, one cannot exclude the possibility that they are not chance findings.

The second hypothesis looked at the relationship between the family's coping and their overall family type. It was at this point that the control variables were also entered into the equation. When the subscales of CHIP were correlated with the subscales of Family Type, a strong correlation between Maintaining Family Integration, Cooperation & an Optimistic Definition of the Situation (CHIP SS 1) and Cohesion and Adaptability emerged. Maintaining Family Integration, Cooperation & an Optimistic Definition of the Situation and Cohesion correlated at .452 ( $p < .01$ ,  $N=39$ ) and with Adaptability  $r = .371$  ( $p < .05$ ,  $N=39$ ). The overall Family Type correlation with this subscale was .488 ( $p = .001$ ,  $N=39$ ). Maintaining Social Support, Self-Esteem, and Psychological Stability (CHIP SS 2) was significantly correlated to Adaptability ( $r = .310$ ,  $p < .05$ ,  $N=39$ ) and Family Type ( $r = .271$ ,  $p < .05$ ,  $N=39$ ). It should be noted that CHIP's third subscale (Understanding the Health Care Situation Through Communication with Other Parents & Consultation with the Health Care Team) was not significantly correlated to cohesion, adaptability, or family type.

One possible explanation for the relationship between the family's coping and cohesion and adaptability could be the fact that these three variables seem to be measuring similar things. On the one hand, Maintaining Family Integration, Cooperation & an Optimistic Definition of the Situation (CHIP SS 1) is exploring family integration and, on the other hand, cohesion is looking at connectedness or a sense of "we-ness." As for this subscale and adaptability, one may say that cooperation plays a vital role when a family has to change its rules and structure.

When the control variables were correlated with the subscales of Family Type, the number of children in the household was again the only significant variable. Number of Children and cohesion had a correlation of .393 ( $p < .05$ , 2-tailed,  $N=39$ ) and Number of Children and



adaptability had an  $r = .450$  ( $p < .01$ , 2-tailed,  $N = 39$ ). Table 5 (on page 68) is a summary of the significant CHIP and control variables correlated with cohesion, adaptability, and family type.

The significant CHIP subscales and the significant control variable can now be further examined using a multiple regression equation. Table 4 summarizes the results from this analysis.

Table 4. Integration, Cooperation, and Optimism (CHIP SS 1), Support, Esteem, and Stability (CHIP SS 2) and Number of Children Regressed onto Cohesion, Adaptability and Family Type

Cohesion Betas			
Variables	Model 1	Model 2	Model 3
Integration, Cooperation, Optimism	.452**		.379*
# of Children		.393*	.300*
R <sup>2</sup>	.204	.154	.289

Adaptability Betas			
Variables	Model 1	Model 2	Model 3
Integration, Cooperation, Optimism + Support, Esteem, Stability	.395*		.341*
# of Children		.450**	.404**
R <sup>2</sup>	.156	.203	.317

Family Type Betas			
Variables	Model 1	Model 2	Model 3
Integration, Cooperation, Optimism + Support, Esteem, Stability	.452**		.401**
# of Children		.428**	.374**
R <sup>2</sup>	.204	.183	.342

\*\* $p < .01$  (1-tailed).

\* $p < .05$  (1-tailed).

As we can see, the three variables were combined and placed into a multiple regression equation with cohesion, adaptability, and family type being the dependent variable at different times. In the first regression analysis, with cohesion as the dependent variable, only Maintaining

Family Integration, Cooperation & an Optimistic Definition of the Situation (CHIP SS 1) was used because Maintaining Social Support, Self-Esteem, & Psychological Stability (CHIP SS 2) was not found to be significantly correlated with cohesion. In the next two regression equations, both CHIP SS 1 and CHIP SS 2 were used due to the relationship found between them and adaptability and family type. These two subscales are highly correlated with each other ( $r=.508$ ,  $p=.000$ ,  $N=39$ ) and as a result they were added together before they were entered into the multiple regression equation.

The results from these analyses show a dramatic increase in the variable's ability to explain a proportion of the observed variance of the family type variable. Using Integration, Cooperation, & Optimism (CHIP SS 1) and Support, Esteem, & Stability (CHIP SS 2), instead of the entire coping measurement, has increased the explanation of the variability in family type from 14% to 20%. As for the Number of Children in the household, this result remained unchanged at 18% of the observed variability of family type being explained by Number of Children. The results above also show that with Integration, Cooperation, & Optimism(CHIP SS 1), Support, Esteem, & Stability (CHIP SS 2), and Number of Children in the household regressed onto family type, 34% of the variance from family type is now explained by these three variables. This is a large increase from the 29% explained previously using Number of Children and the entire CHIP scale.

Once again, the concern that these three variables may be spurious is not supported by the fact that Maintaining Family Integration, Cooperation & an Optimistic Definition of the Situation (CHIP SS 1) plus Maintaining Social Support, Self-Esteem, & Psychological Stability (CHIP SS 2) remained significant after Number of Children was entered into the equation. This goes to show that CHIP SS 1 and CHIP SS 2 had a strong enough relationship with family type that the addition of another variable, Number of Children, did not decrease their significant

relationship by consuming enough of the variance that the original relationship becomes non-existent.

In the final hypothesis, all of the variables were brought together to examine their interactions with each other. Recall, hypothesis 3 stated the family's level of functioning (adaptability and cohesion) would be predicted by their level of pile-up and their ability to cope with the demands of raising an autistic child. When the subscales of each measurement were examined, a correlation between some of the pile-up subscales and family type subscales surfaced. Intrafamily Strains (FILE SS 1) was correlated with both cohesion and adaptability,  $r = -.390$  ( $p < .01$ ) for cohesion and  $r = -.348$  ( $p < .05$ ) for adaptability, in both cases  $N = 39$ . The correlation between Intrafamily Strains and Family Type was  $r = -.398$  ( $p < .01$ ,  $N = 39$ ).

Marital Strains (FILE SS 2) and cohesion were correlated, however, adaptability was not significant in this case. In the equation with cohesion as the dependent variable  $r = -.469$  ( $p = .001$ ,  $N = 39$ ). The correlation between Marital Strains and Family Type was  $r = -.350$  ( $p < .05$ ,  $N = 39$ ). Pregnancy and Childbearing Strains (FILE SS 3) was correlated only with cohesion at  $-.285$  ( $p < .05$ ,  $N = 39$ ). Finally, Losses (FILE SS 7) was correlated with both adaptability ( $r = .282$ ,  $p < .05$ ,  $N = 39$ ) and Family Type ( $r = .295$ ,  $p < .05$ ,  $N = 39$ ). Table 5 shows a summary of the significant variables correlated with family type and its subscales cohesion and adaptability.

**Table 5. Significant FILE and CHIP Subscales and Control Variables Correlated with Cohesion, Adaptability and Family Type**

		COHESION	ADAPTBTY	FAMTYPE
Intrafamily Strains	Pearson Correlation	-.390**	-.348*	-.398**
	Sig. (1-tailed)	.007	.015	.006
	N	39	39	39
Marital Strains	Pearson Correlation	-.469**	-.193	-.350*
	Sig. (1-tailed)	.001	.120	.015
	N	39	39	39
Pregnancy & Childbearing Strains	Pearson Correlation	-.285*	-.248	-.262
	Sig. (1-tailed)	.039	.064	.053
	N	39	39	39
Losses	Pearson Correlation	.142	.282*	.295*
	Sig. (1-tailed)	.194	.041	.034
	N	39	39	39
Integration, Cooperation, Optimism	Pearson Correlation	.452**	.371*	.488**
	Sig. (1-tailed)	.002	.010	.001
	N	39	39	39
Support, Esteem, Stability	Pearson Correlation	.197	.310*	.271*
	Sig. (1-tailed)	.114	.028	.047
	N	39	39	39
Number of Children in the Household	Pearson Correlation	.393 <sup>t</sup>	.450 <sup>tt</sup>	.428 <sup>tt</sup>
	Sig. (2-tailed)	.013	.004	.007
	N	39	39	39

\*\*p<.01 (1-tailed).

\*p<.05 (1-tailed).

<sup>tt</sup>p<.01 (2-tailed).

<sup>t</sup>p<.05 (2-tailed).

Now that the significant variables have been identified, we can move on to explore each of them in more detail using multiple regression. Table 6 shows a summary of these outcomes. It should be noted that when Intrafamily Strains (FILE SS 1) and Marital Strains (FILE SS 2) were used in a multiple regression equation together, they were added together prior to being entered in the equation due to their high correlation with each other ( $r=.487$ ,  $p<.001$ ,  $N=39$ ) and their relatively high internal consistency ( $\alpha=.788$ ,  $k=21$ ,  $N=39$ ). When Pregnancy and Childbearing Strains (FILE SS 3) and Losses (FILE SS 7) were used in the regression analyses, they were entered separately because of their independence with each other, Intrafamily Strains, and Marital Strains.

**Table 6. Multiple Regression Equations with FILE Subscales as the Independent Variables and Cohesion, Adaptability and Family Type as the Dependent Variables**

Cohesion Betas			
Variables	Model 1	Model 2	Model 3
Intrafamily + Marital Strains	-.452**	-.461**	-.375*
Pregnancy Strains		-.298*	-.304*
# of Children			.290*
R <sup>2</sup>	.205	.293	.370

Adaptability Betas			
Variables	Model 1	Model 2	Model 3
Intrafamily Strains	-.348*	-.376*	-.289*
Losses		.316*	.282*
# of Children			.363*
R <sup>2</sup>	.121	.220	.344

Family Type Betas			
Variables	Model 1	Model 2	Model 3
Intrafamily + Marital Strains	-.429**	-.476**	-.385*
Losses		.358*	.325*
# of Children			.290*
R <sup>2</sup>	.184	.309	.385

\*\*p<.01 (1-tailed).

\*p<.05 (1-tailed).

In the first multiple regression equation (model 1), Intrafamily Strains (FILE SS 1) plus Marital Strains (FILE SS 2) was entered as the independent variable and cohesion was the dependent variable. In the next equation (model 2), Pregnancy and Childbearing Strains (FILE SS 3) was added to the equation. Finally, model 3 incorporates the above two variables and Number of Children in the Household into the equation. In the next set of analyses, the same steps were followed however, cohesion was replaced with adaptability as the dependent variable, only Intrafamily Strains (FILE SS 1) was used in model 1 because Marital Strains (FILE SS 2) was not correlated with adaptability, Losses (FILE SS 7) was added to the equation in model 2, and Number of Children was entered in the model 3. Finally, adaptability was replaced by family

type in the final multiple regression equations, Intrafamily Strains (FILE SS 1) plus Marital Strains (FILE SS 2) were once again entered into the equation in model 1, Losses (FILE SS 7) was used in model 2, and Number of Children was entered in model 3.

From this table we can see that Intrafamily and Marital Strains (FILE SS 1 and FILE SS 2) have the most significant impact on a family's cohesion or sense of "we-ness." However, Pregnancy and Childbearing Strains along with the Number of Children in the Household also contribute significantly to the explanation of cohesion's variance. The family's level of adaptability however, is influenced largely by the Number of Children in the Household. This is followed closely by their Intrafamily Strains (FILE SS 1), as well as, Losses (FILE SS 7) they have experienced recently. Once again, the Intrafamily and Marital Strains (FILE SS 1 and FILE SS 2) experienced by the families in this study affected their overall family type or functioning the most. Losses (FILE SS 7) and Number of Children also help to explain the variance from family type, in fact, 39% of family type's variance is explained by these four variables.

A similar set of equations were conducted using coping's significant subscales, Maintaining Family Integration, Cooperation, & an Optimistic Definition of the Situation (CHIP SS 1) and Maintaining Social Support, Self-Esteem & Psychological Stability (CHIP SS 2), and the only control variable that was found to be significant, Number of Children in the Household. Recall Table 4 has the summary of these results.

A final regression analysis was conducted, using Intrafamily Strains (FILE SS 1), Marital Strains (FILE SS 2), Pregnancy and Childbearing Strains (FILE SS 3), Losses (FILE SS 7), Maintaining Family Integration, Cooperation, & an Optimistic Definition of the Situation (CHIP SS 1), Maintaining Social Support, Self-Esteem & Psychological Stability (CHIP SS 2) and Number of Children in the Household. Once again, Intrafamily Strains (FILE SS 1) and Marital Strains (FILE SS 2) were highly correlated and therefore added together into one variable.

Maintaining Family Integration, Cooperation, & an Optimistic Definition of the Situation (CHIP SS 1) and Maintaining Social Support, Self-Esteem & Psychological Stability (CHIP SS 2) were also highly correlated ( $r=.508$ ,  $p<.001$ ,  $N=39$ ) and had high internal consistency ( $\alpha=.870$ ,  $k=37$ ,  $N=39$ ) resulting in these two variables also being added together before they were entered into the multiple regression equation. Table 7 is a summary of the main effects of this final multiple analysis.

**Table 7.** Main Effects of Significant Subscales and Control Variables Regressed onto Cohesion, Adaptability, and Family Type

Cohesion  
Betas

Variables	Model 1	Model 2	Model 3	Model 4
Intrafamily Strains + Marital Strains	-.452**	-.461**	-.418**	-.362**
Pregnancy Strains		-.298*	-.308*	-.311*
Integration, Cooperation, Optimism			.417**	.373**
# of Children				.203
R <sup>2</sup>	.205	.293	.465	.500

Adaptability  
Betas

Variables	Model 1	Model 2	Model 3	Model 4	Model 5
Intrafamily Strains	-.348*	-.376*	-.410**	-.331*	-.311*
Losses		.316*	.244	.223	
Integration, Cooperation, Optimism + Support, Esteem, Stability			.390**	.344*	.383**
# of Children				.311*	.326*
R <sup>2</sup>	.121	.220	.365	.454	.407

Family Type  
Betas

Variables	Model 1	Model 2	Model 3	Model 4
Intrafamily Strains + Marital Strains	-.429**	-.476**	-.472**	-.397**
Losses		.358*	.279*	.257*
Integration, Cooperation, Optimism + Support, Esteem, Stability			.406**	.376**
# of Children				.241
R <sup>2</sup>	.184	.309	.468	.519

\*\* $p<.01$  (1-tailed).

\* $p<.05$  (1-tailed).

In the first set of multiple regression analyses, the Number of Children in the Household is no longer significantly related to cohesion. Therefore, model 3 (Intrafamily Strains, Marital Strains, Pregnancy and Childbearing Strains, and 'Family Integration, Cooperation and an Optimistic Definition of the Situation') best explains cohesion's variance. In fact, 47% of the observed variability in cohesion can be explained by the combination of these variables.

As the independent variables were added into the second multiple regression equation, adaptation being the dependent variable, Losses (FILE SS 7) became insignificantly related to adaptability. This variable was removed from the equation and 41% of the observed variability in adaptability was now explained by Intrafamily Strains, 'Family Integration, Cooperation, and an Optimistic Definition of the Situation', as well as, 'Social Support, Self-Esteem, Psychological Stability', and the Number of Children in the Household.

In the final set of multiple regression analyses, Number of Children in the Household was no longer significantly related to family type after the other independent variables were entered into the equation. When this variable was removed from the equation, 47% of the observed variability in family type was explained by Intrafamily and Marital Strains, Losses, 'Family Integration, Cooperation, and an Optimistic Definition of the Situation' and 'Social Support, Self-Esteem, and Psychological Stability.'



## CHAPTER 6

### DISCUSSION

The results from this research have been surprising at times while predictable at other times. This research was based on three hypotheses (1) high pile-up of demands will be negatively related to coping in families raising an autistic child, (2) families with less coping mechanisms will have a more difficult time adapting to their autistic child and (3) the family's functioning (adaptability and cohesion) will be predicted by their level of pile-up and their ability to cope with the demands of raising an autistic child. In relation to hypothesis one, the results from this research found no relationship between pile-up and coping. The possible reasons for this finding will be discussed shortly. Although this finding was surprising, a relationship between coping and family type was found to exist, as was predicted by hypothesis two. Finally, along with the relationship between coping and family type, a relationship between pile-up subscales and family type also emerged, as was predicted in hypothesis three. Along with discussing these results, I will also include some anecdotal data I compiled while working in the 'autistic community' and talking to parents, educators, and support workers.

#### Hypothesis 1

In Chapter 3, we rejoined the Double ABCX Model at the point when the family had already received the diagnosis of autism for their child. It was at this stage that we presumed the family would have or would be going through the crisis stage. One mother I spoke to during this research said that her family was having a difficult time dealing with the diagnosis dealt to them eleven months earlier. She mentioned her first reaction to the diagnosis was horror and that she did not want to deal with it [the autism]. She felt, at the time of our conversation, that the family was still in the crisis stage and grieving.

From the crisis stage in the Double ABCX Model we moved on to the pile-up of demands these families would now be facing. Pile-up is determined by the demands or changes placed upon a single family member or the family system from experienced stressors and strains in response to a crisis. The logic followed that families with high pile-up would have a difficult time coping with the stresses and strains of raising this autistic child. Once again, coping has been defined as the interaction of resources, perceptions, and behavioral responses in an effort to adapt and achieve a new level of balance in the family system (Patterson & McCubbin, 1983). FILE measured the family's level of pile-up by asking questions about their marital and family relationships, financial situations, as well as, other stressors that could have potentially struck the family within the past 12 months. The results from this study showed that when the full measurement instruments were used, the family's level of pile-up was not correlated with their level of coping. This means that, as the family's level of pile-up increases, their level of coping may not necessarily decrease.

Recall, when the subscales of these measurement instruments were examined, three significant relationships between these subscales emerged. The first relationship was between the family's marital strains and their family integration, cooperation and optimistic definition of the situation. It was found that as marital strains increase, 'family integration, cooperation, and a positive outlook' decreases. The second relationship to emerge was between the family's pregnancy and childbearing strains and their sense of social support, self-esteem, and psychological stability. In this relationship, as the family's strains due to pregnancy and childbearing increased their sense of social support, self-esteem and psychological stability decreased. Finally, the last significant relationship was between work and family transitions and strains and the family's maintenance of social support, self-esteem, and psychological stability. It was concluded that as the family's pile-up of demands pertaining to transitions in both the work

place and the family increased (i.e. decreased satisfaction with work or the child changed schools) their sense of social support, self-esteem and psychological well being also increased.

There are several reasons why ambiguity has emerged between the two variables pile-up and coping. When we look at the subscales of these two variables, intuitively, it makes sense that as marital strains increase the family's feelings of integration and cooperation will decrease which could lead to a negative outlook on the situation. Furthermore, as the stresses and strains increase in a family due to an unplanned or difficult pregnancy or childbearing concerns, these stresses may have a negative impact on a family member's self-esteem and/or psychological stability. Also, as the family experiences increasing demands at work and at home, it is possible that this could lead to an increased sense of social support as they look to relatives, churches, or support organizations for help. In dealing with the increased stresses and strains in a positive and productive manner, this could lead to a positive sense of self-esteem and increased psychological well-being. However, why do the overall instruments not show a relationship between pile-up and coping? This is where the ambiguity emerges.

It has been an amazing experience talking to these families; the strength so many of them have is admirable. One reason why pile-up may not have the influence on family coping that was first hypothesized is because of the positive outlook many of these parents have regarding their children. One mom was describing her child to me and said "although she rocks and is very low functioning [she was beginning to learn how to play with some toys at 4 years of age], she does not tantrum, she is a good eater, and she sleeps throughout the night."

It must be mentioned that not all families had a positive or optimistic outlook for themselves or their child. However, many of the families that completed the questionnaire for this research had their autistic child enrolled in some form of behavior modification therapy, such as Lovaas' Applied Behavioral Analysis (ABA). These parents were much more upbeat,

busy, and had a positive attitude. The benefits of this type of intervention was best described by one mom who said "you have this word AUTISM and your world revolves around this word. Then you do something like the ABA program and soon the word autism falls to the background and becomes much less important. Every now and then you see your child do something strange and think, 'yeah, he's just being autistic' but for the most part you just have a child."

Coping is influenced by the family's perceptions of the situation, as well as, their existing and new resources. The family's perception of their autistic child is crucial in their ability to cope with the situation. For instance, one mother I spoke with told me that her husband had a very difficult time with the diagnosis of their son's autism. He dealt with the situation by spending a lot of time outside mowing the lawn. Eventually, it got to the point where the autistic child was mimicking his father and mowing the carpet inside. Another family had a very different reaction to their child's diagnosis. This family lost their first child shortly after birth and "were never able to take him home." So when they were told that their next son was autistic, they figured it could be a lot worse, at least this time they got to bring him home.

The other important factor influencing the family's pile-up and subsequently their coping are the resources available to them. Many mothers described the first few days after the diagnosis as a time when they developed new or strengthened existing resources through reading and learning about autism. They said that this was not necessarily out of choice per se but out of necessity, they now had to become advocates for their child. Many families not only have to deal with their own feelings surrounding the diagnosis but their extended family's reactions also. Many parents are feeling alienated and abandoned by their families. For instance, one woman told of her mother refusing to baby-sit her son because he cries and hits. Another woman said her sister runs a daycare but she would not take care of her autistic son. This alienation increases stresses and pile-up on a family because they are not receiving the familial support they need at

such an important time. In response to this lack of family support some families have turned to religion for help.

Although the financial factor did not emerge as being significant with any of the other variables in this research, it did come up in many of my conversations with the parents. For instance, 72% of the participants stated that they were experiencing “increased strain of family ‘money’ for food, clothing, energy, and home care.” This was the second most common cause of family stress and strain, after 77% claimed “increase in the number of tasks or chores which don’t get done” was the leading cause of intrafamily strains. Many parents brought up the point that raising children is an expensive proposition; however, when your child requires extra therapy the costs skyrocket. Many families feel obligated to provide whatever therapy possible to help their child “overcome” autism. Such therapies can cost a family \$35,000 per year and run, on average, 3 to 5 years. In many cases the mothers have left the work force to stay home, raise their child and run the therapy program. This leads to the family losing their vehicles, their homes, and incurring enormous debt loads. No matter what the statistics above show or do not show, according to the families I spoke with, financial strains do play a role in their lives when it comes to dealing with pile-up and engaging in different coping strategies.

### Hypothesis 2

This leads us to the second hypothesis which stated that families with less coping mechanisms would have a more difficult time adapting to their autistic child. Recall, coping is based on the family’s perceptions of their situation, as well as, their existing and new resources. This variable was measured using the 45 items in the Coping Health Inventory for Parents (CHIP) and scores from this study ranged from a low of 36 to a high of 118, the highest possible score a family could attain is 135. A higher score is advantageous in that it indicates (1) families are using numerous coping strategies and (2) they are finding these strategies extremely helpful,

recall, that perceived helpfulness is indicative of family coping (McCubbin, 1988). Once again, adaptation and cohesion are variables found under the umbrella of Family Type and were measured using the Family Adaptability and Cohesion Evaluation Scales (FACES II). This variable was measured on a scale from 1 (Extreme Family Type) to 8 (Balanced Family Type). The results from this study found that there was indeed a relationship between coping and family type. This means that as the number of coping mechanisms implemented by a family increases, their level of adaptation and cohesion (family type) also increases. Conversely, as a family's coping mechanisms decrease, their level of adaptation and cohesion (family type) also decreases.

According to the Double ABCX Model, as discussed in Chapter 2, it was at this point in the model that families, theoretically, should be focusing on reducing or eliminating the disruptiveness experienced from the crisis. They should also be attempting to restore equilibrium to the family unit.

The results from this research show that coping alone has a significant impact on a family's cohesion and adaptation. In fact, we can accurately predict the family type using only the coping variable, see Table 2 on page 60. When we examined the subscales, Maintaining Family Integration, Cooperation and an Optimistic Definition of the Situation (CHIP SS 1) had a huge impact on the family's sense of adaptation and cohesion, which would then lead to a strong relationship with Family Type. Maintaining Social Support, Self-Esteem, and Psychological Stability (CHIP SS 2) was also correlated with the family's adaptability and their overall Family Type. It was at this stage that the control variables were entered into the equation and Number of Children emerged as being significant. It is not clear why, out of all of the possible control variables, this one surfaced as being the only significant one. However, these two variables (coping and Number of Children) are significantly related and predict family type (see Table 2).

One possible explanation for coping's impact on family type is that at this stage the family has received the diagnosis of autism, gone through the initial stresses and are now beginning to see some changes in their family unit and some benefits with this diagnosis. For example, one family thought that they would never know what was wrong with their child. When the diagnosis came down, they were "devastated and shocked to know." However, at the time that we spoke, the family was beginning to see some of the benefits of the diagnosis. They were now getting funding and support from the school system in the form of a Special Education Assistant (SEA) that they would have never received without the label of autism attached to this child.

As families identify the stressors and strains (pile-up), they can begin to work through them. For instance, some families found little support from their own relatives or in laws and as a result, they looked to the church, organizations and support groups and found support and guidance there. At this time, in British Columbia, there is very little support from the provincial government. This means that some families are moving to different provinces, such as Alberta, where support for autistic children and their families is substantial. Some families have chosen to immerse their child in behavior modification programs and claim that they are now seeing benefits from the hard work. For instance, one mother was thrilled when her 4-year-old daughter was "learning to play with some toys after a few months of therapy." Another mother, with two autistic boys, had both boys involved in Lovaas and she claimed that the youngest one was almost 'cured'.

Finally, some families got help from their doctors and this decreased the stresses of daily life. Although most people with autism have some level of mental handicap, one autistic boy was severely mentally challenged and also had seizures. His mother told me of his aggressive behavior and his tendency to lash out at things and himself in his fits of anger. She went to the

doctor who put this child on anti-seizure medication, which greatly reduced his anger and tantrums. Before this time, the mother described how she would “have to sit on the floor with [the child], cross her legs over his and hold him close to her until he stopped screaming and kicking, this could take 30 minutes.”

These are examples of just some of the different coping mechanisms implemented by families with autistic children. Yet, all are empowering for the parents and lead to or emphasize the importance of being able to change or adapt for the overall benefit of the family. Furthermore, as the individuals witness the changes within themselves and other family members, this can be perceived as a success or at least they can feel that they have regained some control over the situation. This leads to a greater sense of “we-ness” or cohesion within the family unit. Recall, Bristol and Schopler (1983) said that successful families who have autistic children describe themselves as “close-knit,” “able to roll with the punches,” and able to adjust as the child’s needs change. Remember the father who spent a lot of time outside mowing the lawn because he was having a difficult time with his son’s diagnosis? He is now helping his son with his Grade one homework and the mother exclaimed, “they have come through this and are more cohesive now.”

### Hypothesis 3

In hypothesis 3, the researcher stated that the family’s functioning (adaptability and cohesion) would be predicted by their level of pile-up and their ability to cope with the demands of raising an autistic child. In essence, this hypothesis is saying that pile-up effects coping and coping in turn effects family functioning. As was previously mentioned in the discussion regarding hypothesis one, when both overall measurement instruments were used, the results showed no relationship between pile-up and coping. However, when the subscales were examined, certain pile-up subscales did affect certain coping subscales. Marital Strains (FILE SS



2) had a negative impact on the family's Integration, Cooperation, and their Optimistic Definition of the Situation (CHIP SS 1). The most significant marital strain these families expressed was an increased difficulty with sexual relations between the husband and wife, 46% of families said they were experiencing trouble in this area of their marriage. There were a wide range of questions regarding the family's integration, cooperation, and positive outlook, some of these included: "talking over personal feelings and concerns with spouse," "doing things together as a family," "trying to maintain family stability," "getting other members of the family to help with chores and tasks at home," and "building a closer relationship with my spouse." One is able to see how marital strains could have a negative impact on how families interpret these coping strategies. For instance, if the spouses are arguing more amongst themselves (49% stated an increase in conflict between the husband and wife), then talking over personal feelings or concerns with that spouse may not seem to be a viable option for some.

Pregnancy and Childbearing Strains (FILE SS 3) and Work-Family Transitions and Strains (FILE SS 5) also affected the family's Maintenance of Social Support, Self-Esteem, and Psychological Stability (CHIP SS 2). When a "spouse experiences an unwanted or difficult pregnancy" (the most commonly answered question in FILE SS 3) the results from this study show that it can negatively affect their social support, self-esteem and psychological well-being. For instance, the mother may not be able to work or have outside employment, she may not feel like building close relationships with people, and/or she may not be able to become more self reliant and independent at that time. These statements are just a few examples of CHIP's subscale measuring Social Support, Self-Esteem, and Psychological Stability.

As the pile-up within the family increases, it may breakdown more and more of the possible coping mechanisms available to family members. The lack of coping strategies

influences the family's overall functioning. This relationship was just examined in the discussion regarding hypothesis two.

A relationship that has yet to be examined is that of pile-up's influence on family type. When the entire pile-up measurement instrument (FILE) was used, no relationship between it and adaptability, cohesion or family type emerged. However, as with pile-up and coping, when the subscales were examined several FILE subscales emerged as being significant with family type.

Intrafamily Strains (FILE SS 1) negatively affected the family's adaptability, cohesion, and ultimately their family type. There were seven intrafamily strains that impacted family type the most. These were: an increase in the number of tasks or chores which did not get done (77% of families stated this was the case in their family), an increase in the number of problems or issues which did not get resolved (59%), increased difficulty in managing preschool age children (59%), a member appeared to have emotional problems (56%), increased conflict between the husband and wife (49%), increased arguments between parents and children (49%), and an increase in the amount of "outside activities" which the children were involved in (49%).

Marital Strains (FILE SS 2) also affected the family's cohesion and overall family type in a negative manner. The one marital strain that affected families the most was an increased difficulty with sexual relations between the husband and wife (46% of participants reported this strain). Pregnancy and Childbearing Strains (FILE SS 3) also had a negative impact on the family's level of cohesion. The most common pregnancy and childbearing strain was an unwanted or difficult pregnancy (5%).

Finally, Losses (FILE SS 7) experienced by the family positively influenced their adaptability and family type. Thirty-three percent of families experienced some form of loss within the past year. Fifteen percent 'broke up' a relationship with a close friend, others

experienced the death of a husband or wife's parent or close friend (13%), and a close friend of the family died in the remaining 5% of families who experienced a loss. One possible explanation for the positive relationship between losses and adaptability and family type may be due to experience. This means that when a family loses a close friend or relative for the first time, this experience is probably very traumatic. However, after a number of losses, the family may build up coping strategies to help deal with the stress of losing someone close. These coping strategies may help a family change its structure, roles, and rules (in other words adapt) in response to the loss and therefore help them achieve balance and equilibrium within the family unit.

### Summary

From this research, even though the sample is cross-sectional we can still see a process going on within these families. Although the hypothesized relationships between key variables did not always emerge (when the overall measurement instruments were used) at a smaller level (using the subscales) certain relationships between the variables were found to be occurring within these families. For instance, not all types of pile-up effected the family's coping strategies in a positive or negative manner. Certain types of pile-up such as marital strains had more of an effect on the family's sense of integration and cooperation than say financial or business strains did. As well, pregnancy and childbearing strains, along with, work and family strains were found to affect the family's sense of social support, self-esteem, and psychological well-being more than the strains of legal violations within a family.

As these specific strains piled up, they affected certain coping mechanisms implemented by the family. The gain or loss of such coping mechanisms affected the family's level of cohesion and adaptability, which ultimately affected their family type. The mechanisms the

family used to maintain a sense of integration and cooperation, as well as, their outlook on the situation had the most impact on how the family as a whole would be dealing with the autistic child. This means that leaving room for open communication between the spouses, telling oneself that they have many things to be thankful for, or doing things with the children had the most impact on the family's sense of adaptability and cohesion.

Finally, along with the gain or loss of coping mechanisms, four sources of stresses and strains emerged as also affecting the family's level of adaptability and cohesion. These were intrafamily strains, marital strains, pregnancy and childbearing strains, and losses.

## CHAPTER 7

### CONCLUSION

There are so many variables and issues that have emerged from this study that it is difficult to come up with a concise summation of findings. Ambiguity emerges when one compares the results from the overall measurement instruments versus the results when the subscales of these instruments are interpreted. Hypothesis 1 stated that high pile-up of demands would be negatively related to coping in families raising an autistic child. This hypothesis must be rejected, because no significant relationship was found to exist between pile-up and coping. When the subscales of these two variables were examined, however, the results showed that certain types of pile-up (marital, pregnancy and childbearing, work and family transition strains) had positive or negative affects on certain types of coping (integration, cooperation, social support, and self-esteem). The positive and negative influence pile-up had on these coping mechanisms argues for the rejection of hypothesis 1, because a negative effect of pile-up on coping could not be established.

Hypothesis 2 stated that families with less coping mechanisms would have a more difficult time adapting to their autistic child. Coping was found to be positively related to the family's overall functioning and therefore this hypothesis can be accepted.

Finally, hypothesis 3 stated that the family's functioning (adaptability and cohesion) would be predicted by their level of pile-up and their ability to cope with the demands of raising an autistic child. This hypothesis must be rejected due to the lack of significance found between the pile-up and family type variables. Once again, the overall pile-up measurement instrument was insignificantly related to the family's adaptation, cohesion, or overall functioning. However, the subscales of pile-up did show that certain types of pile-up (intrafamily strains, marital strains,

pregnancy and childbearing strains, and losses) did in fact contribute to the family's level of adaptation, cohesion, and overall level of functioning. The family's coping styles, on the other hand, had the most significant impact on the outcome of their functioning as a family.

According to the results, the families in this study appeared to be relatively "normal" in the face of the adversity of raising a child with autism. On average, these families were moderately stressed, however they were dealing with these stresses by employing adequate levels of coping strategies. These levels of coping enabled the families to be flexible while still maintaining a reasonable level of connectedness, thus resulting in a family that was moderately balanced. One could say that this is an appropriate place on the family functioning spectrum for these families to be, during this stage in their family life cycle.

#### The importance of coping on family functioning

The main point that has been derived from this research is that the family's coping strategies are the most important factor in determining the positive or negative functioning (adaptation and cohesion) a family will be going through during this time of raising their autistic child or children. Although certain types of pile-up and the number of children in the household are influential factors in this process, certain coping mechanisms, such as the family's positive attitude, seem to outweigh the stresses and strains placed on these families. One mother said to me, "this is the life we have been dealt, you just deal with the obstacles that come your way because truly what is the alternative?"

Subjectively, it is easy to imagine why coping is so influential on a family's level of adaptability and cohesion. These families are dealing with numerous stresses and strains, both normative stresses, as well as strains pertinent to raising an autistic child. As mentioned above, most of these families seem to "roll with the punches" out of necessity rather than out of choice.

It is how they choose to deal with these stresses that matters. The more coping mechanisms these families have in their repertoire, the better prepared they will be when it comes to dealing with different stresses and strains. For instance, although intrafamily, marital and pregnancy strains, as well as, losses seem to be the leading causes of pile-up in these families, it is their ability to pull strength from a number of different resources that enables them to cope effectively with these stresses. If a family can seek support and receive guidance from “talking with family members” (i.e. the spouse), “believing in God,” “talking with other parents in the same type of situation,” or “doing things with family relatives” they will be much better off than a family that has only one source of support.

Another type of coping strategy that seems to be very important to these family members is the opportunity to develop themselves individually by finding that “alone” time to reflect and think positively. Sixty-four percent of PMKs mentioned that getting away by themselves was extremely to moderately helpful in their coping with the stresses of raising a child with autism. Eighty-five percent of respondents found that “developing themselves as a person” was extremely or moderately helpful. Becoming more self reliant and independent was also important to 72% of the respondents, believing that things will always work out (69%), and keeping in shape and well groomed was important to 56% of the PMKs. Finally, the most significant coping strategy a member could employ, consisted of a positive outlook on the situation. An overwhelming 87% of family members found it to be extremely or moderately helpful in their daily coping to “tell themselves that they have many things they should be thankful for.”

Objectively, one reason why the relationship between coping and family functioning is so strong may be because these variables are examining similar things. Coping is the central process these families are using to adapt and achieve a new level of balance in their system, responding to the fact that they are raising a child who has autism. Adaptation (one major component in

family functioning) is seen as the family's ability to change its power structure, roles, and rules in response to the stresses and strains of raising an autistic child. Therefore, if a family is trying to cope with this stressful situation, this means that they are willing to change in an attempt to improve their situation. In a few instances CHIP and FACES II ask similar questions to get at either the family's coping strategies or their adaptation and cohesion levels. For example, CHIP asks about "getting other members of the family to help with chores and tasks at home" and at the same time FACES II states, "we shift household responsibilities from person to person," as well as, "in our family, everyone shares responsibilities" (both of these statements attempt to measure the family's adaptation). CHIP also looks into FACES' notion of cohesion by asking if you "trust that your spouse will help support you and your children," FACES II asks if "family members are supportive of each other during difficult times."

In summary, there are a few explanations as to why coping has emerged as being extremely influential on a family's functioning. One reason is indicative of the importance of having options when it comes to seeking support or help, as well as their need to have "alone" time and time to focus on themselves physically, emotionally, and in some cases spiritually. The other reason why coping may be tightly linked to family functioning is the nature of questions these two measurement instruments use. In several cases, similar questions or statements are used to ascertain either the family's level of coping or their level of adaptability or cohesion.

From the point-of-view of a researcher who not only analyzed the results from the questionnaire but also spoke with these parents in depth and heard their concerns for their child and the well-being of their family, there are many issues that this research could not even begin to investigate. Certain issues or topics repeatedly surfaced with many of the parents I spoke to. It would be an injustice to these families if I did not touch on some of their concerns at this point in the paper.



### The process of receiving a diagnosis

It was speculated that there was often a time-lag between when a family suspected something was wrong with their child and when a diagnosis was actually confirmed. Many parents spoke of a 2-year waiting list before being seen by a doctor. In this study I found that most parents suspected a problem when their child was 20 months old and this child was diagnosed when he or she was 3 years, 4 months old. This means that on average, for this sample, parents were waiting 1 year, 8 months before they had confirmation of their fears. This is a long period of time to wait and live with a child that is tantruming, unaffectionate, not eating or sleeping well, and inconsolable. This waiting period is difficult on the parents, their marriage and on the entire family. Finally receiving a diagnosis which confirms the family's fears is often a double-edged sword.

### The double-edged sword

When a diagnosis of autism becomes a reality for families, their first reaction is often one of trauma. One family I spoke with was told that their daughter was not autistic but that they would probably never know what was wrong with her. When this little girl was eventually diagnosed with autism, it was very devastating to the family because they thought they would never know. "It was a shock," the mother told me, "my first reaction was horror and I did not want to deal with it." There is often a lot of guilt, anxiety, and grief these families experience. This is not helped by the fact that many families with autistic children are not "getting the support that most families get from their loved ones" as one mother put it. Another mother mentioned, "how interesting it was how different members of the family have dealt with the diagnosis. For instance, her parents would not deal with it, they would not talk about it, when she gave them literature to read about autism they would not read it. They figured [the autistic child]

was fine because nothing ever happened in their perfect little world.” She went on to mention how alone she felt. She said that even the feelings and reactions between her and her husband were different. Another mother I spoke with described the lack of support from her family like this: “they are too scared to deal with the diagnosis. Other members do not know how to deal with [the autistic child] so they are staying away. It is much like when someone dies and no one knows what to say or how to act, same thing here.”

On the positive side of this sword is the help that families receive from a diagnosis of autism. As many families discover, a diagnosis of pervasive developmental disorder (PDD) or Asperger’s syndrome does not get them help in any system we have set up today. One mother wrote to me and explained, “once we received our diagnosis of PDD, which we paid for privately as we were not willing to wait a year for the official system to kick in, we were on our own. ...We pursued a second diagnosis through ‘the system’ as we quickly discovered that a PDD diagnosis will get you nothing in any system. An autism diagnosis will get you service in the school system.” In a few provinces in Canada, a diagnosis of autism means that respite care will be provided for the family and behavior modification therapies will be subsidized by the government. Finally, receiving a diagnosis means that the families are now able to move on and deal with the issues of raising their child as they see fit. They are no longer living with the fear of the unknown.

#### The current Provincial Government

This is what one mother had to say in a letter to Lois Boone, the Minister for Children and Families,

...Your Ministry states goals like early intervention, prevention and protection. You have shared the research that teaches us all how crucial early intervention is and then you keep children and families on a waitlist for the services they need past the point of effectiveness. You say your

focus is protection, but you provide minimal to no support, watch some families fall apart, and then swoop in with expensive crisis management. In countless cases, the cost of what families were asking for prior to crisis (example: behavioural consultation and/or respite) was less than the cost of your crisis management (example: foster care). That doesn't consider the irreparable emotional scars on families...

It is my impression that these families are not asking for donations or handouts, they are however, asking to be treated with some dignity and respect. Years of waiting lists and band-aid approaches are not the answers these families need in response to the stresses of raising their child with autism.

When a family requests aid from the government they must be prepared to reveal very personal and confidential information. This includes financial information, medical reports, and information regarding the functioning of the family (i.e. whether or not the family is on the verge of collapse). For many families, this intrusion into very personal information is degrading and potentially harmful to the livelihoods of those living in very small communities throughout the province. This past summer a parent in Northern B.C. wrote a letter of protest to the Ministry of Children and Families because she was extremely concerned about the income testing of Supported Child Care subsidy. This income testing would open her family, in a small town, to a further lack of privacy. This is some of what she had to say:

...My husband is self-employed and our income fluctuates greatly month-to-month, year-to-year. This would mean revealing a great deal of financial information regularly to your officers. Revealing that sort of information, as well as our daughters' reports can be very damaging in a community of this size.... Let me tell you about life in an isolated town like this. Most people have been clients of our business. We are landlords to people at government offices and service organizations. And our children play with our physician's children, our chiropractor's children and our life insurance rep's children. There is no such thing as privacy in a town of this type no matter how conscientious the people are. We truly live in a glass bubble...

Another frustration families are faced with is that of respite care, or lack thereof. One mother I spoke with told me that her daughter's one hour per day respite care was taken away

because “according to the government, if a child can go to the washroom alone, wash their hands, and feed themselves they do not need care.” This little girl can do those things so the family’s respite care was taken away. The mother went on to say that, “what the government fails to take into account is the fact that [this little girl] must be supervised at all times. If she is not watched closely she gets into potentially harmful situations... [like sitting in the middle of the stove with all of the elements turned on].” This family’s livelihood is farming and as the mother told me, “when it is harvest season I can have a bath either before my husband leaves for the fields or after he gets home. That means either before 5:00 am or after 12:00 am.”

In the summer of 1999, the provincial government was threatening to take away the \$107 per month families with special needs children receive in order to help finance their children’s respite care. Along with having to deal with the daily stresses of life these families now found themselves attending rallies on the parliament grounds in Victoria in protest. The lack of support families receive from the current provincial government has forced many to move to Alberta where respite care and behaviour modification therapies are subsidized. One family moved from Vancouver to Calgary and now receives \$200 per month for respite care and the mother made a point of mentioning that this money and care has helped her and her family tremendously.

The point of these anecdotes is to remind us that although the statistics from this study show that this sample population is managing, on average, quite well, there are a huge number of families struggling in this province.

#### Behaviour Modification Therapies

I cannot finish without mentioning behaviour modification therapies, and the impact that they have had on many of the families I spoke with while conducting this research. This is not to endorse one therapy or another, it is however, a subjective observation that families who are participating in these therapies seem to be more upbeat, have a positive outlook on their future

and the future of their child, and have regained a sense of control in their lives. I have previously mentioned the downfalls of such therapy, the intrusion, lack of privacy, expense, and time constraints just to name a few. However, all of these aside, I feel that this represents a positive option that enables parents to feel more in control of the situation. Although there is no “cure” for autism, many parents want to help their child develop to his or her full potential, and this type of therapy complements that goal; thus, making parents feel that they are doing the most for their child.

One must be cautious, however, not to put too much weight on one therapy or program as the sole reason why a family is functioning better than another, because there are many other factors that could also be contributing to the family’s positive outlook. For instance, one mother stated that they had started an ABA program 2 ½ years ago and she mentioned how “fortunate they were because her husband had a good education and was able to provide the finances for ABA without devastating the family.” Is it the therapy then that is helping the child and subsequently the family, or the fact that they are educated and have a comfortable income?

### Limitations of the Study

With any research conducted, there will always be some limitations. The first limitation in this study is the self-selected sample. Participants made the choice whether or not to participate in this study. Although many families who did decide to take part were having difficulties in their home life, it is certain there were many families who were overwhelmed by the stresses and strains of raising an autistic child and did not participate. Furthermore, those families who had their child enrolled in some form of therapy seemed to have a much more positive outlook on their child’s future and their family seemed to be coping better with the daily stresses. Therefore, combining these two groups of participants (those participating in behavior

modification therapy and those who were not) may have skewed some of the results to show the families are doing better than many actually are.

Another limitation to this study is its small sample size. Unfortunately, those parents who were being targeted for this study are the ones least likely to participate because of already high demands on their time, huge stress levels, and generally a lack of interest in something that does not show any immediate benefits for improving the quality of their lives.

The notion of possible “content overlap” has been previously discussed. “Content overlap” refers to the semantic similarities between some of the CHIP SS 1 (Integration, Cooperation, Optimism) and FACES II items. There is another argument, however, from McCubbin (1988) who views these instruments as independent variables. In this study, there is support that these measurement instruments are independent. Due to the small sample size, factor analysis could not assist in resolving this issue. Therefore, the researcher used multiple regression analysis. First, all of the significantly related items from CHIP SS 1 and FACES II ( $p < .05$ ) were removed. The items that were highly correlated were thought to be the most semantically overlapped. An alpha was run with the remaining CHIP SS 1 items and a strong alpha remained ( $\alpha = .785$ ). The correlation between CHIP SS 1 and FACES II remained after the highly correlated items were removed ( $r = .287$ ,  $p = .077$ ,  $N = 39$ ), however, this relationship was no longer significant. These results are ambiguous because one could argue that they are due to measurement overlap, on the other hand, they could also be due to the small sample size of this study.

A final limitation in this study is the possibility of increased Type I error when the subscales of the three measurement instruments were used. However, as discussed earlier in the results chapter, although the findings between the subscales could have been by chance alone, one cannot exclude the possibility that they were not chance findings.

### Contributions to the Field

This study has furthered the knowledge in two independent fields. The first is the autistic realm and the second is the Double ABCX Model. The goal of this study was to find out how families with autistic children were coping with the stresses of raising their child with special needs. There is a plethora of research being conducted that looks at the causes of autism (genetic factors seem to be the focus of research today), as well as, other issues pertaining to the person with autism. The families surrounding and supporting these people seem to be outside of the sphere of recent research. This study focused more on the families than on the person with autism and found that they were dealing with a normative amount of pile-up of stresses and strains and, on average, they are coping well with these stresses and strains. It is important to keep in mind however, the sample population: these are largely intact families, the majority are well educated with comfortable incomes, and many have their child in some form of therapy.

The second contribution this study has made is to the Double ABCX Model. The causal model used in this study was adapted from the Double ABCX Model, a process model, this change was made in order to reflect the change in time these parents were experiencing. Unfortunately, the results from this study do not support this model, as two out of the three hypotheses were rejected. According to this sample population, pile-up does not affect the family's level of coping, nor does it influence their overall family functioning. The lapse of time between the crisis stage experienced by this sample population and their participation in this study may have allowed the families to develop adequate coping mechanisms for the pile-up they were experiencing. Perhaps if the time between the diagnosis of autism and the study was shorter, the pile-up these families would be experiencing may have a larger influence on their coping mechanisms.

Previous research on families who have members with chronic illnesses or disabilities such as cystic fibrosis, myelomeningocele, and Prader-Willi Syndrome have used the Double ABCX Model as a framework for these studies. However, as a result of this research, families with autistic children between the ages of two and seven cannot be added to the list of contributors supporting the concepts of the Double ABCX Model.

### Future Research

As mentioned above, those families who are currently participating in a therapy program seem to be dealing better with their child's autism. An interesting study would be to examine the effects of such therapies on family functioning. One could examine the differences in a family's pile-up and coping relative to who is doing some kind of therapy, versus those families who are not. Certain variables must be controlled for or examined very carefully for their confounding effects. For instance, therapies such as Lovaas' Applied Behavior Analysis are very costly both monetarily and time-wise. The reason the family is functioning better may not be a result of the therapy per-se, but rather the fact that the family is financially sound or because the child has constant interaction 6 to 8 hours per day, thus providing both respite care for the parent and social stimuli for the child.

A similar study to the one at hand could be conducted again, however, this time single parent families could be the focus. I would predict that these families would have higher levels of pile-up and certainly different coping strategies as compared to those found in this study. The overall family functioning would be interesting to discover in a single parent sample.

Another study could involve families with autistic children at different ages. For instance, one could examine the pile-up and coping issues surrounding families with teenage members who are autistic. At the same time, one could study the characteristics of this age group, such as



issues of independence, dating, and hormonal changes and how they impact the family's pile-up, coping, and overall family functioning. One could also explore how these teenagers with autism deal with these changes as compared to the 'norm.' I would predict that these teenagers and their families would be dealing with very different issues as compared to the 'norm' due to the fact that a high proportion of autistic children are mentally challenged.

One last idea for a future research project could be the further exploration of some of the correlated variables discussed in the post hoc section of this paper. For instance, why does a family's level of pile-up decrease as the spouse's education increases? Could it be that increased education leads to a form of coping used by the family that decreases their perceived pile-up? Should education then be part of the coping spectrum? There are a host of unanswered questions waiting to be explored.

Although there are still many questions surrounding the nature of autism itself, (i.e. the etiology, possible cures, genetic links) researchers are continually exploring new theories and methods that will hopefully, one day, help to either prevent autism or cure it. Until that research bears its inevitable fruit, it falls on our field of study to understand the effects of this debilitating disease on the family unit, and to help families cope with the stresses of raising their autistic children.

# APPENDIX A

## FREQUENCY CHART FOR THE NINE SUBSCALES OF FILE

		Intrafamily Strains	Marital Strains	Pregnancy & Childbearing Strains	Finance & Business Strains	Work – Family Transitions & Strains
N	Valid	39	39	39	39	39
	Missing	0	0	0	0	0
Mean		264.3077	33.7692	2.3077	99.7692	90.2564
Std. Error of Mean		24.1366	7.4592	1.6102	10.2549	11.5999
Median		238.0000	.0000	.0000	103.0000	85.0000
Mode		159.00	.00	.00	103.00	.00
Std. Deviation		150.7333	46.5830	10.0555	64.0417	72.4412
Variance		22720.5344	2169.9717	101.1134	4101.3401	5247.7220
Skewness		.415	2.732	4.233	.283	.418
Std. Error of Skewness		.378	.378	.378	.378	.378
Kurtosis		-.447	11.829	16.779	-.604	-1.012
Std. Error of Kurtosis		.741	.741	.741	.741	.741
Range		607.00	252.00	45.00	254.00	225.00

		Illness & Family "Care" Strains	Losses	Transitions "In and Out"	Family Legal Violations
N	Valid	39	39	39	39
	Missing	0	0	0	0
Mean		53.5128	13.9487	11.7949	.0000
Std. Error of Mean		8.4839	3.5862	3.1420	.0000
Median		40.0000	.0000	.0000	.0000
Mode		.00	.00	.00	.00
Std. Deviation		52.9821	22.3959	19.6217	.0000
Variance		2807.0985	501.5762	385.0094	.0000
Skewness		.915	1.316	1.237	
Std. Error of Skewness		.378	.378	.378	.378
Kurtosis		-.042	.730	.002	
Std. Error of Kurtosis		.741	.741	.741	.741
Range		192.00	83.00	66.00	.00

## APPENDIX B

### FREQUENCY CHART FOR THE THREE SUBSCALES OF CHIP

		Maintaining Family Integration, Cooperation & an Optimistic Definition of the Situation	Maintaining Social Support, Self Esteem & Psychological Stability	Understanding the Health Care Situation Through Communication with Other Parents & Consultation with the Health Care Team
N	Valid	39	39	39
	Missing	0	0	0
Mean		34.3333	28.4359	14.8718
Std. Error of Mean		1.6796	1.2982	.7915
Median		36.0000	29.0000	16.0000
Mode		29.00 <sup>a</sup>	22.00 <sup>a</sup>	17.00
Std. Deviation		10.4889	8.1072	4.9427
Variance		110.0175	65.7260	24.4305
Skewness		-.186	-.052	-.481
Std. Error of Skewness		.378	.378	.378
Kurtosis		-.638	-.928	-.003
Std. Error of Kurtosis		.741	.741	.741
Range		42.00	31.00	20.00

<sup>a</sup>. Multiple modes exist. The smallest value is shown

## APPENDIX C

### FREQUENCY CHART FOR ADAPTATION, COHESION AND FAMILY TYPE

		Adaptability	Cohesion	Family Type
N	Valid	39	39	39
	Missing	0	0	0
Mean		46.7692	61.2821	4.8462
Std. Error of Mean		1.2552	1.8250	.2656
Median		47.0000	65.0000	5.0000
Mode		47.00	67.00	5.00 <sup>a</sup>
Std. Deviation		7.8387	11.3970	1.6589
Variance		61.4453	129.8920	2.7520
Skewness		-.218	-.969	-.312
Std. Error of Skewness		.378	.378	.378
Kurtosis		-.525	.118	-.633
Std. Error of Kurtosis		.741	.741	.741
Range		32.00	42.00	6.00

<sup>a</sup>. Multiple modes exist. The smallest value is shown

**Directions:**

\* Please read each family life change and decide whether it happened to any member of your family  
 - **including you** - during the past 12 months.

\* Check **Yes** or **No**.

**Did the change happen in your family:**

*During the past  
12 months*

<b>I. Intrafamily Strains</b>		<b>Yes</b>	<b>No</b>
1	Increase of husband/father's time away from family.	<input type="checkbox"/>	<input type="checkbox"/>
2	Increase of wife/mother's time away from family.	<input type="checkbox"/>	<input type="checkbox"/>
3	A member appears to have emotional problems.	<input type="checkbox"/>	<input type="checkbox"/>
4	A member appears to depend on alcohol or drugs.	<input type="checkbox"/>	<input type="checkbox"/>
5	Increase in conflict between husband and wife.	<input type="checkbox"/>	<input type="checkbox"/>
6	Increase in arguments between parent(s) and child(ren).	<input type="checkbox"/>	<input type="checkbox"/>
7	Increase in conflict among children in the family.	<input type="checkbox"/>	<input type="checkbox"/>
8	Increased difficulty in managing teenage child(ren).	<input type="checkbox"/>	<input type="checkbox"/>
9	Increased difficulty in managing school age child(ren) (6-12 yrs).	<input type="checkbox"/>	<input type="checkbox"/>
10	Increased difficulty in managing preschool age child(ren) (2.5-6 yrs).	<input type="checkbox"/>	<input type="checkbox"/>
11	Increased difficulty in managing toddler(s) (1-2.5 yrs).	<input type="checkbox"/>	<input type="checkbox"/>
12	Increased difficulty in managing infant(s) (0-1 yrs).	<input type="checkbox"/>	<input type="checkbox"/>
13	Increase in the amount of "outside activities" which the children are involved in.	<input type="checkbox"/>	<input type="checkbox"/>
14	Increased disagreement about a member's friends or activities.	<input type="checkbox"/>	<input type="checkbox"/>
15	Increase in the number of problems or issues which don't get resolved.	<input type="checkbox"/>	<input type="checkbox"/>
16	Increase in the number of tasks or chores which don't get done.	<input type="checkbox"/>	<input type="checkbox"/>
17	Increased conflict with in-laws or relatives.	<input type="checkbox"/>	<input type="checkbox"/>

<b>II. Marital Strains</b>		<b>Yes</b>	<b>No</b>
18	Spouse/parent was separated or divorced.	<input type="checkbox"/>	<input type="checkbox"/>
19	Spouse/parent had an "affair".	<input type="checkbox"/>	<input type="checkbox"/>
20	Increased difficulty in resolving issues with a "former" or separated spouse.	<input type="checkbox"/>	<input type="checkbox"/>
21	Increased difficulty with sexual relationship between husband and wife.	<input type="checkbox"/>	<input type="checkbox"/>

**Did the change happen in your family:****During the past  
12 months**

<b>III. Pregnancy and Childbearing Strains</b>		<b>Yes</b>	<b>No</b>
22	Spouse had unwanted or difficult pregnancy.	<input type="checkbox"/>	<input type="checkbox"/>
23	An unmarried member became pregnant.	<input type="checkbox"/>	<input type="checkbox"/>
24	A member had an abortion.	<input type="checkbox"/>	<input type="checkbox"/>
25	A member gave birth to or adopted a child.	<input type="checkbox"/>	<input type="checkbox"/>

<b>IV. Finance and Business Strains</b>		<b>Yes</b>	<b>No</b>
26	Took out a loan or refinanced a loan to cover increased expenses.	<input type="checkbox"/>	<input type="checkbox"/>
27	Went on welfare.	<input type="checkbox"/>	<input type="checkbox"/>
28	Change in conditions (economic, political, weather) which hurts the family investments.	<input type="checkbox"/>	<input type="checkbox"/>
29	Change in agriculture market, stock market, or land values which hurts family investments and/or income.	<input type="checkbox"/>	<input type="checkbox"/>
30	A member started a new business.	<input type="checkbox"/>	<input type="checkbox"/>
31	Purchased or built a home.	<input type="checkbox"/>	<input type="checkbox"/>
32	A member purchased a car or other major item.	<input type="checkbox"/>	<input type="checkbox"/>
33	Increased financial debts due to over-use of credit cards.	<input type="checkbox"/>	<input type="checkbox"/>
34	Increased strain on family "money" for medical/dental expenses.	<input type="checkbox"/>	<input type="checkbox"/>
35	Increased strain of family "money" for food, clothing, energy, home care.	<input type="checkbox"/>	<input type="checkbox"/>
36	Increased strain on family "money" for child(ren)'s education.	<input type="checkbox"/>	<input type="checkbox"/>
37	Delay in receiving child support or alimony payments.	<input type="checkbox"/>	<input type="checkbox"/>

<b>V. Work-Family Transitions and Strains</b>		<b>Yes</b>	<b>No</b>
38	A member changed to a new job/career.	<input type="checkbox"/>	<input type="checkbox"/>
39	A member lost or quit a job.	<input type="checkbox"/>	<input type="checkbox"/>
40	A member retired from work.	<input type="checkbox"/>	<input type="checkbox"/>
41	A member started or returned to work.	<input type="checkbox"/>	<input type="checkbox"/>
42	A member stopped working for extended period (e.g., laid off, leave of absence, strike).	<input type="checkbox"/>	<input type="checkbox"/>
43	Decrease in satisfaction with job/career.	<input type="checkbox"/>	<input type="checkbox"/>
44	A member had increased difficulty with people at work.	<input type="checkbox"/>	<input type="checkbox"/>
45	A member was promoted at work or given more responsibilities.	<input type="checkbox"/>	<input type="checkbox"/>
46	Family moved to a new home/apartment.	<input type="checkbox"/>	<input type="checkbox"/>
47	A child/adolescent member changed to a new school.	<input type="checkbox"/>	<input type="checkbox"/>

**Did the change happen in your family:****During the past  
12 months**

<b>VI. Illness and Family "Care" Strains</b>		<b>Yes</b>	<b>No</b>
48	Parent/spouse became seriously ill or injured.	<input type="checkbox"/>	<input type="checkbox"/>
49	Child became seriously ill or injured.	<input type="checkbox"/>	<input type="checkbox"/>
50	Close relative or friend of the family became seriously ill.	<input type="checkbox"/>	<input type="checkbox"/>
51	A member became physically disabled or chronically ill.	<input type="checkbox"/>	<input type="checkbox"/>
52	Increased difficulty in managing a chronically ill or disabled member.	<input type="checkbox"/>	<input type="checkbox"/>
53	Member or close relative was committed to an institution or nursing home.	<input type="checkbox"/>	<input type="checkbox"/>
54	Increased responsibility to provide direct care or financial help to husband's and/or wife's parents.	<input type="checkbox"/>	<input type="checkbox"/>
55	Experienced difficulty in arranging for satisfactory child care.	<input type="checkbox"/>	<input type="checkbox"/>

<b>VII. Losses</b>		<b>Yes</b>	<b>No</b>
56	A parent/spouse died.	<input type="checkbox"/>	<input type="checkbox"/>
57	A child member died.	<input type="checkbox"/>	<input type="checkbox"/>
58	Death of husband's or wife's parent or close relative.	<input type="checkbox"/>	<input type="checkbox"/>
59	Close friend of the family died.	<input type="checkbox"/>	<input type="checkbox"/>
60	Married son or daughter was separated or divorced.	<input type="checkbox"/>	<input type="checkbox"/>
61	A member "broke up" a relationship with a close friend.	<input type="checkbox"/>	<input type="checkbox"/>

<b>VIII. Transitions "In and Out"</b>		<b>Yes</b>	<b>No</b>
62	A member was married.	<input type="checkbox"/>	<input type="checkbox"/>
63	Young adult member left home.	<input type="checkbox"/>	<input type="checkbox"/>
64	Young adult member began college (or post high school training).	<input type="checkbox"/>	<input type="checkbox"/>
65	A member moved back home or a new person moved into the household.	<input type="checkbox"/>	<input type="checkbox"/>
66	A parent/spouse started school (or training program) after being away from school for a long time.	<input type="checkbox"/>	<input type="checkbox"/>

<b>IX. Family Legal Violations</b>		<b>Yes</b>	<b>No</b>
67	A member went to jail or juvenile detention.	<input type="checkbox"/>	<input type="checkbox"/>
68	A member was picked up by police or arrested.	<input type="checkbox"/>	<input type="checkbox"/>
69	Physical or sexual abuse or violence in the home.	<input type="checkbox"/>	<input type="checkbox"/>
70	A member ran away from home.	<input type="checkbox"/>	<input type="checkbox"/>
71	A member dropped out of school or was suspended from school.	<input type="checkbox"/>	<input type="checkbox"/>

**Directions:**

\* Please read each coping behavior listed below.

\* For each coping behavior you used, please record how helpful it was to you and/or your family.

\* Circle **one** number:

3 = Extremely helpful    2 = Moderately helpful    1 = Minimally helpful    0 = Not helpful

\* For each coping behavior you **did not** use, please record your "Reason" by checking **one** of the following:

Chose not to    or    Not possible

☐
☐

How helpful are these coping behaviors:		I do not cope this way because:					
		Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	Chose Not To	Not Possible
1	Talking over personal feeling and concerns with spouse.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
2	Engaging in relationships and friendships which help me to feel important and appreciated.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
3	Trusting my spouse (or former spouse) to help support me and my child(ren).	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
4	Sleeping.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
5	Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
6	Believing that my child(ren) will get better.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
7	Working, outside employment.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
8	Showing that I am strong.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
9	Purchasing gifts for myself and/or other family members.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
10	Talking with other individuals/parents in my same situation.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
11	Taking good care of all the medical equipment at home.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
12	Eating.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
13	Getting other members of the family to help with chores and tasks at home.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
14	Getting away by myself.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
15	Talking with the doctor about my concerns about my child(ren) with the medical condition.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
16	Believing that the medical center/hospital has my family's best interest in mind.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
17	Building close relationships with people.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
18	Believing in God.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
19	Develop myself as a person.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
20	Talking with other parents in the same type of situation and learning about their experiences.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>



<b>How helpful are these coping behaviors:</b>		I do not cope this way because:					
		Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	Chose Not To	Not Possible
21	Doing things together as a family (involving all members of the family).	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
22	Investing time and energy in my job.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
23	Believing that my child is getting the best medical care possible.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
24	Entertaining friends in our home.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
25	Reading about how other persons in my situation handle things.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
26	Doing things with family relatives.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
27	Becoming more self reliant and independent.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
28	Telling myself that I have many things I should be thankful for.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
29	Concentrating on hobbies (art, music, jogging, etc.).	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
30	Explaining family situation to friends and neighbors so they will understand us.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
31	Encouraging child(ren) with medical condition to be more independent.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
32	Keeping myself in shape and well groomed.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
33	Involvement in social activities (parties, etc.) with friends.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
34	Going out with my spouse on a regular basis.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
35	Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
36	Building a closer relationship with my spouse.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
37	Allowing myself to get angry.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
38	Investing myself in my child(ren).	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
39	Talking to someone (not professional counselor/doctor) about how I feel.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
40	Reading more about the medical problem which concerns me.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
41	Trying to maintain family stability.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
42	Being able to get away from the home care tasks and responsibilities for some relief.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
43	Having my child with the medical condition seen at the clinic/hospital on a regular basis.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
44	Believing that things will always work out.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>
45	Doing things with my children.	3	2	1	0	<input type="checkbox"/>	<input type="checkbox"/>

**Directions:**

\* Please read each of the following statements and decide how frequently the behavior occurs in your family.

\* Circle **one** number:

1 = Almost Never    2 = Once in Awhile    3 = Sometimes    4 = Frequently    5 = Almost Always

<b>Please describe your family:</b>						
		Almost Never	Once in Awhile	Sometimes	Frequently	Almost Always
1	Family members are supportive of each other during difficult times.	1	2	3	4	5
2	In our family, it is easy for everyone to express his/her opinion.	1	2	3	4	5
3	It is easier to discuss problems with people outside the family than with other family members.	1	2	3	4	5
4	Each family member has input regarding major family decisions.	1	2	3	4	5
5	Our family gathers together in the same room.	1	2	3	4	5
6	Children have a say in their discipline.	1	2	3	4	5
7	Our family does things together.	1	2	3	4	5
8	Family members discuss problems and feel good about the solutions.	1	2	3	4	5
9	In our family, everyone goes his/her own way.	1	2	3	4	5
10	We shift household responsibilities from person to person.	1	2	3	4	5
11	Family members know each other's close friends.	1	2	3	4	5
12	It is hard to know what the rules are in our family.	1	2	3	4	5
13	Family members consult other family members on personal decisions.	1	2	3	4	5
14	Family members say what they want.	1	2	3	4	5
15	We have difficulty thinking of things to do as a family.	1	2	3	4	5
16	In solving problems, the children's suggestions are followed.	1	2	3	4	5
17	Family members feel very close to each other.	1	2	3	4	5
18	Discipline is fair in our family.	1	2	3	4	5
19	Family members feel closer to people outside the family than to other family members.	1	2	3	4	5
20	Our family tries new ways of dealing with problems.	1	2	3	4	5
21	Family members go along with what the family decides to do.	1	2	3	4	5
22	In our family, everyone shares responsibilities.	1	2	3	4	5
23	Family members like to spend their free time with each other.	1	2	3	4	5
24	It is difficult to get a rule changed in our family.	1	2	3	4	5
25	Family members avoid each other at home.	1	2	3	4	5
26	When problems arise, we compromise.	1	2	3	4	5
27	We approve of each other's friends.	1	2	3	4	5
28	Family members are afraid to say what is on their minds.	1	2	3	4	5
29	Family members pair up rather than do things as a total family.	1	2	3	4	5
30	Family members share interests and hobbies with each other.	1	2	3	4	5

**Directions:**

\* Please read each question carefully. For those questions that require a written response, I ask that you please print your answers. For the questions with multiple choice answers, please mark an 'X' in the appropriate box.

- 1 How old is your autistic child as of today's date? Please record in years and months (i.e. 5yrs,7mon).

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- 2 At what age did you perceive your child may have a problem? Please record in years and months.

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- 3 At what age was your child finally diagnosed with autism? Please record in years and months.

---

- 4 How many children are in your family and what are their ages? (i.e. 2 children, ages 5 & 8).

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- 5 Do any other members of your family have a disability? If yes, could you please describe their disability.

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- 6 What is your relationship to your child with autism? (i.e. mother, father, aunt, etc.).

---

- 7 What is your present age?

☐ 16 - 25 years

☐ 36 - 45 years

☐ 56 - 65 years

☐ 26 - 35 years

☐ 46 - 55 years

☐ 65 and over

- 8 What is your present marital status? Please check the appropriate box(es).

☐ married

☐ separated

☐ cohabiting

☐ divorced

☐ remarried

☐ single

☐ widowed

☐ common law

- 9 If you are divorced, separated, or widowed, how long ago did this occur?

---

- 10 What is your present occupation? Please describe your work in as much detail as possible.

---

11 When you are working or away, who looks after your child(ren)?

- |   |  |  |
|---|--|--|
| <input type="checkbox"/> school   | <input type="checkbox"/> family day home | <input type="checkbox"/> preschool         |
| <input type="checkbox"/> spouse   | <input type="checkbox"/> nanny           | <input type="checkbox"/> licensed day care |
| <input type="checkbox"/> other relative, please specify their relationship to your child: _____ |  |  |
| <input type="checkbox"/> other, please specify: _____   |  |  |

12 What is the highest level of education you have obtained?

- |   |                                   |                                   |
|---|-----------------------------------|-----------------------------------|
| <input type="checkbox"/> no schooling                 | <input type="checkbox"/> 9 years  | <input type="checkbox"/> 13 years |
| <input type="checkbox"/> 1 to 5 years                 | <input type="checkbox"/> 10 years | <input type="checkbox"/> BA/BSC   |
| <input type="checkbox"/> 6 years                      | <input type="checkbox"/> 11 years | <input type="checkbox"/> Masters  |
| <input type="checkbox"/> 7 years                      | <input type="checkbox"/> 12 years | <input type="checkbox"/> MD/PHD   |
| <input type="checkbox"/> 8 years                      |                                   |                                   |
| <input type="checkbox"/> other, please specify: _____ |                                   |                                   |

13 What is your household's annual income?

- |   |   |   |
|---|---|---|
| <input type="checkbox"/> Less than 10,000 | <input type="checkbox"/> 30,000 to 39,999 | <input type="checkbox"/> 80,000 or more |
| <input type="checkbox"/> 10,000 to 14,999 | <input type="checkbox"/> 40,000 to 49,999 | <input type="checkbox"/> Not Applicable |
| <input type="checkbox"/> 15,000 to 19,999 | <input type="checkbox"/> 50,000 to 59,999 | <input type="checkbox"/> Don't Know     |
| <input type="checkbox"/> 20,000 to 29,999 | <input type="checkbox"/> 60,000 to 79,999 |   |

14 How old is your spouse?

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> 16 - 25 years | <input type="checkbox"/> 36 - 45 years | <input type="checkbox"/> 56 - 65 years |
| <input type="checkbox"/> 26 - 35 years | <input type="checkbox"/> 46 - 55 years | <input type="checkbox"/> 65 and over   |

15 What is your spouse's occupation? Please describe their work in as much detail as possible.

16 What is the highest level of education obtained by your spouse?

- |   |                                   |                                   |
|---|-----------------------------------|-----------------------------------|
| <input type="checkbox"/> no schooling                 | <input type="checkbox"/> 9 years  | <input type="checkbox"/> 13 years |
| <input type="checkbox"/> 1 to 5 years                 | <input type="checkbox"/> 10 years | <input type="checkbox"/> BA/BSC   |
| <input type="checkbox"/> 6 years                      | <input type="checkbox"/> 11 years | <input type="checkbox"/> Masters  |
| <input type="checkbox"/> 7 years                      | <input type="checkbox"/> 12 years | <input type="checkbox"/> MD/PHD   |
| <input type="checkbox"/> 8 years                      |                                   |                                   |
| <input type="checkbox"/> other, please specify: _____ |                                   |                                   |

*Once you have completed the questionnaire, please return it to Ms. Keri Smalley.*

*Thank you very much for taking the time to complete this questionnaire. Your input is valuable and very much appreciated. Please look for the results of this study to be printed in the ASBC's newsletter in approximately 6 months time. Once again, thank you very much for your time. - Keri Smalley*

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