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Attributions and Control Cognitions of Parents of Autistic Children: A Model for Predicting Stress and Adjustment

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ATTRIBUTIONS AND CONTROL COGNITIONS OF
PARENTS OF AUTISTIC CHILDREN:
A MODEL FOR PREDICTING STRESS AND ADJUSTMENT

by

Edmund M. Kearney

A Dissertation Submitted to the Faculty of the Graduate School
of Loyola University of Chicago in Partial Fulfillment
of the Requirements for the Degree of
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1990

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VITA

The author, Edmund Martin Kearney, is the son of Dr. Edmund W. Kearney and Mary Jane Kearney. He was born on July 22, 1961 in Chicago, Illinois.

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Edmund has participated in several research projects at Loyola as well, working as a research assistant to Drs. Gene Zechmeister, Jill Reich, and J. Clifford Kaspar. He has co-authored two publications within the cognitive psychology domain, and made three convention presentations within the clinical and cognitive psychology domains. In addition he completed a master's thesis entitled Cognitive Monitoring in College Students: A strategy Usage Design and was awarded a Master's Degree in Clinical Psychology in May, 1987.

Edmund earned "Pass with Distinction" honors on both the Written Qualifying Examination and the Professional Oral Examination. In addition, Edmund completed an APA approved clinical internship at Milwaukee County Mental Health Complex during 1987-1988.

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INTRODUCTION AND OVERVIEW

In 1943 Leo Kanner first described a specific, yet perplexing, set of symptoms marking severe psychological disturbance in a child. These symptoms included a pervasive lack of socialization, gross deficits in language development, and bizarre responses to various aspects of the environment. The description of these symptoms has changed little from Kanner's early work and they are collectively still known today as the syndrome of infantile autism. Moreover, this syndrome has continued to puzzle and frustrate clinicians for over four decades, as they have attempted to further describe, define, and determine causal factors for this disease.

Throughout the clinical and research work of the past five decades, two theoretical issues have been closely, often inextricably intertwined -- the issue of causation and the issue of the role of the parent. In fact, for years the theory that a cold and distant maternal caregiver was an etiological agent in the development of autism, was a central and popular explanatory construct (Bettleheim, 1967). However, more recently, primarily within the past decade, researchers

have begun to aggressively approach both the issue of causation and the role of the parent from strikingly different perspectives.

The study of causal factors has shifted from a search for a particular etiological agent (i.e. cold mother or specific organic/genetic dysfunction) to an examination of the central psychological processes that seem to be aberrant in the autistic child. The two leading theories in this realm are the theories that argue for a central cognitive dysfunction (i.e. Rutter, 1983; Ricks and Wing, 1979) and the theories that argue for a central social dysfunction (i.e. Hobson, 1984). Parallel to these investigations, the study of the role of the parent has also encountered a conceptual and experimental shift. No longer are the parents of autistic children generally studied as potential etiological agents; rather, parents are now beginning to be studied with an emphasis on stresses involved in having the primary caretaking responsibilities for their seriously disturbed son or daughter. As such, studies are now beginning to investigate both the impact of the parent on the development of the autistic child, as well as the impact of the autistic child on the parent (i.e. Bristol & Schopler, 1983; Bristol, 1984). Both these shifts are fairly novel approaches to the study of autism and are only beginning to produce results and

information which are providing the caregivers and professionals with a more thorough understanding of the disorder.

Even with the shift away from viewing the mother as an etiological agent, the great majority of studies investigating the effects of parenting an autistic child have continued to use the mother as their prime area of focus. Few studies have included the father of an autistic child as a subject in an empirical investigation. Thus clearly, many questions remain not only unanswered, but unexplored, in the area of parenting an autistic child. First and foremost on a descriptive level, data relevant to stress, coping, and father-child interactions involving this population is almost completely absent. Researchers and clinicians continue to wonder about the answers to such basic questions as: What areas of life and sources of concern are most stressful for fathers of autistic children? How do they attempt to cope with these stressful and worrisome situations and concerns? Are these fathers' concerns and coping attempts similar to those experienced and practiced by mothers of autistic children, or by the parent of an otherwise mentally handicapped child? One goal of this dissertation is to attempt to extend our knowledge of the caregiver-autistic child relationship by providing some

descriptive data relevant to the stress and coping of fathers within this population.

A further goal goes beyond asking how such parents react and adjust to parenting such a difficult child, to examine what variables might affect that adjustment process. Bristol and her colleagues (1983, 1984) have begun this investigation by examining which variables impact significantly on the mother's attempts to cope with the challenge of parenting an autistic child. Her research has indicated that variables such as age and personality characteristics of the child, as well as available social support for the mother, are important in determining successful adjustment. However, as social psychological and cognitive research over the past decade have consistently demonstrated, one must look not only at external, environmental events in order to predict stress and coping, but also at the cognitive conceptualization of events in order to most accurately predict adjustment.

One approach to examining the cognitive conceptualizations of parents of autistic children and their subsequent adjustment can be found within a subspecialty of social psychology which has arisen in an attempt to explain reactions to negative life events. This field of study has generally relied upon the social-cognitive theories of attribution (Kelley, 1971)

and Just World Theory (Lerner, 1970; 1980) to help explain and predict individuals' cognitive, behavioral, and affective reactions to a wide variety of negative life events. These negative life events have been labelled "victimizing" experiences and include such events as being raped, being robbed, suffering from a serious illness, suffering in a natural disaster, and most recently, parenting a handicapped or ill child. An investigation of the coping of autistic parents utilizing this conceptual theory might further enlighten us by examining the type of intrapsychic stress, as well as the coping mechanisms, operative for these parents. Thus, the second major goal of this project entails applying the theoretical constructs emerging from the victimization literature to organize and make sense of the aforementioned descriptive data.

More specifically, a project utilizing this population and designed to investigate the aforementioned theoretical constructs provides an opportunity to further address two specific theoretical questions currently unanswered within parental victimization research. First of all, recent victimization literature has found that when victims blame themselves for their misfortunes, and blame themselves by asserting that they were victimized because they did not practice some preventive behavior

(e.g. eating nutritiously to prevent cancer), a positive adjustment is found to result (Janoff-Bulman, 1979). This result often leads to the conclusion that when such "behavioral self-blame" is replaced by what authors label "characterological self-blame", or blaming the victimizing experience on some relatively stable personal characteristic, poorer adjustment will follow. Unfortunately, this conclusion has been reached without directly testing this latter hypothesis for parental victims. As yet, no group of parents has displayed enough characterological self-blame to allow direct assessment of their subsequent adjustment. It is quite possible that parents of children with autism, a disorder marked by its severity, unpredictability, violation of community norms of behavior, and history of etiological theories in which mother-blaming was central, might display characterological self-blame more frequently. If so, this relationship between type of blame and adjustment could be more directly tested and clarified.

A second theoretical question again involves the connection between parental cognitions and adjustment. In this case, researchers have identified two types of "control cognitions" (Tennen, Affleck, & Gershman, 1986). The first type is labelled "control over recurrence" and involves victims' worries that the

victimizing experience could happen again. The second is labelled "control over sequelae" and involves victims' concerns over prevention of future problems associated with the victimizing experience. These researchers have argued that when behavioral self-blame is associated with control over recurrence, positive adjustment will be bolstered. Control over sequelae, however, has not been reported to be associated with positive adjustment. It certainly remains unclear, however, whether this finding can be elevated to a general rule within victimization theory, or whether this finding is due to some common aspects of the populations studied thus far. Again it could be argued that the unpredictability and severity of the autistic child's behavior (i.e. sequelae) might alter the relationship between control cognitions and adjustment. It is likely that the nature of the sequelae is important in determining the relative importance of the two control cognitions in predicting adjustment.

In summary, this project is designed to investigate the previously neglected area of parenting the autistic child from three perspectives. First, descriptive data relevant to fathering an autistic child should shed light on the stresses associated with such a role. Secondly, the application of victimization theory should help to further organize and contextualize this paternal

data, as well as begin to shed light on the intrapsychic processes affecting the adjustment of the mothers of these children. Thirdly, by applying victimization theory and method to this unique population, central theoretical questions within victimization theory relevant to the role of self-blame and control cognitions in adjusting to this victimizing experience can be pursued from a fresh and unique perspective.

Chapter II

Review of the Literature

To say that the research literature on fathers of autistic children is sparse is certainly an understatement. A review of the research and clinical literature on fathers of autistic children turns up few citations, of which almost none is an empirical investigation. Thus a review of this specific literature would no doubt prove inadequate in generating specific hypotheses. As such, in order to supplement this literature with the hope of discovering and generating testable hypotheses, two more general areas were investigated. First, the more general topic area of "fathers of mentally handicapped children" was investigated and is reviewed. Unfortunately, once again little clinical or research work has made the father the focus of either study or speculation within the field of parenting the mentally handicapped child. Secondly, the empirical literature relevant to being a mother of an autistic child is presented.

Fathering the Mentally Handicapped Child

Research and conventional wisdom suggests that examining the effect of having a mentally handicapped child on the father is a subject worthy of study for several

reasons. First, early family research suggested that there is a significant relationship between paternal acceptance/rejection of the child and the amount of acceptance/rejection observed in the family. Peck & Stephens (1960) found that examination of how the father is affected by his parenting role of the mentally handicapped child could shed light not only on the paternal relationship with the child and the development of the father as an individual, but also on the more global familial attitudes and resultant relationships within the families of mentally handicapped children.

Secondly and perhaps more directly, Bell and Harper (1977) posit a bidirectional process in considering parent-child relationships. This bidirectional process includes the notions that not only does the parent affect the development of the child, but the child has a strong impact upon the "development" or adjustment of the parent. As such it could be suggested that the effect of having a mentally handicapped child on the father will impact upon the quality and quantity of interactions between the father and his handicapped child, as well as on the adjustment of the father himself.

In essence, the dearth of studies investigating the father-handicapped child interaction is highlighted by the lack of systematic research on such basic issues as the father's adaptive process (i.e. feelings, attitudes and

behaviors), the interrelationship between his feelings, attitudes and his behavior, and the effect his adjustment has on other family members' feelings, attitudes and behaviors. The research literature on fathers of mentally handicapped children can be divided into two general categories: clinical case or theoretical discussions and experimental or data-based accounts. However, it should be kept in mind that neither area has been developed into a systematic attempt to explore this topic area.

Clinical Reports

Even clinical case reports and theoretical treatises of the role of, or effect on, the father within a family with a mentally handicapped child are rare. In fact, most conclusions and hypotheses regarding fathers of these children must be inferred from discussions of "parents" where no specific mention of "mothers" is made. One theoretical notion that has received support in the literature is the notion of chronic stress (Wikler, 1981; n.b. Olshansky (1962) discussed a related notion of chronic sorrow). According to Wikler, the diagnosis of the handicapping condition will be the most disturbing crisis the parent must face, with the father and mother potentially reacting very differently. Moreover, this author notes that stress will also occur periodically for parents raising a handicapped child, most notably whenever there exists a discrepancy between what is expected developmentally and

what occurs in reality. While the notion of chronic stress is intuitively appealing, empirical demonstration of such a phenomenon remains lacking. In addition, Wikler does not empirically address the issue of cognitive, affective, or behavioral correlates of this chronic stress. Nevertheless, Wikler has apparently identified a potentially crucial response pattern within parents of handicapped children, one certainly worthy of further investigation.

Blacher (1984), in a review of 24 articles and books, concluded that most authors described a series of predictable stages parents went through in adapting to having a disabled child. It should be noted that Blacher points out that these stages have not been derived empirically, but rather are based most often on clinical observation and interviews. In addition, although Blacher characterizes these as stages of "parental" adjustment, it should also be kept in mind that the great majority of the sources cited in the review pertain to original discussions of the mother's adjustment process. The authors reviewed by Blacher suggest that parents proceed through three stages of adjustment. The first stage she labels "disintegration" and is characterized by shock, denial, and emotional disorganization. A second stage which Blacher labels "adjustment" is characterized by partial acceptance and partial denial of the disability, as well as a search for someone or something to blame. The third stage Blacher

discusses is labelled "reintegration" and is marked by a return to effective and realistic functioning. Once again, whether these stages, and the associated developmental processes, would be borne out empirically is not presently known.

In summary, few clinical or theoretical discussions of the father's reaction to having a mentally handicapped child can be found in the literature. Moreover, it must be remembered that whether or not these clinical/theoretical discussions can actually add useful and accurate information to aid in our work with this population must wait for a true empirical test of these theoretical notions. These few clinical works suggest that fathers suffer some rather undefined stress associated with raising their mentally handicapped child. Whether or not this stress is "chronic", or perhaps abates as the father begins to "accept" the child's handicap, remains unclear.

Empirical Investigations of Personality Dynamics

Adding to these clinical reports are a few empirical investigations of fathers of mentally handicapped children. Experimental or data based investigations have focused on two primary areas of study. The first area might be labelled "the personality dynamics of the father." Early writers on autism, including Kanner himself, speculated on the possible parental characteristics of the parents of autistic children. Kanner (1954) originally hypothesized

that the parental characteristics might be a milder form of the child's abnormality. Other loosely empirical works have described parents as "reserved" (Creak and Ini, 1960) and fathers as cold, detached, and obsessive (Eisenberg, 1957). Three more recent studies, however, have attempted to explore the personality dynamics of fathers of mentally handicapped children more systematically.

Cummings (1976) attempted to approach this issue by comparing fathers of mentally retarded, chronically ill, and healthy children. Fathers completed the following self-administered tests in their homes: Edwards Personal Preference Scale; a sentence completion test; Self Acceptance Scale of the Berger Inventory; and a modification of the Shoben Parental Attitudes Survey. Cummings' results suggest that fathers of mentally retarded children differed from fathers of healthy children in amount of depressive affect, their sense of paternal competence, their enjoyment of the child, their more negative evaluations of their wife and other children, as well as on the traits of dominance and heterosexuality. While Cummings' data certainly adds to the clinical literature discussed above and provides initial empirical support for a "stress reaction", the generalization of these results to parents of children with other handicaps besides mental retardation remains untested.

More recently, in one of the few studies having specifically investigated fathers of autistic children,

Koegel, Shrieberman, O'Neill, and Burke (1983) examined parental stress, personality features, and family interaction characteristics. These authors used standardized empirical tests such as the Minnesota Multiphasic Personality Inventory (MMPI), the Dyadic Adjustment Scale, and the Family Environment Scale (FES) in order to compare their results with normative data. Results suggested that parents fell within the normal range on all MMPI scales, that parents of autistic children did not differ from normative couples in terms of marital strain, and that no significant difference could be found between the autistic families and normative families on the FES.

This data certainly provides valuable empirical evidence regarding both the personality traits of autistic parents and family adjustment. These authors conclude in addition, however, that no higher incidence of general stress occurred for parents of autistic children. While no evidence of increased stress is presented here, it may be premature to draw such a conclusion. The reliance on either measures of relatively stable individual personality traits or family adjustment may have precluded these authors from gathering valuable information relevant to the individual and the chronic stress often reported in the clinical literature. Moreover, while these authors acknowledge that situation-specific stress reactions have not been ruled out by this study, it may be argued that the measures chosen

further limited the observed stress by ignoring important measures of subjective stress and psychological well being. Thus, the negative finding here regarding a general stress reaction may be due more to methodological issues such as choice of assessment tools and subject selection (i.e. All subjects had recently been admitted to a long term intensive treatment program which certainly may have reduced both individual and family stress.) than to the actual absence of that symptom. Most importantly, however, further empirical work is certainly needed to refine the explanations of the role of stress in the adjustment of these fathers.

A third study approached the issue of personality characteristics of parents of autistic children by focusing exclusively on the possible presence of schizoid personality traits. Wolff, Narayan, and Moyers (1988) interviewed 14 fathers and 21 mothers of relatively high level (i.e. as defined by presence of useful language) autistic children. These authors discovered that 8 of 14 fathers and 8 of 21 mothers were rated as having definite schizoid traits by an interviewer using a semi-structured interview previously designed to tap schizoid personality traits. More specifically, these "schizoid" parents differed from non-schizoid parents on such variables as guardedness, sensitivity to experience (mothers only differed), unusual modes of communication (mothers only), and impaired rapport (fathers only). In contrast, parents did not differ on such

variables as empathy, sociability, and obsessionality.

These authors concluded that they had identified what might be labelled as a "social gaucheness" in these parents.

While these results certainly suggest a possible difference in personality traits between parents of autistic and non-autistic children, problems with the study limit the utility, and perhaps the validity, of these conclusions. First, parents used as subjects in this study were parents of a fairly unrepresentative sample of autistic children. Many autistic children do not display much "useful language", although it remains unclear from the present study how the modifier "useful" was operationally defined. Thus, the generalizability of this finding remains unclear. Moreover, from an internal validity perspective, one might question the diagnostic accuracy of this semi-structured interview designed to diagnose schizoid disorders and describe schizoid traits. For example, one might argue that the results reported by these authors in fact argue against a central schizoid disorder, as no differences were found on such generally accepted core schizoid symptoms as difficulties in empathy and sociability. While these remarks certainly do not invalidate these authors conclusions, further validating and replicating evidence would be necessary before offering conclusive remarks concerning this aspect of these parents' personalities.

These three studies make it difficult to draw

conclusions regarding the personality characteristics and/or adjustment of fathers of mentally handicapped children. Different methodologies, instruments, and subject populations make comparisons difficult, and leave unanswered the question of characteristic personality profiles of fathers of mentally handicapped children, and perhaps even the more basic question of whether fathers of these children suffer from more, or different, stress.

Empirical Investigations of Paternal Stress

A second empirical approach has attempted to address this question of parental stress from a different angle, by exploring different stressful concerns in the mothers and fathers of mentally handicapped children. Gumz and Gubrium (1972) discussed two types of concerns which they labelled as the instrumental and expressive crises. The instrumental crisis includes concerns about providing for the child, as well as worries about his economic future and life potential. The expressive crisis includes stress and concern over directly caring for the mentally handicapped child, and subsequent worries about the child's interpersonal relationships and potential for future happiness. These authors found that fathers have a tendency to experience their mentally handicapped child in terms of instrumental crises, while mothers more often experience their handicapped child in terms of expressive crises. It should be noted, however, that there was much crossover in

these concerns as well, with a high percentage of both mothers and fathers expressing both instrumental and expressive concerns.

In addition, this finding that fathers are quite concerned about the general future (i.e. legal and educational matters) and economic support of their mentally handicapped child has been fairly consistently reported, with fathers of MR and autistic children expressing similar concerns (Hersh, 1970; Love, 1973; Meyer, 1986). In addition, Price-Bonham and Addison (1978) provide a literature review of empirical and clinical work investigating the fathers' reaction to a mentally retarded child. These authors report early writings which generally indicate that mental retardation has very different meanings for mothers and fathers, and that fathers are more affected by the physical appearance of the child than the mother.

Thus, while conclusions regarding differing parental concerns within parents of an autistic child appear premature, the finding that fathers of autistic children do experience this instrumental crisis does appear to have clinical and empirical support. Whether certain attitudes and thoughts affect this crisis, and whether these concerns affect the fathers' interactions with his child or his emotional adjustment are currently unanswered, but important, questions.

Two examinations of the stress experience of fathers of

autistic children have been reported since the initiation of this project. Wolf, Noh, Fisman, and Speechley (1989) administered the Beck Depression Inventory and the Parenting Stress Index (a self report measure designed to investigate which characteristics of the child are most stressful to the parents) to 27 fathers of autistic children. Results indicated that although no significant incidence of depression was found, an overall significant stress reaction was discovered. Unfortunately, further examination of that stress reaction proved impossible, as these authors did not report which child characteristics (i.e. subscale scores from the instrument) were associated with increased or decreased stress. Only the significant impact of such demographic variables as age of the child, age of the father, and education of the father were reported in describing the stress reaction. In addition, multiple regression analysis suggested that the combination of ten demographic variables, along with a measure of social support, accounted for only 25% of the variance in fathers' mood scores.

A second examination of the stress experienced by fathers of autistic children involved simply rating how stressful various autistic behaviors were to the parent of the autistic child. Konstantareas and Homatidis (1989) reported that both mothers and fathers felt that the child's difficulties with verbal communication constituted the most

stressful symptom. In addition, fathers did not report less stress than mothers, although they did report less involvement in caretaking responsibilities.

One almost completely ignored area of study within the paternal stress literature involves the potential importance of the father's attitudes and attributions regarding his child's handicapping condition. Lavelle and Keough's (1980) theoretical work (see also Gallagher, Beckman, & Cross, 1983) described the importance of the attributions and expectations parents of handicapped children often make, noting that it is quite probable that the parents' view of the cause of their child's handicap, and their sense of personal ability to modify or ameliorate the difficulties, may affect their behavior toward the child. Moreover, it would seem logical that one might even conclude that such attributions would affect not only this interactional behavior, but their perceived stress and overall adjustment as well. Whether a father's attributions regarding the cause of his child's autism, and his sense of perceived control over the child's difficulties, constitute important variables in predicting his adjustment were central foci of this investigation.

In summary, the literature on fathers of autistic, and even mentally handicapped, children is sparse and deficient. There is very little descriptive data available regarding the affect, behavior, and cognitions of these parents.

Moreover, no specific pattern of paternal stress has been identified, although some evidence points to increased concern among fathers regarding the management of their disabled child's future. Existing descriptive data has focused exclusively on either global measures of stress or measures designed to investigate which autistic symptoms are most stressful. Moreover, there exists no research investigating the attitudes and attributions of fathers of handicapped children. No research has broached this question, either in an attempt to describe these attitudes, or more importantly to examine those attitudes in connection with the father's affective adjustment and his interactions with his child. This project attempted to begin to address the issue of the attitudes and attributions of the fathers of autistic children in hopes of shining some light on these unexplored empirical questions, and providing some valuable clinical information regarding the functioning of families with an autistic child.

Mothering the Autistic Child

In order to explore and understand more generally the stresses involved in parenting an autistic child in the hopes of further directing early research into the father's role in particular, and the parents' role more generally, a brief review of the mother's adjustment to having an autistic child needs to be examined. Only recently have clinicians and researchers begun to focus on the mother in

terms of her adjustment, rather than in terms of her role as a potential etiological agent. This recent work falls into three general areas: the personality dynamics and mental health of the mother; factors affecting the stress of the mother; and coping attempts designed to relieve that stress.

Empirical Investigations of Personality Dynamics

The first topic, the personality dynamics of parents of autistic children has been partially reviewed above, as the Koegel et al. (1983) investigation found no personality or stress differences between parents of autistic children and normative data. Partially supporting that study is a previous investigation by Cox, Rutter, Newman, and Bartak (1975) who also found no difference in warmth, emotional responsiveness, or sociability between parents of autistic children and parents of dysphasic children. These authors, however, did report that almost one-third of mothers of autistic and dysphasic children reported incidents of depression in response to stress associated with parenting a handicapped child.

Empirical Investigations of Maternal Stress and Coping

DeMyer and her colleagues (DeMyer, 1979; DeMyer and Goldberg, 1983) have been investigating both the issues of the mental health of mothers as well as the examination of areas of life adversely affected, or stressed, in families with an autistic child. In two survey type studies, DeMyer and her colleagues collected data primarily from mothers of

autistic children and adolescents in Indiana, relying primarily on semi-structured interviews. In these interviews, she sought to gather information relevant to the needs of families during different ages of an autistic child, the aspects of family life adversely affected, and the type of help sought, attained, and still needed. In her 1979 study, DeMyer found that 33% of mothers of preschool autistic children had definite mild reactive depressions, while all parents reported feeling often anxious and upset. Similarly, DeMyer and Goldberg (1983) in interviewing parents of autistic adolescents, found that the emotional and mental health of the parents was reported as the third most severely adversely affected area of these parents' lives. Once again, these parents commonly reported feelings of depression and anxiety. In addition, DeMyer and Goldberg reported that family recreation and family finances were the most adversely affected areas of life in families with an autistic adolescent. While DeMyer's surveys have generally supported the notion that raising an autistic child is stressful for the mother and affects both the individual family member as well as the family system, the absence of comparison groups and her failure to use standardized instruments somewhat limit these conclusions.

As discussed above, two studies examining the stresses involved in parenting an autistic child were reported since the initiation of this study. Wolf et al. (1989), in

administering the Beck Depression Inventory and Parenting Stress Index, also found that these mothers exhibited an elevated risk for dysphoria and a significant stress reaction in comparison to parents of normal children. As noted above, further explication of the components of this stress reaction was not offered by these authors. Moreover, as was the case with fathers, the combination of the numerous demographic variables and a measure of social support accounted for only 27% of the variance in mothers' mood scores. In addition, as reported above, Konstantareas and Homatidis (1989) reported no elevated stress reaction for mothers in comparison to fathers, despite their report that they were responsible for significantly more of the caretaking demands involved in parenting an autistic child.

In contrast to these very general investigations of stress, Bristol and her colleagues (1983, 1984) have been directly examining the issues of factors affecting the stress of mothers of autistic children. Bristol argues convincingly that the experience of parenting an autistic child is likely to be stressful because the experience is marked by several variables commonly associated with increased stress. These variables include the ambiguity of the syndrome and its symptoms, the severity of the syndrome, and the "lack of congruence with community norms" that marks the behavior of these children.

Bristol and Schopler (1983) have focused their work

around Hill's (1949) sociological model of family coping, which proposes that whether a stressful event (A) will result in a crisis (x), depends upon the event and the hardships interacting with the family's crisis resources (B) and the definition the family makes of the event (C). Within this ABCx model of stress and adaptation, most of Bristol's empirical work has focused on describing the stress reaction of these mothers, examining how these stresses predicted mothers' and families' adjustment, and determining these families' current and needed crisis resources.

Bristol's (1979; 1983; 1984) early work was designed to expand the work of Holroyd and McArthur (1976), who originally examined the topic of parental stress in raising a mentally handicapped child by contrasting the experience of mothers of autistic children with mothers of Down's syndrome children. The Questionnaire on Resources and Stress (QRS), originally developed by Holroyd (1974) to measure the influence of a chronically ill or handicapped person on other family members, was used by both Holroyd and McArthur, as well as by Bristol, to measure the stresses encountered by parents of autistic children. In Holroyd and McArthur's study, the questionnaire was mailed to mothers of Down's syndrome children, while mothers of autistic children were interviewed using the questionnaire as a guide. Using discriminant analysis, Holroyd and McArthur found that

mothers of autistic children (age 3-12) were more upset and disappointed about their child, were more concerned about the child's dependency and future vocational problems, and were often more concerned about the effect of the child on the family than mothers of Down's syndrome children. Unfortunately, several methodological problems weaken the findings of this study. Besides the obvious difference in data collection methods between the groups of mothers (i.e. mailed surveys vs. clinic interviews), the fact that the samples were not matched on SES and IQ weakens the conclusions that can be drawn from this particular study.

In a study designed to replicate and expand Holroyd and McArthur's (1976) findings, Bristol (1979) administered the QRS to mothers of autistic children in North Carolina. In this study, data was collected on the stresses reported by 40 mothers of autistic children. Bristol (1983) in summarizing her research of 1979, reports that older autistic children (9.5-19 years) were more stressful than younger autistic children, and that parents of these children exhibited a "greater realism and pessimism" regarding the child's future. In addition, while mothers of very young autistic children reported such stresses as the constant caretaking demands of the child and worries about his or her physical survival, mothers of older autistic children reported stresses centered more around self-help issues, public behavior, and maintaining family functioning.

Moreover, Bristol (1983) expanded Holroyd and McArthur's (1976) work by investigating how these stresses predicted mothers' behavior and family problems. Bristol reported that for the group of 40 mothers, the autistic child's "difficult personality characteristics, management problems, degree of dependency, and lack of services were the best predictors of parent and family problems."

In a second study, Bristol and Schopler (1983) investigated whether particular characteristics of the family environment in families with an autistic, or autistic-like, child would be related to family stress and successful adaptation to the child. Bristol assessed the family's adaptation to the child, the marital adjustment, and presence of depression by interviewing, rating, and testing 45 mothers of autistic and autistic-like children (n.b. 27 were diagnosed as autistic.) Family evaluation suggested that successful adaptation (i.e. fewer depressive symptoms, better marital adjustment, greater feelings of competence in coping with the child) was related to the degree of cohesion, expressiveness, and active recreational orientation of the family. Moreover, Bristol and Schopler report that successful family adaptation was closely related to the perceived adequacy of the mother's social support, the pattern of coping strategies she used, her beliefs regarding the child's handicap, and other simultaneous stresses on the family. These authors do report that

central beliefs including believing in her child's treatment program, believing in God, and believing in her child's future improvement were commonly successful coping strategies. In addition, they report that the common strategy of comparing oneself with a less fortunate other is another cognitive coping strategy employed by these mothers. However, investigation of attributional and/or control beliefs was not a focus of that study.

While this data has added richly to our understanding of the importance of the resources of the family and the characteristics of the child, little light has yet to be shed on the thoughts and attitudes of the parents beyond the coping strategy "beliefs" reported above. Although both Holroyd and McArthur (1976) as well as Bristol (1979) report a high degree of pessimism and negative attitudes toward the child in mothers of autistic children, little clear data relevant to the family's cognitive conceptualization of having an autistic child is provided by the QRS. In addition, thus far no data has been reported on the attributions the parents make and how these attributions relate to their coping attempts. The investigation of these variables also constituted a major focus of this present study.

Analysis of Parenting Literature

In analyzing the parenting literature, one must consider the question: Given the research data on parents of

autistic children, what information or central components are currently missing? The first and most obvious deficiency in the research is the lack of research data involving fathers of autistic children. Few studies have empirically examined this population, and even clinical reviews have devoted little time to discussing their role. As a result such basic questions as the following have not been answered for this population: What is the role of fathers in the autistic child's development? How does the father adjust to the stresses and demands of having an autistic child? Does this different parenting demand affect the fathers direct interaction with the child, and his interaction with his family? Are certain incidents and developmental periods more or less stressful on the father? How do the father's thoughts, expectations, and feelings affect his ability to adjust to his autistic child? While these very general and global questions only touch the surface of appropriate research domains for social scientists studying fathers of autistic children, hundreds of more specific research oriented questions could be readily generated in attempting to compile descriptive data on fathers of autistic children.

A second major gap is the lack of an organizing theory, or even a theoretical application, in the current research on parents of autistic children. The closest one comes to such a theoretical organization of the data can be found in

Bristol's recent extensive work with the mothers of autistic children. In this work, Bristol (1983) employs social support theory and sociological theory to organize her findings regarding mothering an autistic child.

Unfortunately this theory and Bristol's research have thus far de-emphasized the importance of the parents' cognitions regarding parenting their autistic child in attempts to account for the stress reaction of parents. Further research with these populations must proceed under a theoretical guide, hopefully a guide which attempts to consider both intrapsychic and environmental variables.

A third major problem in the literature also emanates from this lack of theoretical direction. The question of how one can intervene to combat the stress and strain of parenting a mentally handicapped child has already arisen. While it would seem that the answer to this question must grow out of the answer to the theoretical questions posed above, researchers and clinicians have seemingly leapfrogged the theoretical question and have begun to eagerly address the issues of treatment and intervention. For example, experimental programs at UCLA have begun a group for fathers of children with various types of mental handicaps (i.e. Down's Syndrome, autism, neurological disorders) (Meyer, 1986). The theory behind this group, however, does not take into account the possibility that parenting an autistic child may be a far different

experience from parenting a Down's syndrome child.

While it is doubtful that such intervention could be harmful, it could be argued that a universal treatment model might not be the most appropriate for fathers of all mentally handicapped children. For example, research might eventually indicate that fathers of autistic children worry a great deal about their child's future, and adjust best when: 1.) they attribute their child's handicap to some preventable behavior during pregnancy; and 2.) they have fewer concerns over whether or not they will be able to control the behavior of their child. In contrast, fathers of Down's syndrome children might also worry about their child's future, yet might adjust best when they understand the genetic basis of the disorder and have fewer concerns over the disease recurring in subsequent children. It is doubtful then, that a support group designed for fathers of Down's syndrome children aimed at changing the causal attributions of the fathers to orient around a biological/genetic explanation while promoting genetic counseling before future parenting, will be effective with fathers of autistic children. Without the prerequisite assessment research however, program developers might not realize that a group designed around helping the fathers of autistic children learn to control their child's behavior might be more beneficial. Unfortunately, because the foundation research on the problems of fathers of mentally

handicapped children is lacking, it remains difficult to adequately evaluate these currently ongoing programs, or plan appropriately for future beneficial programming.

Thus, in conclusion, three primary problems are clearly present in the research on parents of autistic children. There is a gross lack of descriptive data involving fathers of these children. Secondly, there has been little attempt to investigate internal, cognitive, or intrapsychic, factors affecting either parents' coping process in any systematic or theory-based manner. Thirdly, the literature and clinical work have begun to skip over the question of "What problems do these individuals encounter?" As a result, clinicians are beginning to design help oriented programs aimed at addressing currently unsubstantiated problem areas.

Victimization Theory as an Explanatory Construct

Given the dearth of empirical investigations and explanatory constructs available to guide an exploration of the process of parenting an autistic child, one must look elsewhere for an organizing framework. Although not directly within the field of research on autistic or mentally handicapped children, examination of some preliminary attempts to examine the adjustment of mothers to having a "disabled" child (i.e. chronically ill, high risk infants) might provide one with a potential organizing construct. This research, carried out primarily by Affleck and his colleagues (Affleck, Allen, Tennen, McGrade, &

Ratzan, 1985; Affleck, Tennen, & Gershman, 1985; Allen, Tennen, McGrade, Affleck, & Ratzan, 1983; Tennen et al., 1986) is based on an offshoot of the currently popular social cognitive studies of victimization. These researchers have argued that parents of disabled children have undergone a "victimizing" experience, and that their cognitive and emotional reaction, as well as their attempts at adjustment, can be best explained by applying and refining victimization theory.

The application of this theory of victimization to parents of autistic children, in an attempt to organize and give theoretical meaning to the descriptive data, could be quite helpful. Instead of posing general descriptive questions, one might begin to systematically investigate parents' causal attributions, their feelings of control, the process of adjustment, and the interrelationship among these variables in order to develop a more thorough and theoretically based understanding of these parents. Therefore, in order to place this theoretical application into correct perspective, a brief review of victimization theory is presented.

Review of Victimization Theory

The experience of negative life events, and the stresses and adaptational attempts which follow, has been an important and fast developing area of study within social psychology over the past decade. Research on "victims" of

crimes, diseases, and accidents has been completed, as well as more theoretical papers proposing explanatory constructs for interpreting these studies (Taylor, 1983; Janoff-Bulman; Wortman, 1983). Although various theories have been applied as potential explanatory constructs, the great majority of work has focused around applications of attribution theory (Kelley, 1971) and Just World theory (Lerner, 1970; 1980).

According to attribution theory, individuals search for a causal explanation in order to understand, predict, and control the situations which may be somehow threatening. Thus researchers have focused upon examining the causes one attributes for a negative life event (i.e blames others vs. blames self vs. blames chance), and whether these causal thoughts help to control the threat and/or aid in the adjustment process. Just world theory, which suggests that most individuals operate under the cognitive notion that "good things happen to good people and bad things happen to bad people", is commonly applied in combination with attribution theory to further explain the reactions of victims. While attribution theory posits that we search for a cause or explanation, just world theory suggests that such a search will often result in our blaming ourselves for a "bad" life event. Thus, researchers on victims have attempted to focus on not only the attributions made, but the impact of self-attributions as an important variable in predicting adjustment. While numerous studies apply these

theories to quite disparate victim groups such as rape victims (Janoff-Bulman, 1979), cancer victims (Taylor, Lichtman, & Wood, 1984), and victims of natural disasters, a brief review of the general methodology and conclusions is offered here in order to familiarize the reader with the general trends currently found in the literature.

The methodological approach in studies of victims of negative life events has been fairly consistent. Generally the individual who experienced the negative event (i.e. the victim) is interviewed and asked questions relevant to his/her attributions, perceptions of control, and subsequent adjustment. In addition, subjects generally complete a battery of questionnaires/test instruments designed to further assess their attributions, explore their perceptions of control, and provide a psychometric assessment of their current level of psychological functioning. Often, no comparison groups are included, and only recently have authors urged the use of standardized and normed instruments of assessment so that comparisons can at least be made with normative samples (Shulz & Decker, 1985).

Results of Victimization Studies

Despite the similarities in methodology across various victimization studies, only three general findings have been found to be consistent reflections of the attributional processes of victims. The first general finding is that individuals clearly make attributions and form theories

concerning their misfortunes (Taylor, p.490). That is, whether the victimizing event is a crime or a disease or some other undesirable event, victims readily volunteer several explanations involving why this event occurred.

Secondly, more recent research has suggested that certain attributions are associated with more adaptive adjustment. Janoff-Bulman (1979) in her work with rape victims has found that individuals who blame themselves, rather than blaming others, appear to have adapted better to their victimizing experience. In her empirical work (Janoff-Bulman, 1979), this author has further refined her theory and her interpretation of her results to propose two types of self-blame. The first, labelled "behavioral self-blame", refers to the attribution of negative life events to one's own modifiable behavior. For example, behavioral self-blame of a rape victim might include attributing the rape to a failure to take precautionary safety measures in certain instances, or of a cancer victim might include attributing the disease to improper nutrition or diet. The second type of self-blame is "characterological self-blame" and involves attributing negative life events to stable aspects of the "self", such as one's personality. Most importantly, Janoff-Bulman argues that her results suggest that it is behavioral self-blame which can lead to more adaptive coping, while characterological self-blame would result in poorer adjustment. Empirical work has generally

supported these theoretical distinctions of self-blame as well as the association between behavioral self-blame and adjustment (Janoff-Bulman, 1979; Affleck, Tennen, Croog, & Levine, 1987). It should be noted, however, that not all studies have directly supported the theory that increased behavioral self-blame is associated with positive adjustment (Taylor, Lichtman, and Wood, 1984). In Taylor et al.'s work with victims of breast cancer, self-blame was "uncorrelated" with adjustment. These authors, however, failed to formally separate behavioral from characterological self-blame in their analyses. It thus remains unclear how these results impact upon the existing data concerning the relationship between self-blame and adjustment.

A third general issue in this literature involves the role of perceived control in predicting or determining adjustment. Janoff-Bulman (1979) has argued that behavioral self-blame is adaptive because it helps victims perceive the future as controllable. It is no doubt too early to say how strongly the research literature will support either the link between behavioral self-blame and perception of control, or the link between perception of control and adjustment, but much preliminary research strongly suggests that these links are important variables in understanding the adjustment to undesirable life events. For example, Timko and Janoff-Bulman (1982) found support for the link between behavioral self-blame and perceived control over

recurrence of breast cancer; and, Taylor et al. (1984), in also studying the victims of breast cancer, found that belief in future control of the cancer was associated with "good" adjustment. Thus early research suggests that it is perceived control over recurrence that is important in predicting positive adjustment.

Thus, although the research on victimization and negative life events has focused on quite disparate populations, certain consistencies appear to be at least generally supported. The notion that individuals make attributions, that they often blame themselves, that this self-blame, when applied behaviorally as opposed to characterologically, is associated with positive adjustment, and that perceived control over future recurrence is important in positive adjustment, all have emerged as legitimate findings worthy of more aggressive experimental assessment.

Parents as Victims Research

The Question of Characterological and Behavioral Self-blame

As stated above, another population in which the issue and theory of victimization has been studied involves the parents of children who suffer from a handicapping or disabling condition. This research has focused on the mother's causal attributions and perceptions of control in parenting diabetic children, developmentally disabled infants, and infants with perinatal complications (Affleck

et al., 1985; Tennen et al., 1986). Several findings have emerged and have begun to contribute to theories of victimization in general. The first finding reflects a very low level of characterological self-blame among mothers of diabetic children and infants with perinatal complications. Tennen et al. (1986) report that just 2.4% of their sample of 50 mothers attributed their infant's condition to characterological features of themselves, while Affleck et al. (1985) did not report characterological blame in their report on 34 mothers of diabetic children.

Whether these low percentages of characterological self-blame are representative of the attributions parents of disabled children make in general, or merely representative of parents of these populations, is a question currently left unanswered. One way of further investigating the generality of this finding would be to examine the level of characterological blame in a group of parents who, it might be expected, would be higher in characterological blame. It could be argued that parents of autistic children might be more likely to attribute the blame for their child's handicap to characterological aspects of themselves for several reasons, such as having been exposed to the early, characterologically oriented, theories of causation, the severity and unpredictability of the behaviors associated with the disorder, and the lack of emotional responsiveness characteristic in these children.

Research using parents as victims has shown support for the positive relationship between behavioral self-blame and adjustment, as mothers of infants with perinatal complications who engaged in more behavioral self-blame were found to be better adjusted (Tennen et al., 1986). However, as yet, no group of parents has reported enough characterological self-blame to allow for direct assessment of their adjustment. Thus, due to the few studies carried out investigating the relationship between self-blame and adjustment in parents of handicapped children, it remains uncertain whether this relationship, prevalent in other victimization studies, operates similarly in this situation. Moreover, it was felt that if the hypothesized higher rate of characterological blame were found in this population, this relationship between type of self-blame and adjustment could be more directly studied than in the past.

Although the specific relationship between self blame and adjustment is as yet undetermined, one type of attribution has been consistently associated with negative or poor adjustment. Previous attribution research has consistently discovered that victims who blame their misfortune on someone else tend to have significantly greater problems with adjustment. This relationship has held for victims of both disease and accidents (Taylor et al., 1984; Janoff-Bulman and Wortman, 1976). A further goal of this study was to attempt to extend this robust finding

to the population of parents as victims.

The Question of Perceived Control

Tennen et al. (1986) in further discussing the relationship between behavioral self-blame and adjustment, argue that path analysis of their data suggests that behavioral self-blame effects adjustment through its association with individual's perceived control over recurrence of the victimizing experience. As stated above, individuals' perception of control has been an often studied phenomenon within the victimization literature, with findings generally, but not consistently, supporting the notion that perception of future control is associated with behavioral self-blame and positive adjustment. Moreover, Tennen et al. argue that any inconsistencies in these findings are attributable to the type of future control investigators have asked about. They theorize that one must distinguish between control over recurrence (whether the victimizing event could occur again to the victim) and control over sequelae (i.e. whether future associated problems could be prevented and/or controlled). Within this distinction, then, it is argued that only when behavioral self-blame is associated with perceived control over recurrence, will positive adaptation be bolstered. As these authors argue, by blaming oneself behaviorally, "the victim can maintain the self protective belief that the future will be different from the past." The results of these authors'

study of this hypothesized relationship, utilizing parents of infants with perinatal complications, supports this path of relationships, and further indicates that cognitions such as perceived control over sequelae were not associated significantly with adjustment and mood.

Although this model and hypothesized network of relationships between the variables of behavioral self-blame, control over recurrence, and positive mood is important clinical and research information in understanding victimization within this parental population, the question of the role of perception of control may not be fully answered as yet. While it is true that individuals' feelings of control over recurrence have predicted their adjustment, it remains unclear whether this finding can be elevated to a general rule within victimization theory, or whether this finding is due to some common aspect of the populations studied thus far.

Research to date has examined parents of diabetics, infants with perinatal complications, and developmentally disabled infants. Concerns over controlling sequelae to these disorders has not been predictive of parental adjustment. It is possible that control over sequelae is not much of a concern or source of ongoing stress because sequelae with these children are perhaps generally more predictable, less disruptive to everyday life, and certainly not usually grossly deviant from community standards or

norms of behavior. However, it might be argued that while these parents might expect chronic struggles, crises, and stressful periods with these children, these expectations might be qualitatively quite different than the expectations and ongoing concerns of parents of an autistic child.

Perhaps the predictability of behavior is an important variable in understanding the role of these control cognitions. It would seem evident that the syndrome of autism might differ from the diseases already studied on the variable of behavioral predictability. Predictability can first of all be thought of in terms of ability to predict short term behavior. The behavior of a diabetic child can broadly be defined as predictable. A diabetic child with a normal blood sugar level is no more likely to tantrum in a store or act in an aggressive manner than one of his non-diabetic peers. Granted a fluctuation in that blood sugar level might alter his behavior; however, regular checking and appropriate diet can more often than not prevent the occurrence of that fluctuation. In that way, the child's behavior is predictable. In contrast, the parent who brings his autistic child to the store has no such guarantee. A mild variation in the route to the store, the style of a store display, or the order of shopping can unpredictably produce a behavioral reaction in such a child that may range from mild annoyance to aggressive acting out. No physical or psychological test has been found to be able to predict

this child's reaction; and thus, the child's immediate behavior is unpredictable in severity, dangerousness, frequency, as well as in time and place of occurrence.

It might secondly be argued that the autistic child's behavior and development are less predictable in the long range as well, certainly at least when the child is young. Such questions as "Is my child able to learn?", "Will he ever learn language?", "Will he ever learn to relate to another individual?", and "Will he be able to care for himself?", are basic questions that the parents of the autistic child struggle with when they consider the sequelae of their child's disease. Moreover, unfortunately, these questions are largely unanswerable for the parent as even professionals have great difficulty making long term predictions for such seriously disturbed children. The certainty of an unpredictable future, and the prospect of an unimproved one, are certain to cause stress on a parent raising such a child. In contrast, while the future of a diabetic child is far from rosy and stress free, it is not marked by the cruel reality that this child may never be able to experience such basic human experiences as communication, interpersonal connection, and certainly independence.

A second way in which the sequelae of autism dramatically differ from the sequelae of most other diseases lies in the fact that the autistic's behavior often grossly

deviates from the norms and common standards of the community. When an autistic child becomes upset, the usual temper tantrum behavior of yelling, screaming, or even flopping on the floor are elevated to include self-destructive, injurious and bizarre behaviors such as head-banging, rocking, and twirling. Moreover, the behavior of such a child is not only grossly deviant when upset; rather, it frequently falls well outside the norm. In contrast to a diabetic child, an MR child, or a physically disabled child, an autistic child is likely to be found rocking in aisle 3, twirling in aisle 4, and loudly repeating familiar commercials verbatim in aisle 5 of the local grocery store.

In essence then, it is being argued that the sequelae of the autistic syndrome are quite different from the sequelae of other disorders studied thus far. As such, it might be premature to conclude, as Tennen et al. (1986) did, that it is control over recurrence, not control over sequelae that is important in predicting parental adjustment to the victimizing experience of having a handicapped child. It remains possible that the nature of the sequelae is more important in determining the relative importance of control cognitions in predicting adjustment. An examination of the control cognitions of autistic parents provides us with an excellent test of the limits of the control hypothesis.

CHAPTER III

THE PRESENT STUDY

This study was designed to investigate two major concerns and interests. On a descriptive level, one major goal of this project was to collect data which could provide both the clinician and the researcher with a beginning understanding of the experience of parenting an autistic child. Therefore, on this descriptive level, the central questions included: What are the stresses involved in fathering an autistic child? In what ways do fathers experience that stress and the emotions that accompany that stress. Are their experiences of stress, and the subsequent adjustment process, similar to the experiences of mothers of these children?

Secondly, on theoretical, inferential, and predictive levels, this study attempted to investigate the relationship between the attributions and control cognitions a parent of an autistic child possesses, and their subsequent adjustment. More specifically, questions in this realm included: What is the role of characterological self-blame in predicting adjustment? Are control over sequelae cognitions important in predicting parental adjustment when parents are faced with a disorder marked by unpredictable

and bizarre behavior? Is the relationship between these three variables (i.e. blame, control, and adjustment) different for fathers and mothers of autistic children? The answer to these questions provided important empirically based information within the field of parenting a handicapped child as well as within victimization theory. It is the answers to these questions which formed the focus of the hypotheses for this study.

Descriptive Analyses

The descriptive assessment focused on an investigation of the parents' experience of stress. It first of all was hypothesized that mothers would demonstrate stress reactions similar to those documented by Bristol (1984) and by Holroyd and McArthur (1976) in which mothers of autistic children expressed problems with depressed mood, excessive time demands, and limits on family opportunities. Early work with fathers of otherwise handicapped children suggested that fathers, like mothers, would be concerned with family opportunities and family integration, yet might differ from mothers in their reactions to financial problems, thoughts about the child's future, and tension around bringing their autistic child to public places (Gumz and Gubrium, 1972; Price-Bonham and Addison, 1978). Given these related findings, four specific hypotheses were proposed:

Hypothesis 1. Mothers of autistic children will demonstrate significant problems with depressed mood,

excessive time demands, and limits on family opportunities as measured by subscales 1, 2, and 9 of the QRS. Significance will be determined by comparing mean subscale scores with norms provided by Holroyd (1987). Mean subscale scores must fall above the 75th percentile to be considered significant.

Hypothesis 2. Fathers of autistic children will demonstrate significant problems with pessimism over the child's future, lack of family integration, limits on family opportunities, financial problems, occupational limitations in the child's future, and social obtrusiveness of the child as measured by subscales 7, 8, 9, 10, 13, and 14 of the QRS. Significance will be determined by comparing mean subscale scores with norms provided by Holroyd (1987). Mean subscale scores must fall above the 75th percentile to be considered significant.

Hypothesis 3. Fathers will demonstrate significantly greater stress reactions to financial problems, occupational limitations, social obtrusiveness, and pessimism over the child's future than mothers of autistic children, as measured by subscales 7, 10, 13, and 14 of the QRS. Statistical significance will be tested using one-tailed t-tests.

Hypothesis 4. Mothers will demonstrate significantly greater stress reactions to excessive time demands and

depressed mood emanating from caring for the autistic child than fathers, as measured by subscales 1 and 2 of the QRS. Statistical significance will be tested using one-tailed t-tests.

Inferential and Theoretical Data

On the inferential and theoretical levels, this proposed project aimed to collect data which would begin to address the issue of parents' attributions, control cognitions, and how these affect their coping processes. It was hypothesized that the relationship between these variables would not be as simple or direct as previous research has suggested (Tennen et al., 1986). Moreover, it was hypothesized that the relationship between these variables would differ from earlier investigations due to the nature of the disorder being investigated.

Early research on mothers of handicapped children indicated that those mothers who engaged in behavioral self-blame while feeling greater control over the recurrence of the handicapping condition in future children adjusted well. Feelings of control over sequelae were not associated with positive adjustment in these individuals. Whether this predictive pattern would hold for mothers of autistic children was debatable. As discussed above, the unpredictability, seriousness, and bizarre nature of the behaviors associated with autism might make it more probable that concerns over controlling sequelae, would also be

important in predicting positive adjustment in these mothers. Therefore, the following specific hypotheses were offered:

Hypothesis 5. Control over Sequelae cognitions will be significantly and positively related to emotional adjustment for mothers of autistic children. Control over sequelae will be measured using the "Control over Sequelae" score derived from the control questionnaire. Emotional adjustment will be measured using the Total POMS score. The degree of relationship will be measured using a Pearson Product Moment Correlation.

Hypothesis 6. Control over recurrence will be significantly and positively related to emotional adjustment for mothers of autistic children. Control over recurrence will be measured using the "Control over Recurrence" score derived from the Control Questionnaire. Emotional adjustment will be measured using the Total POMS score. The degree of relationship will be measured using a Pearson Product Moment Correlation.

Hypothesis 7. The relationship between control over sequelae cognitions and emotional adjustment will be significantly stronger than the relationship between control over recurrence cognitions and emotional adjustment for mothers. Control over sequelae and control over recurrence scores will be derived from the

Control Questionnaire. Emotional adjustment will be measured using the Total POMS score. Pearson correlation coefficients will be transformed and tested for a significant difference using a t-test designed to measure differences between dependent correlations.

The question of whether these cognitive patterns and relationships were gender specific, or specific to the maternal or paternal parenting role, was addressed directly by comparing the relationship of the mothers' attributions, control cognitions, and adjustment with that of the fathers'. One similarity was first hypothesized. Again due to the unpredictable, pervasively incapacitating behavior of the autistic child, it was hypothesized that the fathers' control over sequelae cognitions would be positively related to emotional adjustment.

Hypothesis 8. Control over sequelae cognitions will be significantly and positively related to emotional adjustment for fathers of autistic children. Control over sequelae will be measured using the "Control over Sequelae" score derived from the Control Questionnaire. Emotional adjustment will be measured using the Total POMS score. The degree of relationship will be measured using a Pearson Product Moment Correlation.

Two differences between mothers and fathers were also hypothesized. First, research discussed above (Price-Bonham and Addison, 1978) suggested that fathers were more

disturbed by behaviors of the handicapped child which violated community norms and standards. Thus, it was hypothesized that the role of control over sequelae cognitions would take on a greater importance for fathers of autistic children than for mothers.

Hypothesis 9. The relationship between control over sequelae cognitions and emotional adjustment will be significantly stronger for fathers than for mothers. Control over sequelae cognitions will be measured using the "Control over Sequelae" score derived from the Control Questionnaire. Emotional adjustment will be measured using the Total POMS score. The difference in strength of relationships will be tested by converting correlation coefficients to Fisher z scores and testing for significant differences.

Previous research on parents of handicapped children has not uncovered a significant incidence of characterological self-blame in mothers of handicapped children. It was expected, given the theoretical history of characterological blame within the clinical and research work on autism, that a significant incidence of characterological self-blame would be found in these mothers. The prediction of increased characterological self-blame in mothers was based on the long history of maternal blaming in the psychological literature. This characterological blaming is rarely applied to fathers of

these children either in the research literature or in clinical practice. It was thus hypothesized that fathers would demonstrate less characterological blame than mothers. Whether this lack of characterological blame would be replaced by behavioral self-blame, other blaming, or attributions to chance was difficult to predict specifically, but was assessed in order to provide valuable clinical and research information.

Hypothesis 10. Mothers will report more characterological self-blame than fathers.

Characterological self-blame will be measured using that Characterological Self-Blame score derived from the Attributions Questionnaire. The difference will be tested for statistical significance using a one-tailed t-test.

Previous authors have concluded that increased characterological self-blame would be associated with greater adjustment problems. This conclusion, however, was not based on a direct finding of such a relationship. Rather, this conclusion was generalized from the well documented finding that behavioral self-blame is associated with better adjustment. While such a relationship between characterological self-blame and adjustment is intuitively appealing and can be hypothesized to exist, it was hoped that this study would provide the opportunity to test this relationship directly. In addition, it was hoped that this

study would provide the opportunity to examine if the relationship between behavioral self-blame and adjustment held for this population.

Hypothesis 11. Characterological self-blame in mothers will be inversely related to emotional adjustment. The magnitude of this relationship will be statistically significant. Characterological self-blame will be measured using the "Characterological Self-Blame" score derived from the Attributions Questionnaire. Emotional adjustment will be measured using the Total POMS score. The degree of relationship will be measured using a Pearson Product Moment Correlation.

Hypothesis 12. Behavioral self-blame in mothers will be positively related to emotional adjustment. The magnitude of this relationship will be statistically significant. Behavioral self-blame will be measured using the "Behavioral Self-Blame score derived from the Attributions Questionnaire. Emotional adjustment will be measured using the Total POMS score. The degree of relationship will be measured using a Pearson Product Moment Correlation. Other hypothesized relationships were tested in this study,

such as the predicted lack of relationship between control over recurrence and adjustment in fathers, greater concern over control over recurrence in mothers than fathers, and the inverse relationship between blaming someone else and

adjustment in both parents. These were considered secondary hypotheses in this study because they did not emanate directly from the current research literature either within victimization theory or parenting.

Predictive and Causal Modeling

This study can, in many ways, be considered an exploratory study, investigating through questionnaires and interviews the process of parenting the autistic child. As such, it was unclear exactly how many parents would agree to participate in this study. It was planned that at least 25 mothers and fathers would participate. It was originally proposed that if sample size were increased (or if mothers' and fathers' data were combined to form one data set due to the lack of significant differences between these groups), then a post hoc multiple regression analysis would be conducted. Although only 25 mothers and 25 fathers were recruited, the post hoc predictive modeling was attempted.

Such an analysis was designed to produce a predictive model of parental adjustment. It was planned in order to test the underlying hypothesis that the thoughts and feelings regarding control and causation are important variables in understanding the adjustment process of a parent of an autistic child. It was proposed that this model would be conceptualized and reported as a post hoc analysis, and thus would need replication before issues of valid prediction could be adequately addressed. However,

given the exploratory nature of this study, such a post hoc analysis would add rich data to the relevant clinical and research literature.

CHAPTER IV

METHOD

Subjects

A sample of 25 married couples, each with a non-institutionalized autistic child between the ages of 5 and 11, participated in this study. In all 25 cases, both the mother and father were the biological parents of the autistic child and were residing with that child at the time of the study. Parents resided in one of three midwestern states (Illinois, Indiana, and Wisconsin). Eighteen of the 25 couples were recruited for participation through their local chapter of the Autism Society of America. The remaining seven couples were recruited through cooperative arrangements with two local schools and two local agencies specializing in providing services for families with an autistic child. All subjects participated voluntarily and no services were made contingent upon participation.

Mothers. Mothers' ages ranged from 24 to 47 years, with a mean age of 36.76 years. Of the 25 participants, 22 were white, 2 were black, and 1 was oriental. Mothers reported a wide range of educational experiences as 8 mothers reported their highest completed grade level to be the 12th grade (i.e. high school graduate), 10 mothers had

some college credit but had not earned a degree, 6 mothers had earned a college degree, and 1 mother was pursuing an advanced graduate level degree. Somewhat in contrast to this, 3 mothers reported working full time outside the home, 8 mothers indicated they worked part time outside the home, and 14 mothers reported not working at all outside the home. For mothers working full time outside the home, the mean annual salary was \$30,000; mothers working part time earned an average of \$5,687 annually (see Table 1).

Fathers. Fathers' ages ranged from 30 to 44 with a mean age of 36.96 years. Of the 25 fathers, 22 were white, 2 were black, and 1 was oriental. Fathers too reported a range of educational experiences, as 6 fathers reported finishing their formal education after the 12th grade, 8 fathers reported receiving some college credits but not graduating, 6 fathers had completed their education with the attainment of a college degree, and 5 fathers had received an advanced graduate level degree. All 25 fathers reported currently working full time outside the home, earning an average of \$32,960 annually (see Table 1).

The Autistic Children. The autistic children's ages ranged from 60 to 130 months, with a mean age of 86.88 months. Of the 25 autistic children studied, 20 were male and 5 were female -- a balance reflecting the sex ratio statistics reported by Rimland (1964), Rutter (1968), and numerous other researchers.

Table 1

Annual Income Reported for Mothers, Fathers and Household

<u>Income</u>	<u>Mother</u>	<u>Father</u>	<u>Household</u>
\$0	15	0	0
\$1-9,999	5	0	0
\$10,000-19,999	2	0	0
\$20,000-29,999	1	7	5
\$30,000-39,999	2	11	9
\$40,000-49,999	0	4	5
Over \$50,000	0	3	6

Mothers reported that all children had been diagnosed as autistic by a medical doctor. Although no absolute confirmation of this diagnosis could be made by this investigator, the combination of parents' reports, behavior ratings of the child, and membership of 76% of these families in the Autism Society of America bolsters the validity of these diagnostic reports. The ages at which these children were diagnosed as autistic ranged from 18 to 96 months, with the mean age at diagnosis being 46.36 months (Median = 42 months). From these two responses (age of child and age at diagnosis), a measure of time since diagnosis was calculated. It was discovered that the most recent diagnosis had occurred within the past month, while the most remote had been 88 months ago. The mean time since diagnosis was 40.76 months.

All children were currently in some form of specialized educational placement. For 22 of these, this meant a special classroom within the public school system; for 3 of these, this placement was in a private school specializing in children with severe emotional and mental handicaps. In addition, mothers reported that 7 of the 25 children currently were receiving additional special services, including five for speech/language therapy, 1 for individual counseling, and one for recreational activities.

Descriptive analysis of the autistic child's behavior was obtained from mothers' responses to the Child Behavior

Rating Scale subsection of the Family Information Questionnaire. This list and description of 27 behaviors commonly associated with autism was adapted from an observational measure developed by Paolella (1973). Content validity analysis suggests that Paolella's list of behaviors associated with autism corresponds well to the clinical and research literature describing infantile autism (Kanner, 1943; DSM-III-R, 1987). In addition, reliability analyses suggests that the instrument is internally consistent (Cronbach $\alpha=.78$). Mothers rated each behavior using a 5-point Likert scale ranging from "very rarely" observed to "very often" observed (See Appendix A).

Table 2 represents the mean ratings, standard deviations, and frequency with which each behavior was reported to have occurred at least "sometimes" (i.e. a rating of at least a 3) in this sample of 25 children. Overall, it can be seen that 16 of these 27 representative behaviors occur at least "sometimes" in more than half of this sample. The most frequently reported (and highest rated) behaviors were those labelled "Primitive non-verbal communication" (88%), "abnormal preoccupations" (84%), and "poor persistence" (84%). These percentages indicate that a very high percentage of the sample is able to engage in non-verbal interaction, such as making eye contact and gesturing, but rarely are they able to communicate verbally. In addition, these ratings indicate that most autistic

Table 2

Frequency Ratings of Behaviors Commonly Associated with
Autism

<u>Behavior</u>	Mean Frequency <u>Rating</u>	<u>S.D.</u>	Number of subjects displaying behavior at least <u>"sometimes"</u>
Autism	2.75	1.36	13
Withdrawal	2.21	1.41	10
Primitive-nonverbal Communication	3.79	1.22	22
1-2 year old relating	3.38	1.53	18
Primitive perceptions	3.25	1.26	18
Lack of response to Auditory Stimuli	2.13	1.12	11
Lack of response to Painful Stimuli	1.79	1.41	06
Absence of verbal-expressive Language	2.88	1.75	13
Non-communicative language	1.92	1.53	07
Echolalia	2.54	1.72	11
Poor persistence	3.58	1.28	21
Coordination problems	3.25	1.42	16
Hyperkinesis	3.17	1.55	16
Hypokinesis	1.79	1.02	04
Stereotyped Movements	3.29	1.37	18
Non-adaptability	2.67	1.24	13

Table 2 (cont.)

<u>Behavior</u>	Mean Frequency <u>Rating</u>	<u>S.D.</u>	Number of subjects displaying behavior at least <u>"sometimes"</u>
Abnormal preoccupations	3.50	1.14	21
Other obsessions	2.83	1.44	16
Eating difficulties	2.38	1.53	09
Sleep Disturbances	3.08	1.56	15
Incontinence	3.00	1.67	15
Self Injury	1.38	.88	01
Aggression	2.25	1.23	11
Tantrums	2.29	.99	08
Anxieties	2.17	1.09	09
Special Abilities	2.88	1.62	14
TOTAL Behavior Rating (Overall mean)	2.72	.53	

children reportedly display the usual preoccupations with simple objects and an inability to focus attention for any reasonable period of time.

In contrast, only one of the 25 children engages in serious self-injurious behaviors, and few demonstrate a "lack of response to painful stimuli" (24%) or "hyperkinesis" (16%). In addition to these individual behavior ratings, a total behavior rating was calculated for each child by taking the grand mean across all behavior ratings. This mean was used as one index of severity in predictive modeling attempts to forecast adjustment reactions (see Chapter V).

The Family Unit. Although the family unit was not the prime focus of study of this investigation, basic demographic characteristics are reported here to help place results into context. Of the 25 families studied, 7 only had children older than their autistic child, 12 only had children younger than their autistic child, 1 had children both older and younger than their autistic child, and 5 had no other children besides their autistic child.

Moreover, based on mothers' reports, 10 of the 25 families were receiving special services aimed at the family as a whole. These family services included such things as respite care services (7), parent group meetings (2), and couples counseling (1).

Mothers were also asked to complete a Family Role

Rating Scale as part of the Family Information Questionnaire (see Appendix A). This scale asked mothers to indicate who in the family was responsible for completing various tasks associated with having an autistic child. Mothers rated the distribution of family responsibilities using a 5-point scale with the following delineations: 1 = Only dad helps with this chore; 2 = Dad helps most with this chore, but others help too; 3 = Mom and Dad help equally; 4 = Mom helps most with this chore, but others help too; 5 = Only mom helps with this chore. Mothers rated family participation on five tasks associated with daily living skills, three tasks associated with teaching and/or playing with the child at home, and five tasks associated with contacting agencies, other parents, and professionals regarding issues related to their autistic child. Reliability analysis suggests an internally consistent instrument (Cronbach alpha=.81).

The distribution of roles across families is reported in Table 3. The individual task ratings within each domain were then averaged to provide an overall mean domain score. Mean ratings and standard deviations for these three domains, as well as a total mean family role score are reported in Table 4.

Table 3 indicates that mothers report that they bear the majority of the responsibilities associated with parenting the autistic child. This division of responsibilities is most clearly seen in mothers' role in

Table 3

Distribution of Family Responsibilities Associated with
Caring for an Autistic Child

<u>Responsibility</u>	Dad helps more than <u>Mom</u>	Dad and Mom help <u>equally</u>	Mom helps more than <u>Dad</u>	Child needs <u>no help</u>
Daily Living Skills				
Toileting	1	10	7	7
Eating	2	5	2	16
Bathing	1	9	12	3
Dressing	1	6	12	8
Undressing	1	3	7	14
Teaching/Recreation				
Language	2	6	16	1
Playing	1	13	10	1
Teaching D.L.S.	0	11	14	0
Contacts				
School Contacts	0	4	21	0
Doctor Contacts	0	2	23	0
Agency Contacts	0	5	19	1
Parent Contacts	0	2	23	0
Political Contacts	1	4	13	7

Table 4

Mean Family Responsibility Ratings for Tasks Associated with
Caring for an Autistic Child

<u>Responsibility</u>	<u>Mean</u>	<u>SD</u>
Daily Living Skills (#'s 1-5)	3.74	.77
Teaching/Recreation (#'s 6-8)	3.64	.47
Contacts (#'s 8-13)	4.36	.69
Overall Family Role (Total 1-13)	4.02	.50

making contacts with other professionals and agencies.

Across all five tasks associated with making contacts with agencies and professionals, only 1 of 25 fathers was reported to bear the majority of the responsibility. This disparity in responsibilities is less dramatic, although still clearly present, when considering the domains of daily living skills and teaching/recreation. Further investigation of Table 3 again indicates that fathers bore the majority of the responsibility in no more than 2 of 25 cases, across all daily living skill activities and teaching activities.

Moreover, these trends can be supported statistically as well. Using results reported in Table 4, mean domain ratings and the mean overall rating can be compared with an expected mean value of 3.00 to test the null hypothesis that mothers do not report carrying a greater burden of family chores than fathers. T-tests comparing the observed means against the expected mean suggest that mothers ratings across all three domains (and overall) are significantly greater than the 3.00 rating that would be expected if parents were sharing the chores equally ($t(24)=6.17$ for Daily Living Skills Domain; $t(24) =21.3$ for Teaching/Recreation Domain; $t(24)=8.50$ for Contacts Domain; and $t(24)=8.50$ for the overall rating). This statistical analysis supports the observation that mothers report that they shoulder a greater burden of the family

responsibilities associated with caring for an autistic child than fathers. This pattern replicates the findings of Milgram and Atzil (1988) who reported that mothers do about two-thirds of the parental care work in families with an autistic child.

Materials

Parents were asked to complete the following five questionnaires:

1.) The Family Information Questionnaire is a three part non-standardized instrument (See Appendix A). The first part consists of questions tapping parental demographic information (i.e. age, race, occupation, etc.) and general family information. The second part of the Family Information Questionnaire is the Child Behavior Rating Scale, which asks parents to rate the frequency with which they observe specific autistic behaviors. This has been discussed in detail above. The third part is entitled the Family Role Rating Scale and asks parents to indicate who in their home is responsible for completing various chores. Description of this scale, as well as results, can be found in the preceding section.

2.) The Attributions Questionnaire is a 19 item non-standardized instrument designed to investigate parents' theories concerning the cause(s) of their child's autism, as well as to examine the frequency of their blaming behavior (See Appendix B). Previous empirical work exploring

parental theories of causation for their child's disabling condition has suggested that such attributions could be efficiently divided into five general categories (Tennen et al., 1986; Affleck et al., 1985; Affleck et al., 1987). These five categories include blaming one's own personality (i.e. characterological self-blame), blaming one's own behavior (i.e. behavioral self-blame), blaming chance, blaming someone else, and blaming something else. In order to obtain a measure of each of these types of blame, a two-part rating scale was constructed.

The first part (Causes Questionnaire) attempts to investigate each parent's personal theory regarding the cause or causes responsible for his/her child's autism. A list of 14 possible causes of autism was presented to the parents. This list was generated by examining the theoretical and clinical literature regarding the etiology of autism. No attempt was made to limit this list to theories which have more empirical support; rather, an attempt was made to create a more exhaustive list. Moreover, each cause listed is an example of one of the aforementioned five types of attributions. For example, attributing the cause of your child's autism to a doctor's error during delivery would be an example of "blaming someone else". Parents were asked to rate on a six point scale, ranging from "not a factor at all" to "completely responsible", how much they consider each possible cause to

have actually been a causal factor in their child's autism.

The second part of the scale (Blame Questionnaire) attempts to measure how frequently parents' find themselves blaming various causes for their child's autism. Parents were asked to rate on a 6 point scale, ranging from "never" to "always" how frequently they find themselves attributing blame to each of the five general causes listed above.

Five scores were derived from the Attribution Questionnaire. These scores include: a measure of characterological self-blame; a measure of behavioral self-blame, a measure of blaming chance; a measure of blaming someone else; and a measure of blaming something else. All measures were calculated by adding the rating from the Cause Questionnaire (rating from part one) to the rating from the Blame Questionnaire (rating from part two) for each of the five general types of attributions. When more than one question in part one tapped into the same general type of attribution, the question which received the highest rating was used to calculate the score for that type of attribution.

More specifically, the measure of characterological self-blame for the mother was calculated by adding the rating from the question reflecting the parent's attribution of characterological self-blame on part one (Question 11) to the rating of the question measuring the frequency of characterological self-blame in part two (Question 1). The

measure of behavioral self-blame for the mother was calculated by adding the higher of the two ratings from the two questions measuring behavioral self-blame on part one (Questions 2 and 9) to the rating of the frequency of behavioral self-blame on part two (Question 2). The measure of blaming someone else was calculated by adding the highest rating of the three questions reflecting blaming someone else on part one (Questions 8, 10, and 12) to the rating of the frequency of this blaming others on part two (Question 4). The measure of blaming something else was calculated by adding the highest ratings from the six questions reflecting blaming something else on part one (Questions 1, 3, 5, 6, 7, and 8) to the rating of the frequency of this blame on part two (Question 5). The measure of blaming chance was derived by adding the measure of blaming chance on part one (Question 13) to the rating of the frequency of blaming chance on part two (Question 3).

3.) The Control Cognition Questionnaire is a seven item non-standardized rating scale (See Appendix C). Research investigating the adjustment of individuals to a victimizing experience has suggested that two type of control cognitions can be identified (Tennen et al., 1986). The first, labelled "control over recurrence", refers to individuals' thoughts about whether the victimizing experience might happen to them again. This construct has been measured by asking individuals to rate (using Likert type scales) how

much control they felt they had over this recurrence. In this study, this construct, control over recurrence, was measured similarly using one question from the seven item rating scale. This question asked the parents to rate how much control they feel they have over the outcome of future pregnancies in terms of preventing autism. This, and all ratings, were based on a six point rating scale which ranged from "almost no control" to "almost complete control".

The second type of control cognition refers to controlling the subsequent symptoms or sequelae of a victimizing experience. This construct has been measured by asking individuals to rate (using Likert type scales) how much control they felt they had over the course of their illness or over the symptoms which followed from a victimizing experience (Taylor et al., 1984; Affleck et al., 1985). This construct is labelled "control over sequelae" and was measured in two ways in this study. First, we measured "control over current sequelae" by asking parents to rate how much control they felt they had over modifying their child's current autistic behavior, language, and learning abilities. These three ratings were averaged to produce a "Control over Current Sequelae" score. Second, we measured "control over future sequelae" by asking parents how much control they felt they had over influencing their child's future autistic behavior, language, and learning abilities. These three ratings were averaged to produce a

"Control over Future Sequelae" score.

4. The Questionnaire on Resources and Stress (QRS) (Holroyd, 1974) is a 285 item, standardized, true-false instrument designed to measure the influence of handicapped persons on other family members (See Appendix D). This measure yields scores on 15 subscales which form three general factors: Parent Problems; Family Problems; and Problems with the Child. A total stress score, or full scale measure is also calculated.

The Parent Problem factor includes subscale measures of poor health/mood, excessive time demands, negative attitudes towards the handicapped individual, overprotection-dependency, lack of social support, overcommitment-martyrdom, and pessimism. The Family Problem factor includes subscale measures of lack of family integration, limits on family opportunities, and financial problems. The Problems with the Child factor includes subscale measures of physical incapacitation, lack of activities for the child, occupational and educational limitations for the child, social obtrusiveness, and difficult personality characteristics.

Reliability of the QRS has been demonstrated in several independent empirical works. Holroyd (1987) reports a Kuder-Richardson 20 reliability correlation of .96 for the full scale QRS, indicating an internally consistent instrument. Kuder-Richardson reliability estimates for all

subscales are also reported by Holroyd. No test-retest reliability coefficients are yet available.

Validity of the QRS has been extensively demonstrated through numerous criterion validation studies. These studies have demonstrated that the QRS is useful in discriminating populations which differ in diagnosis, degree of handicap, parent attributes, and availability of community resources (Holroyd, 1987). Holroyd (1987) further reports that evidence of construct validity is beginning to accumulate, based primarily on preliminary studies correlating the QRS with other measures and using the QRS to measure changes following treatment. Further evidence of reliability and validity is detailed in Holroyd ((1987; 1988).

A final strength of the QRS should be noted. Holroyd (1987) provides extensive normative data for the QRS, including norms for mothers of autistic children, mothers of Down's syndrome children, and caregivers of numerous disabling conditions. These data provide norms for each subscale of the QRS.

5.) The Profile of Moods States-Bipolar (POMS-B) (Lorr & McNair, 1984) is a 72 item adjective list which asks subjects to rate the degree to which each adjective describes their current feelings. Subjects in this study were asked to indicate the degree to which each adjective described their mood "over the past week", as opposed to

"right now" (see Appendix E). This slight modification allows for a more accurate assessment of the mood of a parent who is struggling with a chronic stressor. Parents rated each adjective using a 4 point scale which ranged from "much unlike this" to "much like this" in indicating how well each adjective reflected their recent mood. This instrument is designed to measure six bi-polar mood states labelled as "composed-anxious", "elated-depressed", "agreeable-hostile", "energetic-tired", "confident-unsure", and "clearheaded-confused". Twelve adjectives represent each construct. In addition, a total mood score is derived.

This instrument is a widely utilized research scale that has been shown to be a reliable and valid measure of mood. Evidence of reliability and validity can be found in McNair, Lorr, and Droppleman (1971) and Lorr, McNair, and Fisher (1983). Moreover, this measure has been demonstrated to be a reliable and valid measure of mood in victimized populations such as individuals adjusting to the diagnosis of breast cancer (Taylor et al., 1984) and mothers of developmentally disabled infants (Affleck, McGrade, Allen, & Queeney, 1985).

In addition to the aforementioned questionnaires, parents' control cognitions and attributions of cause were to be assessed through a semi-structured interview. No specific hypotheses were to be tested directly using data from the interview alone; the information gathered here was

to be used to supplement, highlight, and elaborate upon the quantitative data obtained through the numerous questionnaires. The format and content of the interview were drawn from similar interviews designed to assess the effects of victimization across a wide range of victimizing experiences (e.g. Affleck et al., 1985; Shulz & Decker, 1985; Taylor et al, 1984; and Tennen et al., 1986). A complete text of the planned interview can be found in Appendix F. Unfortunately, due to the necessity of recruiting subjects from out of state, in depth in-person interviews could not be completed for most members of this study. For several subjects, less structured phone interviews supplemented the quantitative data and will be discussed in order to assist in the interpretation of the quantitative results.

Procedure

Subjects were recruited through personal and professional contacts. As discussed above, the majority of parents (76%) were recruited through local chapters of the Autism Society of America (ASA). Because most subjects resided out of state, initial contact was made with the president of the local chapter of the ASA. Procedures for contacting individual parents to request participation then proceeded according to the individual suggestions of the chapter's president. In almost all cases this involved sending the chapter President several cover letters, and

consent forms requesting participation, to be distributed to parents in her chapter (See Appendix G). Included with each letter and form was a stamped return envelope addressed to the experimenter. If parents either chose to participate, or wanted more information before making a decision, they would return the form to the experimenter, granting permission to contact them directly. This procedure was developed in cooperation with several local ASA chapters in order to preserve the confidentiality of both those parents who chose not to participate (i.e. the experimenter would never receive the names of these parents), as well as those parents who chose to participate (i.e. local chapter presidents would not be aware of who agreed to participate and who declined). On each consent form, both mothers and fathers were asked to sign indicating their intention to participate. For those parents not recruited through a local ASA chapter, similar recruitment methods and precautions were established in cooperation with the referring organization.

Upon agreement to participate, each parent was mailed out a packet of materials. Each packet contained a letter of introduction and general instructions (see Appendices H and I), the Attributions Questionnaire, the Control Cognitions Questionnaire, the QRS and an answer sheet, and the POMS-B. In addition, packets addressed to mothers also contained the Family Information Questionnaire. This was

not included in both parents' packets for two reasons. First, it was felt that much of the information gathered would have been redundant if requested from both parents. Secondly, the literature is replete with failed efforts at gaining fathers' participation in studies similar to this. By including this questionnaire only in the mothers packet, it was hoped that the fathers' work load would be somewhat diminished and that this would lead to greater response rate from the fathers. All packet materials were number coded to guarantee anonymity.

Parents were asked to return the completed packet of materials using an enclosed stamped and addressed return envelope. A due date of three weeks after reception of materials was included in each cover letter. Parents who did not respond by one week after the due date were called and reminded about the study and importance of completing the questionnaires as soon as possible. Overall, 45 packets of information were sent out to parents; 28 were eventually returned to the experimenter, producing a return rate of 62.2%. Of these 28 packets returned, 3 were considered unusable due to failure to follow instructions. Select interviews took place by phone after receiving completed questionnaires from both parents.

One final diversion from the originally proposed procedure should be noted. It had been planned that each child's teacher would complete a Child Behavior Rating Scale

to corroborate the behavior ratings of the parents. Due to the inability to recruit subjects in close geographical proximity to the experimenter, cooperative arrangements with school districts scattered throughout the midwest would have been required to procure this data. Given the limited resources of this project, this was an impossibility.

After completion of the data collection, parents were sent a brief letter thanking them for their participation and offering a bit more information about this research project (See Appendix J.). In addition, parents were reminded that they would have the opportunity to discuss the findings from this project with the experimenter at a local meeting during the late spring of 1990. These local meetings were arranged with the president of the local chapter of the ASA (or director of the cooperating institution if not affiliated with the ASA).

CHAPTER V

RESULTS

Results will be presented in three separate sections. First, descriptive results pertaining to parents' experiences of stress and adjustment are presented. These results focus on data obtained from the QRS instrument and the POMS instrument and address the first four aforementioned hypotheses. Secondly, theoretical questions addressing the role of control and attributional cognitions in the adjustment process of parents are considered through the descriptive and inferential analyses proposed by hypotheses 5 through 12. Thirdly, an attempt at post hoc causal modeling is presented, both as a way to explore the current data from a more experimental perspective, as well as to suggest future avenues of inquiry.

Across all sections, the major a priori experimental hypotheses (see Chapter III) are considered first, followed by secondary hypotheses and supplemental analyses. In addition, it should be noted that unless specifically noted, outcomes of statistical tests are treated as statistically significant if they reach the traditional .05 level of significance.

Descriptive Results of Stress and Adjustment

The QRS as a Measure of Stress in Parents

In order to examine the stresses reported by parents of autistic children, 15 subscale and 1 total score were derived from the QRS for each subject. Means, standard deviations, and percentile scores for mothers and fathers are presented in Table 5. Percentiles were determined using norms provided by Holroyd (1987). The reference group for these norms was parents of school-aged children.

Mothers. It was first hypothesized that mothers of autistic children would report significant problems with depressed mood, excessive time demands, and limits on family opportunities as measured by QRS subscales 1, 2, and 9 respectively. Mean scores on all three subscales (5.60, 7.36, and 2.48) fell well above the 90th percentile. Since an a priori significance level of the 75th percentile was set, it can be concluded that this hypothesis is statistically supported.

Further examination of mothers subscale scores in Table 5 revealed several additional important findings. First, mothers' mean subscale scores fell below the 90th percentile on only three occasions. That is, mothers exhibited significant additional stress reactions in all areas measured by the QRS except for those areas tapping financial problems (scale 10), lack of family integration (scale 8), and lack of out-of-home activities for their autistic child

Table 5

Mean, Standard Deviation and Percentile Scores for all QRS
Subscales for Mothers, Fathers, and a Comparison Group

<u>Scale</u>	<u>Mother</u>			<u>Father</u>			<u>Bristol</u>	
	<u>M</u>	<u>SD</u>	<u>%</u>	<u>M</u>	<u>SD</u>	<u>%</u>	<u>M</u>	<u>SD</u>
<u>Personal Problem Scales</u>								
1. Poor health/mood	5.60	3.34	93	4.36	2.98	84	5.5	2.9
2. Excess Time Demands	7.36	3.26	99	5.28	2.82	84	6.9	3.2
3. Neg. Attitude towards Index Case	13.40	3.25	99	12.00	4.04	99	11.4	4.0
4. Overprotection/Dependency	6.84	2.25	94	7.20	2.06	97	6.4	2.4
5. Lack of Social Support	5.56	1.69	98	5.04	1.14	95	3.4	1.4
6. Overcommitment/Martyrdom	4.32	.90	92	3.64	1.08	83	3.8	1.0
7. Pessimism	4.08	2.27	90	4.12	2.44	90	3.8	2.1
<u>Family Problem Scales</u>								
8. Lack of Family Integration	4.80	3.48	87	3.20	2.27	64	4.5	3.1
9. Limits on Family Opportunity	2.48	2.24	93	2.44	2.58	92	3.2	2.6
10. Financial Problems	3.72	3.94	68	4.04	3.18	75	4.3	2.8
<u>Problems of Child Scales</u>								
11. Physical Incapacitation of Index Case	3.32	1.60	99	2.96	1.27	89	3.4	2.2
12. Lack of activities for Index Case	1.84	1.46	87	2.32	1.15	92	2.3	1.6
13. Occupational Limits for Index Case	3.88	.88	94	4.08	.99	95	4.0	1.2
14. Social Obtrusiveness	2.76	1.39	97	2.32	.85	95	2.6	1.2
15. Difficult Personality Characteristics	17.32	5.37	99	16.20	5.07	99	19.2	5.6
TOTAL QRS SCORE	87.24	26.19		79.08	23.42			

* Mothers score differs significantly from fathers at p of .05.

** Bristols means are included here for comparison purposes. Her means are based on a sample of 40 mothers of autistic children.

(Scale 12). Moreover, even in two of these three areas (i.e. lack of activities and lack of family integration), mothers' scores reflected an elevated stress reaction, with mean subscale scores exceeding the a priori significance level of the 75th percentile.

It should be specifically noted that mothers in this study demonstrated strikingly strong personal stress reactions in all areas measured by the QRS (i.e. scales 1-7). All personal problem subscale means exceeded the 90th percentile. Moreover, in three specific areas (scales 2, 3, and 5), mothers' mean scores fell in the 98th and 99th percentiles. These subscale scores indicate mothers are experiencing serious problems in the domains of excess time demands, lack of social support, and negative attitudes¹ towards their autistic child (See endnote 1).

In order to compare results obtained from this sample with results obtained by Bristol, Schopler, and their colleagues in an investigation of over 40 mothers of autistic children, Table 5 also presents subscale mean and deviation scores as reported by Bristol (1979). As is evident, subscale scores obtained in this present study closely match subscale scores reported by Bristol. Two slight variations, however, are noteworthy. Mothers in the current study exhibited slightly more negative attitudes toward their autistic child and reported less social support than the mothers Bristol studied. Apart from these slight

differences, however, it appears that the stresses experienced and reported by both groups of mothers are remarkably similar.

In sum, QRS responses indicate that mothers of autistic children report significant feelings of sadness (Scale 1), pressure, and time constraints from caring for their autistic child (Scale 2), strong feelings of concern over what others might think about her or her child (Scales 3 and 14), a lack of supportive personal and professional resources (Scale 4), and a great concern about the child's future and how it might impact upon herself and her family (Scales 7 and 9). These concerns in mothers seem to be exacerbated by two additional stressors. The first is a belief that only she can adequately care for her autistic child (Scale 5). The second is the reality that she is caring for a child who is quite delayed in his ability to care for himself, and possesses numerous personality and behavioral characteristics which are considered quite unusual, often socially inappropriate, and very resistant to change (Scales 11, 14 and 15).

Fathers. A second hypothesis concerning stress reactions involved the fathers' reactions to parenting an autistic child. It was hypothesized that fathers would report significant problems with pessimism over the child's future, lack of family integration, limits on family opportunities, financial problems, occupational limitations

in the child's projected future, and social obtrusiveness of the child as measured by QRS subscales 7, 8, 9, 10, 13, and 14 respectively. Mean scores on five of these six subscales reached or exceeded the set significance level of the 75th percentile. Only fathers' scores on the scale measuring family integration problems fell below the 75th percentile. As such, this hypothesis is generally supported with the noted exception.

Additional examination of fathers' subscale scores in Table 5 revealed several other important findings. Fathers, like mothers, also exhibited strong personal stress reaction. In three specific areas tapping personal problems, fathers exhibited stress levels corresponding to the 95th percentile or above. Like mothers, fathers reported strong negative attitudes towards their autistic child and strong feelings that they were not receiving adequate social support. In addition, fathers also reported significant problems on the overprotection/dependency scale. A significant score on this scale indicates that fathers believe that their child is too dependent upon assistance from others and is overprotected. In addition, fathers also reported significant stress in the personal problem domains of depressed mood, excess time demands, and overcommitment, as scores on these subscales surpassed the 75th percentile cutoff.

In summary, fathers' expressed significant stress

reactions across numerous domains. Stressors which seem to be particularly burdensome for fathers were concern over what others might think about his child and about him, feelings that his child was too dependent upon care, and great concern for the child's future and how it will impact upon himself and his family. Again these concerns seem to be exacerbated by a general lack of personal and professional support as well as by the reality of dealing with a seriously disabled child.

Mother-Father Comparisons. Hypotheses 3 and 4 were concerned with direct comparisons of the stress profiles of mothers and fathers. More specifically, hypothesis 3 stated that fathers would demonstrate significantly greater stress reactions than mothers in regards to financial problems, occupational limitations for the child, social obtrusiveness of the child, and pessimism over the child's future. In order to test these hypotheses, separate one-tailed t-tests were performed using the mean subscale scores from the QRS. Although the pattern of means reported in Table 5 suggested that fathers did indeed report slightly more stress in all these areas except concerns over social obtrusiveness, none of these differences approached statistical significance (all p 's $> .10$). Thus, hypothesis 3 is not supported by the current data.

The fourth hypothesis expressed the prediction that mothers would demonstrate significantly greater stress

reactions to depressed mood and excessive time demands. Examination of the means reported in Table 5 indicate that mothers did indeed report greater problems with depressed mood (5.60 vs. 4.36) and excess time demands (7.36 vs. 5.28). In order to test these comparisons statistically, two one-tailed t-tests were performed. Statistical results indicate that although mothers did not report statistically greater problems with depressed mood ($t(48)=1.38$; $p > .05$), mothers did demonstrate significantly greater stress reactions to the excess time demands required of them, $t(48)=2.41$; $p < .05$, partially supporting this hypothesis.

More general analysis of the different parental patterns reported in Table 5 indicates a general pattern of slightly greater stress reactions in mothers than fathers, culminating in a higher mean total QRS score for mothers than fathers (87.24 vs. 79.08). In order to test this difference for statistical significance, a post hoc t-test was calculated. Results indicated, however, that this difference was not statistically reliable ($t(48)=1.16$; $p > .05$).

Further perusal of Table 5 indicated numerous other slight differences between mothers' and fathers' stress reactions. In order to test these slight differences, two-tailed t-tests were calculated for the remaining nine untested comparisons. Alpha level was temporarily adjusted to .01 in order to guard against any significant increase in

the probability of type I error. Using this adjusted alpha, no comparisons reached statistical significance. Only the comparison of scores on Scale 6 approached significance, as mothers displayed a trend towards greater overcommitment and a martyr-like belief that only she can adequately care for her autistic child, ($t(48)=2.42$: $p=.019$)

In essence, mothers and fathers both reported significant stress reactions across many domains. While the pattern of mothers' scores was somewhat higher than the fathers' scores, only the greater stress reaction to excess time demands by mothers proved to be a statistically reliable difference.

The POMS as a Measure of Emotional Adjustment in Parents.

Before turning to inferential analyses, descriptive data from a second measure of adjustment can be briefly reported. Mothers and fathers completed a measure of current mood, entitled the Profile of Mood States (POMS). The POMS measures six bi-polar mood states labelled as "Anxious-Composed", "Depressed-Elated", "Hostile-Agreeable", "Tired-Energetic", "Unsure-Confident", and "Confused-Clearheaded", as well as a total score measuring "overall positive and negative affect" (Lorr & McNair, 1988). Mothers' and fathers' mean T-scores and standard deviations for each of these measures are presented in Table 6.

Mothers. Examination of mothers' mean scale scores reveal that no score, including the total mood score, fell

Table 6

Mean Subscale T-Scores of Mothers and Fathers on the POMS-B

<u>Scale</u>	<u>Mothers</u>		<u>Fathers</u>	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
1. Anxious-Composed	46.80	5.96	49.04	8.60
2. Hostile-Agreeable	42.72	7.45	43.48	7.31
3. Depressed-Elated	47.64	8.06	44.80	7.77
4. Unsure-Confident	49.00	8.57	49.96	8.56
5. Tired-Energetic	46.40	5.70	51.08	8.60
6. Confused-Clearheaded	50.40	7.02	51.32	11.07
TOTAL POMS	47.10	5.15	48.26	6.68

more than one standard deviation above or below the T score mean of 50. More specifically, all scale scores except one fell within one standard deviation below the normalized standardized mean score of 50. Further examination reveals that mothers' lowest score occurred on the scale labelled "Hostile-Agreeable".

In order to determine if any statistically significant differences occurred between scales, a within-subjects repeated measures analysis of variance (ANOVA), using mean standardized scale scores as the dependent variable, was performed. Mothers' scores did differ depending upon the bipolar mood being rated, $F(5,120)=5.55$, $MSe=31.16$. In order to further identify the specific differences between these six means, the lowest mean scale score was compared against all other mean scale scores using one-tailed t-tests for dependent means. Alpha level was temporarily adjusted to .01 to guard against Type I error. T-test results suggested that mothers expressed significantly more frequent feelings of anger than feelings of anxiety ($t(24)=2.95$), feelings of depression ($t(24)=3.15$), feelings of uncertainty ($t(24)=3.31$), feelings of fatigue ($t(24)=3.74$), or feelings of confusion ($t(24)=4.69$). In total, however, mothers' profiles indicated only a slight tendency towards negative affect.

Fathers. Examination of fathers' mean scale scores revealed that all scale scores fell within one standard

deviation of the normalized standardized mean score of 50. Fathers' most extreme scores fell on the negative affect side of scales measuring hostility and depression. Overall, however, fathers' profiles also exhibited only a slight tendency towards negative affect.

In order to determine if any statistically significant differences occurred between scales, a repeated measures ANOVA was again performed. Fathers' scores did differ depending upon the bipolar mood being rated, $F(5,120)=7.31$, $MSe=38.07$. In order to further identify the specific differences between these six means, the lowest two mean scores were separately compared against all other mean scale scores using one-tailed t-tests for dependent measures. Alpha level was again temporarily adjusted to .01 to guard against false rejection of the null hypothesis of no difference. T-test results suggested that fathers reported more frequent feelings of anger than feelings of anxiety ($t(24)=4.23$), feelings of uncertainty ($t(24)=3.68$), feelings of fatigue ($t(24)=4.89$), or feelings of confusion ($t(24)=3.71$). In addition, t-test results suggested that fathers reported significantly more frequent feelings of depression than feelings of anxiety ($t(24)=3.09$), feelings of uncertainty ($t(24)=3.65$), feelings of fatigue ($t(24)=4.13$), or feelings of confusion ($t(24)=2.77$).

Mother-Father Comparisons. Comparison of mothers' and fathers' mood scores indicate only slight differences. The

largest contrast occurred on Scale 5, measuring the bipolar mood state labelled "Tired-Energetic", with mothers indicating more fatigue than fathers (46.40 vs 51.08). A two tailed t-test indicated that this difference was statistically reliable, $t(48)=-2.27$; $p < .05$. No other comparisons approached significance and no reliable difference was noted in the total score measuring overall affect.

Overall, mothers and fathers both exhibit only a slight tendency towards negative affect. For both, feelings of hostility comprise the strongest negative affective dimension. For fathers, feelings of depression were relatively strong as well, being experienced more frequently than other feelings, with the exception of hostility.

Experimental Measures and Inferential Analyses

Two experimental instruments, a Control Cognitions Questionnaire and an Attributions Questionnaire, were utilized in inferential analyses designed to test hypotheses related to both victimization theory and parenting research. Each instrument will be discussed separately below.

Control Cognitions

The first instrument was the Control Questionnaire, which measured parents' feelings regarding controlling the current and future sequelae of autism, as well as the possible recurrence of this disorder in subsequent offspring. As detailed in Chapter III, three measures were

derived from the Control Questionnaire corresponding to one's feelings regarding controlling current sequelae, controlling future sequelae, and controlling recurrence. Mothers' and fathers' mean ratings for these three dimensions are reported in Table 7.

Descriptive Data--Mothers. Examination of Table 7 indicates that mothers' ratings of perceived control (on a 6 point scale) reflected moderate levels of control over both the current and future sequelae resulting from autism. In contrast, mothers reported feeling less control over recurrence (2.60) than over either current (3.67) or future (3.59) sequelae. A within-subjects repeated measures ANOVA using control scores as the dependent variable was performed to test differences between these means. The ANOVA results indicate that mothers' feelings of control did differ depending upon the type of control they were asked to rate, $F(2,48)=5.57$, $MSe=1.58$. In order to pinpoint specific differences, t-tests for related measures were performed contrasting these three groups. T-test results suggested that mothers expressed significantly more control over current and future sequelae than over recurrence, $t(24)=2.49$; $t(24)=2.25$.

Fathers. Fathers' overall level of control over sequelae also fell into the moderate range. Moreover, like mothers, fathers reported feeling less control over recurrence than control over sequelae. Again a repeated

Table 7

Mean Control Ratings of Mothers and Fathers of Autistic Children

<u>Type of Control</u>	<u>Mothers</u>		<u>Fathers</u>	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Control over Current Sequelae	3.67	1.02	3.24	.80
Control over Future Sequelae	3.59	1.03	3.08	1.07
Control Over Recurrence	2.60	2.16	2.12	1.76

measures ANOVA using control ratings as the dependent variable was performed to test differences between these means. The ANOVA results indicate that, like mothers, fathers feelings of control did differ depending upon the type of control being rated, $F(2,48)=5.09$; $MSe=1.42$. In addition, t-tests for related measures were performed in order to further specify the differences in ratings. T-test results suggested that fathers expressed significantly more control over current and future sequelae than over recurrence, $t(24)=2.57$; $t(24)=2.10$.

Mother-Father Comparisons. In comparing mothers' control ratings with fathers' control ratings, a pattern of higher control ratings by mothers for all three types of control is apparent. In order to test if these differences were statistically reliable, three independent t-test were performed. No t values approached significance, indicating that this observed pattern was not comprised of any statistically reliable differences in control ratings between mothers and fathers. Rather, as noted above, the general pattern of control ratings, with control over current and future sequelae ratings being significantly higher than control over recurrence ratings, is strikingly similar between mothers and fathers.

The Relationship between Control and Adjustment

Mothers. The first hypothesis corresponding to the relationship between control and adjustment suggests the

investigation of the role of sequelae cognitions. Hypothesis 5 stated that control over sequelae cognitions would be significantly and positively related to emotional adjustment for mothers. Pearson Product Moment Correlations representing the relationship between control cognitions and adjustment were calculated and are presented in Table 8. A Pearson Correlation of .39 was found between control over current sequelae and current mood; indicating a statistically reliable relationship. In addition, a positive, albeit non-significant, relationship ($r=.25$) was found between control over future sequelae and current mood. Moreover, this pattern of relationships was corroborated when control over sequelae cognitions were related to total stress (as measured by the total QRS score) reported by mothers. As is again evident in Table 8, a strong and statistically significant relationship was found between control over both current and future sequelae cognitions and stress ($r=-.39$; $p < .05$; $r=-.49$; $p < .05$). In sum, these relationships suggest a strong association between control over sequelae cognitions and current adjustment in mothers of autistic children, lending support to this hypothesis.

It was further hypothesized (Hypothesis 6) that control over recurrence cognitions would be significantly and positively related to current mood. Further examination of Table 8 indicates that a non-significant, small negative correlation ($r=-.08$) was found. It thus can be concluded

Table 8

Pearson Correlations Representing the Relationship between
Control Ratings and Adjustment in Mothers and Fathers

	<u>Mothers</u>		<u>Fathers</u>	
	<u>QRS</u>	<u>Total</u>	<u>QRS</u>	<u>Total</u>
Control over Current Sequelae	** -.39	** .39	** -.49	** .37
Control over Future Sequelae	*** -.49	.25	*** -.71	*** .51
Control over Recurrence	* -.32	-.08	.25	.08

* $p = .058$

** $p < .05$

*** $p < .01$

that no significant relationship was identified between mothers thoughts regarding controlling possible recurrence of autism in subsequent offspring and current mood. In addition, although a stronger relationship was found between control over recurrence cognitions and stress as measured by the QRS ($r=-.32$), even this relationship did not reach conventional levels of significance.

Hypothesis 7 more directly addressed the issue of whether the association between control over sequelae and adjustment would be stronger than the association between control over recurrence and emotional adjustment. In order to compare the strength of associations statistically, Pearson correlation coefficients were transformed and tested using a t-test for differences between dependent correlations (Bruning & Kintz, 1977). T-test results suggested that the relationship between control over current sequelae and adjustment ($r=.39$) was significantly stronger than the relationship between control over recurrence ratings and emotional adjustment ($r=-.08$), $t(22)=2.01$. Thus for mothers of autistic children, the relationship found between control over sequelae and adjustment was both statistically significant in and of itself, as well as significantly stronger than the non-significant relationship discovered between control over recurrence and emotional adjustment.

Fathers. A further purpose of this study involved

determining whether the relationships between control cognitions and adjustment documented for mothers would also be found when investigating fathers of autistic children. More specifically, hypothesis 8 proposed that control over sequelae cognitions would be significantly and positively related to the emotional adjustment of fathers. Pearson correlations were calculated to test this hypothesis and are presented in Table 8. The relationship between control over current sequelae and emotional adjustment was both positive and statistically reliable ($r=.37$; $p < .05$). In addition, the relationship between control over future sequelae and emotional adjustment was an even stronger $.51$ (Pearson r). Moreover, as was the case with mothers, these associations between control over sequelae cognitions and adjustment were corroborated by the strong negative correlations discovered between these control cognitions and a measure of total stress ($r=-.49$; $r=-.71$). In addition, as was the case with mothers, control over recurrence cognitions were not significantly associated with either adjustment or stress ($r=.08$; $r=.25$). In essence then, these correlations lend strong statistical support to this hypotheses, suggesting a significant relationship between control over sequelae cognitions and adjustment in fathers of autistic children.

Mother-Father Comparisons. One final hypothesis (Hypothesis 9) regarding the associations between control over sequelae cognitions and adjustment concerned the

comparison of the strength of these relationships between mothers and fathers. It was hypothesized that the relationship between control over sequelae cognitions and adjustment would be stronger for fathers than mothers. Examination of Table 8 reveals that Pearson correlations representing the relationship of control over current sequelae and adjustment was .37 for fathers and .39 for mothers, clearly not supportive of this hypothesis. Moreover, the correlation between control over future sequelae and emotional adjustment was .51 for fathers and .25 for mothers. This difference was tested statistically through conversion of Pearson correlations to Fisher Z scores. It was discovered that this comparison did not represent a statistically reliable difference ($z=1.02$), again not supportive of this hypothesis.

In summary, a strong positive correlational relationship was discovered between control over sequelae cognitions and adjustment in both mothers and fathers. Moreover, no such relationship was discovered between control over recurrence cognitions and adjustment in either mothers or fathers. In both mothers and fathers, the relationship between control over sequelae cognitions and adjustment was found to be significantly stronger than the relationship between control over recurrence and adjustment. No differences were found between mothers and fathers in relative strength of any of these relationships.

Attributional Cognitions

The second experimental instrument utilized was the Attributions Questionnaire designed to measure parents thoughts, and corresponding feelings of blame, regarding possible causes of their child's autism. Five scores were calculated from this Attributions Questionnaire: a characterological self-blame score, a behavioral self-blame score; a blame chance score; a blame someone else score; and a blame something else score. Mothers' and fathers' mean ratings for each type of blame are reported in Table 9.

Descriptive Data--Mothers. Examination of Table 9 indicates that mothers most frequently blamed "chance" (8.40) and "something else" (7.16) as the prime causes of their child's autism. Far less frequently did mothers blame themselves, either characterologically or behaviorally, or blame someone else. In order to test these trends statistically, a repeated measures ANOVA using mean attribution ratings as the dependent variable was performed. According to this analysis, mothers did blame certain causes significantly more than other causes, $F(4,96)=33.35$, $MSe=5.77$. In order to further identify the specific differences, six separate t-tests for dependent measures were performed contrasting the highest two means (i.e. blame chance and blame something else) with the lowest three mean ratings (i.e. characterological self-blame; behavioral self-blame; blame someone else). Alpha level was

Table 9

Mean Attribution Ratings of Mothers and Fathers

<u>Type of Blame</u>	<u>MOTHERS</u>		<u>FATHERS</u>	
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Characterological-Self	2.32	.90	2.40	1.19
Behavioral-Self	2.52	.96	2.48	1.09
Chance	8.40	3.33	6.48	3.93
Someone Else	3.84	2.41	2.76	1.36
Something Else	7.16	2.97	6.00	2.53

temporarily adjust to .01 to guard against Type I error. Results indicate that mothers tended to rate blaming chance significantly higher than characterological self-blame, behavioral self-blame, and blaming someone else ($t(24)=9.27$; $t(24)=8.33$; $t(24)=4.54$). In addition, mothers tended to rate blaming something else significantly higher than these three lowest rated attributions as well ($t(24)=7.66$; $t(24)=6.97$; $t(24)=4.35$).

Fathers. A similar pattern can be noted for fathers, as they too most frequently blamed "chance" (6.48) and "something else" (6.00), and quite infrequently blamed either themselves or someone else. Again a repeated measures ANOVA tested this pattern for statistical significance. ANOVA results suggested that fathers also tended to blame certain causes significantly more than other causes, $F(4,96)=20.85$, $MSe=4.96$. The six t-tests performed using mothers' ratings were repeated here using data from the fathers. They indicated that fathers rated blaming chance significantly higher than characterological self-blame, behavioral self-blame, and blaming someone else ($t(24)=5.07$; $t(24)=5.03$; $t(24)=4.35$). In addition, fathers rated blaming something else significantly higher than these three lower rated attributions as well ($t(24)=6.27$; $t(24)=6.35$; $t(24)=5.60$).

Mother-Father Comparisons. One specific hypothesis (Hypothesis 10) concerned the comparison of the level of

characterological self-blame in mothers and in fathers. It had been hypothesized that mothers would report significantly greater levels of characterological self-blame than fathers. Again, examination of Table 9 reveals that while both mothers and fathers ascribed little blame to their own personality, fathers actually reported slightly, albeit not significantly, more characterological self-blame than their spouses ($t(48)=-.27$).

The Relationship between Attributions and Adjustment

Three hypotheses can be addressed by examining the relationship between these attributional thoughts and the measures of adjustment. Table 10 presents Pearson Product Moment Correlations measuring the association between these constructs for both mothers and fathers.

Mothers. The first hypothesis concerning attributions (Hypothesis 11) speculated that characterological self-blame in mothers would be significantly and inversely related to emotional adjustment. A Pearson correlation between mothers mean characterological blame scores and emotional adjustment revealed virtually no relationship ($r=-.01$). This lack of association is corroborated by the very weak and non-significant relationship discovered between characterological self-blame and total reported stress ($r=-.09$). Clearly then, this hypothesis was not supported.

A second and related hypothesis (Hypothesis 12) stated that behavioral self-blame in mothers would be positively

Table 10

Pearson Correlations Representing the Relationship between Attribution Ratings and Adjustment for Mothers and Fathers

<u>Type of Blame</u>	<u>Mothers</u>		<u>Fathers</u>	
	<u>QRS</u>	<u>POMS</u>	<u>QRS</u>	<u>POMS</u>
Characterological	-.09	-.01	-.01	-.25
Behavioral	.08	-.13	-.05	-.09
Chance	* -.34	.11	-.13	-.07
Someone else	** .47	-.19	.29	** -.51
Something else	.12	* .37	-.29	-.16

*

p<.05

**

p<.01

related to emotional adjustment. Again, examination of Table 10 reveals that the Pearson correlation measuring this association was small, non-significant, and actually not even supportive of the directional aspect of this hypothesis ($r=-.13$). In addition, it should be noted that this lack of association was again corroborated when the relationship between behavioral self-blame and stress also proved to be slight and not statistically significant ($r=.08$).

Examination of the remainder of Table 10, however, does yield some interesting and noteworthy observations. For mothers, emotional adjustment was significantly and positively related to the attribution of "blaming something else" ($r=.37$), indicating that the more mothers blamed some other specific cause for their child's autism, the more positive their recent mood. Complementing this finding are two significant relationships found when type of blame is related to stress. Here, there appear to be significant relationships between chance attributions and amount of stress ($r=-.34$) and frequency of blaming someone else and amount of stress ($r=.47$). These findings, taken together, suggest that the more mothers blamed either chance or something else as the cause for their child's autism, the more positive was their adjustment; and in contrast, the more frequently they ascribed blame to someone else, the more stress they reported experiencing. These, of course, remain only associational trends here and do not necessarily

suggest anything about causal connections between these variables.

Fathers. For fathers, examination of Table 10 reveals that only one Pearson correlation measuring the strength of association between types of attributions and adjustment proved statistically reliable. A significant relationship was discovered between the tendency to "blame someone else" and emotional adjustment ($r = -.51$). This strong inverse relationship could suggest a significant negative role for this type of blame in the emotional adjustment process. In addition, no significant positive relationships were discovered between attributions and adjustment.

In summary, attribution ratings suggested that both mothers and fathers tended to blame chance or "something else" as the prime causes for their child's autism. Rarely did they ascribe blame to either themselves or someone else. Moreover, a significant positive relationship was found between blaming chance or blaming something else and adjustment in mothers. For fathers, no attributional pattern demonstrated a significant positive relationship with emotional adjustment. On the negative side, a strong inverse relationship was noted for mothers and fathers between the tendency to blame someone else for one's child's autism and positive emotional adjustment.

Predictive and Causal Modeling:

Multiple Regression and Discriminant Function Analysis

A central focus of this study was to examine, clarify, and explicate the nature and role of control and attributional cognitions in the process of adjustment. While associational relationships between these variables have been presented above, the issues of causation and prediction have not yet been addressed. As discussed in Chapter III, given the exploratory nature of this study, a final statistical approach will be undertaken in an attempt to examine potential causal/predictive relationships which may underlie the aforementioned cognition-adjustment associations. Contrary to the conditions stated in Chapter III, however, data obtained from mothers and fathers will continue to be considered separately, with predictive/causal relationships examined first for mothers and then for fathers.

Mothers

The Composite Adjustment Score. A three step statistical procedure was implemented in order to answer these questions regarding prediction and causation. First, the two measures of adjustment (the QRS Total Score as a measure of total stress; the POMS Total Score as a measure of mood and emotional adjustment) were standardized and combined with equal weightings, yielding a new composite adjustment score. Since higher POMS standard scores suggest

more positive adjustment and lower QRS standard scores suggest more positive adjustment, the QRS Total standard score was subtracted from the POMS Total standard score to produce the composite adjustment score. This new composite adjustment score is thus oriented such that a higher score indicates more positive adjustment while a lower score indicates poorer adjustment.

In order to prepare for the multiple regression analyses, it was necessary to first examine which non-experimental variables (i.e. demographic variables and ratings of behavior and family roles) exhibited significant associations with this outcome measure of adjustment. Pearson correlations of all demographic variables with this composite adjustment score were calculated. For mothers, only two variables demonstrated a statistically significant relationship with adjustment. The variables representing age of the mother and the overall behavior rating of the child demonstrated significant inverse relationships with adjustment ($r = -.42$ and $r = -.38$ respectively), indicating that mothers' overall positive adjustment was associated with younger age and fewer behavior problems. Variables such as age at diagnosis, time since diagnosis, age of the child, family income, and all other demographic variables were not significantly associated with adjustment.

Multiple Regression. Secondly, a multiple regression approach was initiated, in an attempt to elucidate which

independent variables might best predict the dependent variable of overall adjustment. Due to the small sample size and exploratory nature of this study, the more conservative hierarchical regression method was chosen over the more atheoretical stepwise approach. In this hierarchical approach, the non-experimental covariates are entered into the regression equation first, so that the proportion of variance of the dependent variable which they account for is partialled out before examining the impact and importance of the experimental variables. For the purpose of this study, potential predictive experimental variables were considered to be the five measures of attributional thought and two of the three measures of control cognitions.³ The potential non-experimental covariates were considered to be all demographic and behavioral variables.

The non-experimental variables considered to be covariates of the total adjustment score were specified through examination of the zero-order and partial correlation matrices.⁴ For mothers, the variables of age of the mother and total behavior rating of the child were found to be significant covariates of adjustment. According to the hierarchical regression procedure, these variables were then forced into the equation first, as predictor variables. Age of the parent and behavior rating of the child together accounted for 32.18% (26.02% adjusted) of the variance in

the composite adjustment score.

The second step in the hierarchical regression procedure involves the forward stepwise introduction of the experimental variables into the regression equation. In this process, each experimental variable's correlation with the dependent variable is examined, after the effects of the covariates have been partialled out. This computerized process then adds the variable with the highest significant partial correlation to the regression equation. This partialling process continues, comparing each excluded variable with the dependent variable, after partialling out the effect of all variables already in the model. Using the present data, no experimental variables had significant partial correlations with the composite adjustment measure and thus none is entered into the regression equation. Thus, using this very conservative approach, it can be concluded that the current experimental variables did not add statistically significant explanatory power, above and beyond any significant covariates, to attempts to estimate overall adjustment in mothers.

Discriminant Function Analysis. The third step in an attempt to gauge the explanatory power of the experimental variables involves a less conservative statistical procedure. In contrast to multiple regression, in which a set of independent variables are weighted in order to optimally predict a dependent variable, discriminant

analysis weights the predictor variables in a manner which yields maximum discriminations between two or more qualitatively different groups. In this study, discriminant function analysis was undertaken in order to determine if the experimental variables taken together could differentiate between groups having higher versus lower composite adjustment scores. These two distinct groups (high adjustment; low adjustment) were formed using a median split technique, yielding one group of "high adjustment" mothers ($n=13$) and one group of low adjustment mothers ($n=12$). Table 11 presents means, standard deviations, and F-tests for the predictor variables of high and low adjustment.

A stepwise selection procedure chose variables to include in the discriminant function based upon a specified selection criterion. For this study, minimum Wilks' lambda was chosen as the selection criterion. Wilks' lambda is a measure of discrimination between groups; using this as the selection criterion for a discriminant analysis assures that variables will be chosen which force the groups to be as statistically distinct as possible. As in other "stepwise" procedures, the variable that best discriminates is chosen first for the function. Next, the variable which, when combined with the first, will produce the best discrimination is selected. Remaining variables are then tested in similar progressive fashion to ultimately

Table 11

Means and Standard Deviations of Predictor Variables of High and Low Adjustment in Mothers

<u>Variable</u>	<u>Adjustment</u>	<u>Mean</u>	<u>SD</u>	<u>t(23)</u>
Age of Mother	High	33.70	4.37	2.56 *
	Low	38.73	5.08	
Behavior Rating	High	2.64	.46	.61
	Low	2.77	.58	
Characterological Blame	High	2.40	.70	.36
	Low	2.27	1.03	
Behavioral Blame	High	2.40	.84	.50
	Low	2.60	1.06	
Blame Chance	High	8.90	2.89	.60
	Low	8.07	3.65	
Blame Someone Else	High	2.60	1.27	2.28 *
	Low	4.67	2.66	
Blame Something Else	High	8.50	2.95	1.95
	Low	6.27	2.71	
Control over Current Sequelae	High	4.23	.89	2.50 *
	Low	3.29	.95	
Control over Recurrence	High	3.20	.74	1.14
	Low	2.20	.51	

*
p < .05

determine the best combination of variables.

In the present study, 7 experimental variables (level of characterological self-blame; level of behavioral self-blame; level of blaming chance; level of blaming someone else; level of blaming something else; control over current sequelae; and control over recurrence) and two covariates (age of the mother and behavior rating of the child) were chosen for possible inclusion in the discriminating function. Stepwise discriminant function analysis suggested that a combination of four of these variables yielded maximum discriminating power. These four variables (characterological blame, blaming chance, blaming someone else, and control over current sequelae) combined to form a discriminant function which correctly classified 84% of the current 25 cases as either high adjustment or low adjustment (see Table 12). This classification accuracy is statistically significant when compared to a chance rate of 50 % ($X^2 = 17.00$; Wilks' lambda = .4087; $p < .01$). It should, however, be noted that a model derived through discriminant analysis fits the sample from which it was derived better than it would fit a new sample from that population. With this caveat in mind, this accuracy rating might be seen as an inflated estimate of the function's true accuracy.

Discriminant function analysis also produces standardized discriminant function coefficients. These coefficients reflect the relative importance of each

Table 12

Classification Matrix from Discriminant Function Analysis of
Data from Mothers of Autistic Children

<u>Actual Group</u>	<u>Predicted Group</u>	
	Low Adjustment	High Adjustment
Low Adjustment	11	1
High Adjustment	3	10

Overall Classification Rate of 84% Accuracy

discriminating variable. The standardized discriminant function coefficients are presented in Table 13.

Examination of Table 13 indicates that the function is weighted most heavily in the positive direction by the measure of control over current sequelae. The function is weighted most heavily in the negative direction by the measure of "blaming someone else" for one's child's autism.

Finally, discriminant function analysis also produces canonical correlations. Canonical correlations are the measure of how closely a function and a grouping variable (i.e. adjustment) are related. This statistic is introduced here since the canonical correlation squared reflects the proportion of variance in the discriminating function explained by the groups. A canonical correlation of .77 was found between the aforementioned function and groups. This indicates that 59.29% of the variance in the discriminant scores can be accounted for by group difference (high or low adjustment).

In sum, two procedures were used to test the explanatory power of the experimental variables in predicting mothers' adjustment. Using the conservative hierarchical regression procedure, it was concluded that experimental variables did not contribute significantly to explaining the adjustment of mothers, after the effects of mothers' age and behavior of the child were controlled for. In contrast, using the less conservative discriminant

Table 13

Standardized Discriminant Function Coefficients

<u>Variable</u>	<u>Coefficient</u>
Characterological Blame	.4164
Blame Chance	-.5224
Blame Someone Else	-.9095
Control over Current Sequelae	1.0655

function analysis, mothers membership in either a high adjustment or low adjustment group was shown to be a function of the mothers' scores on four experimental variables (characterological blame, blaming chance, blaming someone else, and control over current sequelae) even when the covariates of age of the parent and behavior of the child were included as possible contributors to the discriminant function.

Fathers

The Composite Adjustment Score. A similar three step analysis was performed on data collected from fathers of autistic children. Once again, first, the two measures of adjustment (QRS Total Score and POMS Total Score) were standardized and combined, yielding a new composite adjustment score.

Once again, in order to prepare for the multiple regression analyses, it was necessary to first examine which non-experimental variables exhibited significant associations with this composite adjustment measure. Again, Pearson correlations of all demographic variables with this composite adjustment measure were calculated. For fathers, two variables exhibited statistically significant positive relationships with adjustment--the variables representing age of the child and family income ($r=.56$ and $r=.51$ respectively). In addition, one variable exhibited a significant inverse relationship with adjustment--the

overall behavior rating of the child ($r=.46$). In essence for fathers, like mothers, adjustment appears to be hindered as they encounter a more severely behaviorally disabled child. In contrast to mothers, however, fathers' adjustment is bolstered by adequate financial resources and when parenting an older child.

Multiple Regression. Secondly the conservative hierarchical multiple regression approach was initiated. Examination of the zero-order and partial correlations of the non-experimental variables with this adjustment measure indicated that the variables of age of the child and total family income were significant covariates. These two variables were thus forced into the equation first as predictor variables. "Age of the child" and "Income" were found to account for 50.12% (45.59% adjusted) of the total variance in the composite adjustment score⁷

The forward stepwise procedure then examined each of the experimental variables for entry. Only one experimental variable's partial correlation with adjustment warranted entry. The variable, "blaming someone else", had a strong negative partial correlation with adjustment ($r=-.59$) and was added to the model. No other variables' partial correlations reached significance. This model then, including the variables of child's age, income, and the level of blaming someone else accounted for 67.66% (63.04% adjusted) of the variance in the composite adjustment

scores. Moreover, this regression model's predictive power was statistically significant, $F(3,21)=14.64$; $MSe=1.25$.

Discriminant Function Analysis. The less conservative discriminant function analysis was then undertaken using the seven experimental variables and two non-experimental covariates. Once again, a median split technique was used to form a high adjustment and low adjustment group. Table 14 presents means, standard deviations, and F-tests for the predictor variables of high and low adjustment.

A stepwise selection criteria chose variables to include in the discriminant function based upon the maximization of Wilk's lambda. Stepwise analysis revealed that a combination of two variables yielded maximum discriminating power. These variables were the measures of the tendency to blame someone else for your child's autism and the measure of control over future sequelae. These variables combined to form a discriminant function which correctly classified 80% of the current 25 cases as either high or low adjustment (see Table 15). This classification accuracy is statistically significant when compared to a chance rate of 50% ($\chi^2_{(2)}=14.90$, Wilks' lambda=.47; $p<.01$).

Table 16 presents standardized discriminant function coefficients for this function. These coefficients indicate that the function is weighted in a negative direction by the measure of blaming someone else and in a positive direction by the measure of control over future sequelae. Moreover, a

Table 14

Means and Standard Deviations of Predictor Variables of High and Low Adjustment in Fathers

<u>Variable</u>	<u>Adjustment</u>	<u>Mean</u>	<u>SD</u>	<u>t(23)</u>
Age of Child	High	97.00	6.99	2.46*
	Low	75.92	4.71	
Income	High	40,125	3995	.83
	Low	37,046	4825	
Characterological Blame	High	2.00	0.00	1.83
	Low	2.83	1.64	
Behavioral Blame	High	2.23	.83	1.21
	Low	2.75	1.28	
Blame Chance	High	6.92	4.37	.58
	Low	6.00	3.52	
Blame Someone Else	High	2.00	0.00	3.53*
	Low	3.58	1.62	
Blame Something Else	High	5.46	2.54	1.11
	Low	6.58	2.50	
Control over Future Sequelae	High	3.49	1.00	2.13*
	Low	2.64	.99	
Control over Recurrence	High	2.54	2.26	.80
	Low	1.92	1.51	

*

p < .05

Table 15

Classification Matrix from Discriminant Function Analysis of
Data from Fathers of Autistic Children

<u>Actual Group</u>	<u>Predicted Group</u>	
	Low Adjustment	High Adjustment
Low Adjustment	10	2
High Adjustment	3	10

Overall Classification Rate of 80% Accuracy

Table 16

Standardized Discriminant Function Coefficients

<u>Variable</u>	<u>Coefficient</u>
Blame Someone Else	-.8777
Control over Future Sequelae	.7695

canonical correlation of .72 was found between the function and the groups, indicating that 51.44% of the variance in the discriminant scores can be accounted for by group membership (high or low adjustment).

In sum, both multiple regression and discriminant function analysis were used to test the explanatory power of the experimental variables in predicting fathers' adjustment. Using the conservative hierarchical regression approach, it was discovered that the experimental variable "blaming someone else " added significant predictive power to the regression equation derived from the non-experimental covariates. Moreover, the entire model comprising the three variables of age of the child, income, and level of blaming someone else accounted for a highly significant 63.04% of the variance in adjustment. Discriminant function analysis corroborated the central role of this attributional cognition and demonstrated that fathers' membership in either a high or low adjustment group was shown to be a function of the experimental variables of "blaming someone else" and "control over future sequelae", even when the covariates of child's age and income were included as possible contributors to the function.

CHAPTER VI

DISCUSSION

The purposes of this study, as stated in Chapter I, were threefold. The first goal was to gather descriptive data relevant to the stresses involved in parenting, particularly fathering, an autistic child. A second objective involved interpreting and organizing this parental adjustment data within the conceptual framework of victimization theory. The third purpose involved addressing some specific questions currently unanswered within victimization theory itself. A discussion of results pertaining to the first goal is presented first, followed by a combined discussion of the theoretical issues.

Parental Stress and Adjustment

Mothers

Results of mothers' responses to the QRS indicated that mothers of autistic children demonstrated a significant stress reaction marked by universally strong personal stress reactions, most especially in the areas of excess time demands, negative attitudes towards the child, and lack of social support. QRS scores indicated that these problems were exacerbated by such additional stresses as the belief that only she could adequately care for her disabled child,

the reality of caring for a seriously and pervasively impaired individual, and family problems resulting from having an autistic child as a family member.

The above general pattern, and specifically the stress reactions of depressed mood, excess time demands, and limits on family opportunities, had been core hypotheses based in part on the previous studies of mothers of autistic children completed by Bristol (1979; 1983) and Holroyd and McArthur (1976). In fact, the stress profile first reported by Bristol (see Table 5) is extremely closely replicated here. Mothers in both studies expressed significant personal problems with depressed mood, excess time demands, concerns about what others might think about them and their child, and concern over the child's future. In addition, both groups of mothers reflected significant familial concerns as well as pervasive disabilities in their autistic child. This finding of similar results across these two studies provides strong evidence for the representativeness of the sample studied here.

The only two minor differences occurred on scales measuring negative attitudes toward the child and social support. Examination of methodology suggests that this difference may have been due to a subject selection factor. At the time of study, Bristol's subjects were involved at various stages in a university program providing services to these parents (n.b. some ratings were taken prior to

treatment). Such services may have affected the social support and negative attitude indices of this measure. In essence, however, the stress profile reported here provides strong replicatory evidence for the stress pattern first reported by Bristol and by Holroyd and McArthur.

In addition to replicating the work of Bristol, this pattern of results also supports, in part, some of the early empirical and clinical reports of the adjustment of mothers of autistic children. Earlier work with these mothers has frequently reported the finding of depressive and anxious reactions (Cox et al., 1975; DeMyer, 1979). Although the responses to the measure of current mood (POMS-B) did not corroborate these findings, responses to the measure of stress did indicate that a significant depressive stress reaction was common in most of these mothers. Further work in this area might be geared toward explicating these disparate results regarding the presence or absence of depressive symptomatology on the stress and mood questionnaires.

In addition to supporting and refining the earlier work on mothers of autistic children, these results can be considered in light of the previous empirical work which focused on mothers of mentally handicapped children. One theoretical issue was addressed in the empirical work of Gumz and Gubrium (1972). As discussed in Chapter II, these authors posited two central types of stresses experienced by

parents of mentally handicapped children. The first was labelled "instrumental crises" and included concerns about providing for the child, as well as worries about his economic and future potential. The second was entitled "expressive crises" and included stress and concern over directly caring for the child, and subsequent worries about the child's future potential for happiness and for healthy relationships. Gumz and Gubrium indicated that mothers of mentally retarded children often report significant levels of expressive crises. Mothers of autistic children in this study certainly corroborated this pattern, reporting significant stress in the areas of excess time demands, overcommitment, and pessimism about the child's future. These authors also reported that mothers of mentally retarded children report less stress in regards to instrumental crises, although a significant incidence of these stressors was not uncommon. This pattern was not fully supported here, as mothers displayed equally high levels of stress in areas associated with instrumental crises (i.e. occupational limitations) as in areas associated with expressive crises.

Fathers

Fathers also exhibited a strong personal stress reaction across most areas of life measured by the QRS. Overall, fathers expressed their greatest difficulties in the areas of concern over what others might think about

the child and about themselves (i.e. negative attitude scale), feelings that the child was overprotected, and worries about the child's and family's future. Once again, it should be noted that fathers' profiles suggested that these stresses were exacerbated by a lack of support and the reality of caring for a seriously disabled individual.

Little theoretical work was found upon which to base hypotheses regarding the stresses experienced by fathers of autistic children. One literature review of both empirical and clinical studies of fathers of mentally handicapped children (Price-Bonham and Addison, 1978) suggested that fathers were generally quite affected by the physical appearance and public actions of their handicapped child. This general finding was corroborated here, as fathers of autistic children did indicate a strong sensitivity to how others might view their child and themselves, as well as concerns over the social obtrusiveness of their child.

A second hypothesized area of stress for fathers involved concerns about the child's future, especially in terms of occupational/economic opportunities and provisions. As discussed above, Gumz and Gubrium (1972) reported that fathers of mentally handicapped children experienced significant stress in these areas, which they labelled as instrumental crises. Their research also suggested that fathers experienced significant, albeit less severe, expressive crises as well. This pattern received strong

support from data gathered on fathers of autistic children in this study. Instrumental crises were apparent in fathers' high scores on the scales measuring occupational limitations and feelings that the child was being overprotected and was too dependent upon others for care. Expressive crises were demonstrated in fathers' significant, albeit slightly moderated, responses to the stresses of excess time demands, depressed mood due to caring for the child, and pessimism regarding the child's future personal accomplishments and happiness.

Mothers and Fathers

Gumz and Gubrium's theory regarding expressive and instrumental crises also suggested certain comparative hypotheses when considering mothers and fathers. These authors suggested that although both mothers and fathers experience both instrumental and expressive crises, mothers would experience more expressive crises than fathers, while fathers would experience more instrumental crises than mothers. This theoretical pattern was not fully supported by the current data. Mothers indicated they were experiencing extremely high amounts of stress from problems associated with both instrumental and expressive crises. This pattern indicated that while mothers did report more problems which would fall under the general rubric of expressive crises, mothers did not report less stress than father's in areas associated with instrumental crises.

In contrast to these QRS results, fathers, like mothers, did not demonstrate any significant emotional adjustment difficulties as measured by the POMS-B. Although both mothers and fathers did demonstrate significantly more anger and hostility than other emotions, no mood score could be considered significantly different from that expected in the general population.

If one considers this pattern (stress without concomitant emotional maladjustment) in light of the clinical and theoretical treatises concerning parenting a mentally handicapped child, two possibilities emerge as potential explanations. As discussed in Chapter II, Blacher proposed that parents experience a three stage adjustment process. According to Blacher, the first stage is called the "disintegration" stage, as shock, complete denial and emotional disorganization characterize the parents' reaction. Clearly parents in this study did not present evidence of this stage. The second stage in the process of adjusting to parenting a mentally handicapped child is marked by partial acceptance and partial denial of the disability and its accompanying stresses. This is called the "adjustment" stage. It is possible then that parents studied in this project were in the adjustment phase. In this case, it might be argued that parents were able to acknowledge and comment upon specific stressors related primarily to the increased demands of caring for a

pervasively disabled child. In contrast, however, parents were not able to acknowledge how these stressors impacted upon them in an emotional manner. In addition, in the informal phone interviews with parents, it was quite common to hear a mother or father talk about the denial process in his or her spouse, while not admitting to any of his or her own.

It also remains a possibility, however, that these parents are in the third stage, the reintegration stage, marked by a return to realistic and effective functioning. Unfortunately this study was not designed to include the necessary comparison groups or longitudinal analyses necessary to definitively answer these questions. Therefore no final word can be offered here. Theoretically, the answer to this question must rest upon one's opinion of whether the current stress is interpreted as merely a realistic response to a very stressful situation, or due in part to an ongoing personal struggle, occasionally resulting in the use of denial, to accept the full disability which afflicts their child.

This debate over stages might be most easily resolved, however, if one were to combine Blacher's stage model with Wikler's notion of "chronic stress". Wikler posits that stress will occur periodically for parents raising a handicapped child, most notably whenever there exists a discrepancy between what is expected developmentally and

what occurs in reality. The integration of these two models suggests a cyclical process in which parents battle through several adjustment phases, temporarily and periodically reaching reintegration phases, until faced with another strong reminder of the child's pervasive developmental disability. Upon being faced with this disability, parents renew their battle with acceptance and denial in another adjustment phase. Here then, it might certainly be said that our parents have passed beyond the disintegration phase and are currently struggling within this "adjustment cycle."

This notion of an "adjustment cycle" as opposed to an "adjustment stage" is bolstered by the lack of any significant relationship between time since diagnosis and adjustment in this study. Parents do not seem to adjust "better" simply because their child was diagnosed several years earlier. Rather, it appears that parents continue to struggle with the sequelae of autism in different ways throughout the childhood (and probably adolescent and adult) years of their sons and daughters.

Conclusions

In sum, both mothers and fathers report significant stress reactions which might be characterized as both instrumental and expressive crises. Although mothers and fathers did not report significant emotional adjustment problems, this result combined with the stress profiles might best be interpreted within the theoretical framework

of the "adjustment cycle". These results taken together, however, certainly strongly challenge Koegel et al.'s (1983) conclusion that no higher incidence of general stress occurs for parents of autistic children. As was discussed in Chapter II, Koegel et al.'s measures tapping relatively stable individual personality traits or family adjustment most probably precluded these authors from gathering information relevant to the individual and chronic stresses reported by parents in this study.

Cognitive Variables of Control and Attribution

Two important cognitive variables were investigated as to their role in the adjustment of parents of autistic children. Previous research within victimization theory studies had suggested that the variables of perceived control and attributional thought were important constructs in understanding these parents' adjustment. Thus, it was hoped that by examining these cognitive processes in parents of autistic children, questions pertaining to the adjustment of these parents and questions regarding the theoretical relationship between these variables and adjustment could be simultaneously addressed.

Control Variables

Both mothers and fathers reported moderate levels of perceived control over current and future sequelae associated with autism, while indicating significantly less control over the possible recurrence of this disorder in

subsequent offspring. A major focus of this study involved relating these control cognitions to measures of adjustment. It had been first hypothesized that control over recurrence cognitions would be significantly and positively related to adjustment in mothers and fathers. This hypothesis grew out of the previous finding in victimization studies, and parental victimization studies, that control over recurrence was a central variable in predicting and understanding emotional adjustment. This relationship was not replicated here. Control over recurrence was not shown to have any relationship to adjustment in either mothers or fathers of autistic children.

The failure to find any positive relationship between perceived control over recurrence and adjustment was not expected. However, the failure to inquire into parents' future childbearing plans makes this finding difficult to interpret. Parents were not asked whether they planned to have more children; parents were only asked about how much control they felt they had over the recurrence of autism in subsequent children. A high control rating here might indicate a rather unrealistic sense of control over the health of future offspring or a previous decision not to have any more children. Unfortunately this confounding makes interpretation of this finding somewhat difficult. It should be noted, however, that parents overall indicated a relatively low level of perceived control over recurrence.

Very few parents indicated the very high control ratings that would be associated with the decision to have no more offspring.

This lack of support for Tennen et al.'s (1986) original parental victimization model was, however, complimented by further evidence not supportive of this model. Previous parental victimization studies had also concluded that parents' control over sequelae cognitions were not essential variables in understanding adjustment, and in fact, were not associated at all with emotional adjustment (Tennen et al., 1986). This reported pattern was strongly contradicted by the present data in several ways. First, strong relationships were found between control over sequelae cognitions and all measures of adjustment for both mothers and fathers of autistic children. Moreover, for both mothers and fathers, these control cognitions proved to be central variables in attempts to differentiate better adjusted parents from more poorly adjusted parents in post hoc discriminant analysis attempts.

Although this pattern of results contradicts previous findings and strongly challenges Tennen et al.'s (1986) model of parental victimization, these results were not unexpected. In fact, the relationship between control over sequelae and adjustment had been hypothesized for parents of autistic children. In proposing this hypothesis, a possible theoretical rationale had been detailed (see Chapter II) and

can be briefly summarized here. Previous research within parental victimization theory has focused on parents of diabetic children, parents of infants with perinatal complications, and parents of developmentally delayed infants. It was argued that control over sequelae concerns would not be as serious a source of concern with these parents since the sequelae associated with these disorders are generally more predictable, less disruptive to everyday life, and certainly not as grossly deviant from community standards or norms of behavior as sequelae resulting from autism. While it cannot be absolutely concluded that these distinctions have resulted in the challenging findings reported here, any new models attempting to explain the relationship between perceived control and adjustment in parents of disabled children should now incorporate these disparate results.

Two general conclusions emerge from these results. First, for parents of autistic children, control over sequelae cognitions are important variables in understanding the adjustment process. Secondly, within parental victimization theory it seems premature to conclude that adjustment to victimizing experiences is dependent upon control over recurrence cognitions and not control over sequelae cognitions. It certainly appears to be premature to elevate Tennen et al.'s conclusions to the level of a general rule or model within victimization theory. A more

valid conclusion may well be that the nature of the sequelae (i.e. severity, predictability, etc.) is important in determining the relative importance of various control cognitions in the adjustment process. In addition, future empirical work might benefit from more detailed examination of this control over sequelae variable.

Attributional Cognitions

The second cognitive variable investigated was the attributional thoughts of parents regarding the cause(s) of their child's autism. Results of the Attributions Questionnaire suggested that mothers and fathers relied most heavily on the attributions of "chance" or "something else" to account for their child's autistic condition. Mothers and fathers infrequently blamed someone else for their child's disorder, and almost never reported any kind of self-blame --either characterological or behavioral. No significant difference in attributional style was noted between mothers and fathers.

This pattern suggested several things. First, it is clear that the old theoretical notion that mothers' have caused their child's autistic condition through problems during the attachment phase is either not being accepted by parents or not being promoted by professionals as much as in the past. During informal interviews, several parents expressed surprise that "anyone would believe that anymore", and many parents told of professionals who had quickly

assured then that they were not the cause of their child's problems.

Parents' quick and universal endorsement of the notion that they were not to blame for their child's autism, however, might also be in part the result of an underlying demand characteristic of this study. Parents reported that professionals have consistently told them not to blame themselves for their child's disorder and informed them of the historic tendency to blame the mother. Parents in this study may have been eager to demonstrate to the investigator their "professional knowledge" regarding the etiology of autism. As such, they would be inclined to quickly endorse the notion that they were not to blame. These responses, however, may not necessarily be indicative of the true attributional struggle that parents are experiencing. It seems quite possible that many parents still entertain and consider the notion of self-blame, even after being informed by professionals. They may, however, have hesitated in sharing these intimate thoughts with an unknown investigator who had identified himself as a professional in the very field that had previously counseled them against self-blame.

Secondly, parents reported a variety of reasons which fall into the "blame something else" category. As noted earlier, however, almost all these reasons had a biological/organic component. The different biological reasons ranged from common genetic and brain abnormality

explanations to the less common "allergy" explanations.

In essence, it might be said that the parents' variability in responses is reflective and reminiscent of the varying professional opinions regarding the causation of this unique disorder.

Another major focus of this study involved investigating the relationship between parents' attributions and their adjustment to parenting an autistic child. Several specific hypotheses emanated directly from the literature within victimization theory. Victimization studies have frequently reported a positive relationship between behavioral self-blame and adjustment. This relationship has been demonstrated in patients victimized by disease (Taylor et al., 1984) and crime (Janoff-Bulman, 1979). However, this common finding was not replicated here, as no statistically reliable relationship was noted between behavioral self-blame and any measures of adjustment for mothers or fathers.

The most parsimonious explanation for this finding appears to be a statistical, rather than a theoretical, one. Mothers' and fathers' ratings of questions asking about behavioral self-blame indicated that they almost never felt that their behavior had somehow acted as a contributing causal factor for their child's autism. Such consistently low ratings lack the variability necessary to validly study the relationship between behavioral self blame and

adjustment. That is, when almost no incidence of behavioral self-blame is found, no correlational relationship can be demonstrated. Therefore, it is felt that this finding should not be interpreted as necessarily challenging previous reports of the existence of a positive relationship between behavioral self blame and adjustment in certain populations.

A second and related hypothesis concerned the role of characterological self-blame in the adjustment process. Previous research had concluded that there existed an inverse relationship between characterological self-blame and adjustment. As noted in Chapter II, however, this conclusion was never based upon a direct empirical finding of such an association; rather it was concluded from the well-documented finding that behavioral self-blame is associated with greater control over recurrence and thus, more positive adjustment. It has been argued that since characterological self-blame would not lead to increased control over recurrence, it would be inversely related to adjustment. Empirical support for this relationship had never been found primarily because of the very low frequency of characterological self-blame reported by victims within victimization studies (Tennen et al., 1986; Affleck et al., 1985). It was hypothesized here that a higher incidence of characterological self-blame might be found in parents, particularly mothers, of autistic children because of the

uniqueness and severity of the disorder and the historically documented tendency to blame the mother for her child's autism (Bettleheim, 1967). It was further hypothesized that upon finding this higher level of characterological self-blame, the aforementioned inverse relationship between this type of blame and adjustment could be empirically documented for the first time.

Unfortunately for scientific purposes, mothers and fathers in this study very infrequently ascribed the cause of their child's autism to characterological aspects of themselves. Therefore, once again because of the lack of variability in characterological blame ratings, weak non-significant measures of association were found when relating this attribution to measures of adjustment. Once again then, when no incidence of characterological self-blame was found, no significant associations could be demonstrated. A true empirical test of the relationship between characterological self-blame and adjustment awaits the finding of a significant incidence of characterological self-blame.

A third, albeit non-major, hypothesis involving parents' attributions concerns the role of attributions which involve "blaming someone else". Previous research had reported a rather robust inverse relationship between this type of blame and adjustment (Taylor et al., 1984; Janoff-Bulman and Wortman, 1976). It had been hypothesized that a

similar relationship would be found in parents of autistic children. Although parents did report rather infrequent reliance on this type of blame, a strong relationship between blaming someone else and poorer adjustment was discovered for both mothers and fathers. This finding corroborates similar findings in studies of other victims as discussed above.

Unfortunately, in the present study as in most previous studies of this finding, there was no way of determining whether this tendency to blame someone else was actually rooted in a specific identifiable mistake made by another individual (i.e. a doctor). This failure to attempt to evaluate whether this blaming was "realistic" or "unrealistic" somewhat limits the interpretation of this finding. It might be profitable, both in terms of victimization theory, as well as in understanding parental adjustment, to begin to incorporate some assessment of the realistic basis of this type of blame. It remains quite possible that those individuals engaging in realistic blame of others might adjust differently from those individuals unrealistically blaming others.

In addition, clinicians have often wondered whether this tendency to blame someone else might not represent some "masked" self-blame. It would be interesting to examine whether such "masked" blaming was more likely to be present in unrealistic, as opposed to realistic, blaming of another

individual. If in fact this "masking" phenomenon could be documented, and if a relationship with the tendency to unrealistically blame another individual could be demonstrated empirically, the inverse relationship between this tendency to blame someone else and adjustment would be more interpretable. Further empirical investigation of the understanding of the "blame someone else" construct should consider these possible explanatory constructs.

Attributions and Control Cognitions as Predictive Constructs

A third underlying issue must also be considered before abandoning the discussion of parents' control and attributional cognitions. One hypothesis which lay at the foundation of this study involved the issue of whether knowledge of a parents' attributions and control cognitions might in some way help to predict adjustment. This issue grew out of the previous work with parents of autistic children which generally ignored cognitive variables such as perceived control and attributions in explaining and predicting adjustment (Bristol, 1979, 1983). These early studies focused almost exclusively on such variables as the age of the child, social support received by the mothers, and coping strategies employed in order to explain adjustment.

In order to directly address the issue of the role of the cognitive variables in the adjustment of mothers and fathers, significant demographic variables which also might

affect adjustment had to be isolated first. Interestingly, the demographic variables associated with adjustment in mothers differed significantly from the demographic variables associated with adjustment in fathers. For mothers, their age and their overall behavior rating of the child were inversely related to adjustment. That is, the younger the mother and the fewer behavior problems reported, the better her adjustment. Certainly this finding of an association between adjustment and the child's behavior was intuitively expected. Specific reasons for the inverse relationship between age of the mother and adjustment are less obvious, and thorough explanation awaits further investigation. It is possible that younger mothers have more energy than those who are older; however, this finding remains hard to interpret in light of the lack of significant association between such variables as age at diagnosis, age of the child, and time since diagnosis with adjustment.

Somewhat in contrast to mothers, fathers' adjustment was significantly associated with the age of the child, the family's income, and the behavior of the child. The finding that more problematic behaviors were associated with poorer adjustment was again expected. The finding that having an older autistic child was associated with more positive adjustment in fathers was not expected. Previous research had indicated an inverse relationship between age of the

child and adjustment in mothers (Bristol, 1979). Because our sample did not include children in their adolescent years, it is difficult to interpret these findings. It is possible that the older children in this study were less stressful than younger children perhaps due to a higher level of adaptive behavior. It remains possible, however, that this linear relationship would not hold as children reached their adolescent years and parents are more directly faced with problems due to increased physical stature of the child and future vocational/care problems.

The finding that family income was positively associated with adjustment for fathers was anticipated. Previous research had suggested that financial issues would be a major stressor for fathers (i.e. Gumz and Gubrium, 1972). In fact, it had been hypothesized that this concern would be reflected on the scale measuring financial problems on the QRS. No significant incidence was found on this scale, perhaps reflecting the generally high incomes reported by most families in this study. However, when the variation in income within even this fairly well-off sample was associated with adjustment, a positive finding emerged. Thus, although one could not conclude that absolute financial pressures existed for these families, increased income was still associated with more positive adjustment for these fathers.

Above and beyond the findings concerning the non-

experimental, demographic variables, correlational analyses already reported and discussed above have suggested the importance of the cognitive variables of control over sequelae and the attributional tendency to blame someone else. These findings, however, were significantly strengthened by the results of the multiple regression and discriminant function analyses. For mothers, although no cognitive variables met inclusion criteria within the conservative hierarchical multiple regression procedure, two central cognitive variables proved to be the most important discriminators of high adjustment versus low adjustment in mothers. These variables of control over current sequelae and blaming her child's autism on someone else emerged as the central discriminating variables, even when the covariates of age of the parent and behavior of the child were included as potential discriminating variables.

For fathers, using the conservative hierarchical multiple regression approach, the cognitive variable of fathers' tendency to blame someone else for his child's autism emerged as an important predictor variable, even after the effects of the child's age and family income had been partialled out. Moreover, in a result similar to that reported for mothers, two cognitive variables emerged as the lone significant discriminators of high and low adjustment in fathers. These variables of control over future sequelae and blaming his child's autism on someone else emerged as

the only significant discriminating variables, even when the covariates of age of the child and family income were included as potential discriminating variables.

These two findings taken together strongly support the underlying hypothesis upon which this study rested. That is, our understanding of the stress-adjustment reaction of parents of autistic children is significantly strengthened when we broaden our investigation to include cognitive and attitudinal variables. More specifically, the cognitive variables of control over sequelae and blaming someone else have been found to be central explanatory constructs in understanding the adjustment process of both mothers and fathers of autistic children. Any future investigations of this adjustment process should now give careful consideration to the impact of these cognitive variables.

The failure to identify the variables of control over recurrence and self blame as central predictive variables should be noted as well. While an interpretation of this last finding is difficult to make, it is clear that future empirical work should consider the notion of the "adjustment cycle" in understanding the impact of all cognitive variables, especially those which might suggest the role of traditional intrapsychic forces such as denial, guilt, and shame. Unfortunately, it was difficult to pinpoint where in the adjustment cycle our sample stood; therefore, the specific impact of these variables could only be speculated

upon.

Future Directions

Implications for Parents of Autistic Children

When one considers the implications of this study in regard to future work with parents of autistic children, one must consider both the clinical and the empirical realms. Clearly a stress reaction for mothers and fathers has been documented here. Moreover, mothers' and fathers' adjustment has been shown to be, at least in part, a product of their control and attributional cognitions. From these findings, several clinical issues should be considered.

Support groups for parents of autistic children are becoming increasingly prevalent. While most of these are attended almost exclusively by mothers, some programs are designing groups for fathers of handicapped children (Meyer, 1986). In addition, many parents seek out individual guidance in coping with their autistic child. Results of this study suggest that these group (or individual) sessions should not be merely supportive and/or educational, but that the issues of blame and control should be thoroughly considered.

More specifically, an ideal program for such parents might include several parts. First, a group oriented towards discussing and sharing concerns over the issues of blame and control should be included. More specifically, this group might provide a forum for parents to exchange

their thoughts and feelings regarding causation, without the demand of conforming to the professional opinion that parenting is not to blame for this disorder. Parents should be clear as to the current state of the etiological theories; parents should not, however, be discouraged from discussing personal concerns which do not conform to these theories. That is, even though professionals inform parents that they are not to blame, parents may still worry about their role.

Secondly, since perceived control over sequelae was shown to be a strong predictor of adjustment, this issue might be addressed outside the group as well. A comprehensive program which included teaching parents to use behavioral, educational, and therapeutic techniques to help make their child's behavior somewhat more predictable and manageable might alleviate some of the parents' concerns over controlling the immediate sequelae of autism. The combination of this applied intervention for parents with the more traditional verbal discussion of control concerns⁸ might be most beneficial to these parents.

This might be taken a step further in an effort to consider the clinical and empirical ramifications simultaneously. A controlled experimental investigation, in which parents are encouraged to discuss and consider these cognitive variables, would help to establish the integral role of these cognitions in the adjustment process.

Specific investigations might include explorations of whether interventions aimed at either decreasing individual's tendency to blame someone else or increasing parents' feelings of control over sequelae might aid adjustment. While these specific interventions can not be suggested for clinical implementation directly as a result of this correlational study, such a clinical/empirical effort is certainly warranted by the results reported here.

A second issue that has been shown to be worthy of further endeavors is the inclusion of fathers in both future clinical and research projects involving this population. Clinically, the stress profile and cognitive variables reported here should be kept in mind when working with this population. Empirically, work with the father lags significantly behind empirical work with the mother. This study suggests that useful and important information can, and should, be gathered from fathers concerning their role in the parenting process. Within the study of fathers of autistic children, continued investigation of the adjustment process would be quite valuable. Inclusion of observational measures of interaction, the impact of fathers' involvement on the development of the child, and the fathers' role in the family's adjustment process all deserve immediate attention. In addition, these investigations should, of course, go well beyond the continued study of just fathers of autistic children. Fathering, in general, is a poorly

understood process; the process of fathering a disabled or special child has hardly been investigated and deserves attention.

Empirical investigations of mothers of autistic children should continue as well. Well documented discussions of the stress reactions of mothers are now available. More work needs to focus on the adjustment process, investigating further the cognitive variables and relating these cognitive variables to the external variables focused on by Bristol (1983). In addition, as suggested above, intervention studies could add valuable clinical and empirical information. Intervention efforts designed to manipulate (i.e. realistically increase) mothers control over sequelae cognitions might be most beneficial.

In essence, there currently exists in the literature a series of rather disjointed and disparate studies documenting the stress reaction of parents of autistic children. This study focused on the impact of cognitive variables. Earlier studies have focused on the role of demographic and subject variables. Still other studies have focused on the role and importance of social support. In order to contribute additional clinical and empirical information to the field, much work attempting to integrate these findings needs to be initiated. Studies with these parents now need to simultaneously consider the cognitive variables, subject variables, and external (i.e. social

support) variables, as well as the theoretical perspectives of victimization theory and sociological theory (i.e. see Bristol, 1984) in an attempt to build a comprehensive model of adjustment.

Implications for Victimization Theory

This study attempted to investigate two central, yet unanswered issues within victimization theory. First the role of characterological blame in the adjustment process was investigated. Unfortunately, this study could not shed additional light on this relationship. Efforts to address this relationship using other populations, other methods, or even other parents of autistic children at a different point in the mourning/adjustment cycle should continue.

Secondly, the role of different types of control cognitions was investigated. The model, which had been in use in understanding parents as victims, had posited that control over recurrence was central to the adjustment process, while control over sequelae was not. Our results seriously challenge this model and suggest that issues related to the type of victimizing experience and nature of the sequelae involved need to be much better understood before such a model will be found to accurately reflect the adjustment process. Studies with other populations, as well as studies which focus more on the measurement of these control variables, could add significant information to our attempts to understand the adjustment process involved in

coping with a victimizing experience.

ENDNOTES

1

Holroyd (1987) acknowledges that the label "Negative Attitudes towards the Child" of Scale 3 is somewhat of a misnomer. Holroyd reports that items on Scale 3 reflect "social sensitivity, both in terms of what people might think of the child and of the respondent..." She further indicates that a more appropriate label for this scale might be "Oversensitivity to Illness or Handicap."

2

It should be noted that "blaming something else" almost always referred to blaming a biological/organic cause for their child's autism. Examples of this type of blame include blaming genetics, blaming disease/illness after birth, and blaming brain abnormalities.

3

An extremely high correlation between control over current sequelae scores and control over future sequelae scores ($r=.90$) was discovered. Therefore, in order to avoid the problem of multicollinearity as discussed by Pedhazur (1982), only the control over sequelae score which had a higher zero-order correlation with the dependent variable was used for regression analyses.

4

As noted above, the variables of age of the mother and behavior of the child exhibited significant zero-order correlations with the composite adjustment score. Partial correlations were calculated between all non-experimental variables and the composite adjustment score. The variable with the highest zero-order correlation was partialled first (age of mother). The only variable which exhibited a significant partial correlation with adjustment was behavior of the child (partial correlation=.42). Secondly then, the variables of age of the mother and behavior of the child were both partialled out. No other variables' second order partial correlations reached significance. Therefore, the variables representing age of the mother and behavior of the child were considered significant covariates for further analyses.

5

Within multiple regression analyses, including

additional variables in the regression equation can never decrease the value of R-squared. Therefore, most authors urge the reporting of the R-squared "adjusted" statistic. This statistic adjusts for the number of independent variables used in the regression equation and is thus used to better determine whether including another independent variable will increase the explanatory power of the equation (Schroeder, Sjoquist, and Stephan, 1986).

6

Wilks' lambda is a multivariate measure of group differences over several discriminating variables. Wilks' lambda is a statistic which considers both differences between groups and the cohesiveness within groups. Variables which increase cohesiveness while maximizing group differences produce smaller lambda's. Since lambda is an inverse statistic, at any one step the variable which produces the smallest lambda is entered into the equation. Variables are entered in a stepwise fashion until no excluded variable significantly increases the discriminating power of the function (Klecka, 1980).

7

As noted above, the variables of age of the child, family income, and behavior of the child exhibited significant zero-order correlations with the composite adjustment score. Partial correlations were calculated between all non-experimental variables and the composite adjustment score. The variables with the highest zero-order correlation was partialled first (i.e. age of the child). The only variable which then exhibited a significant partial correlation with adjustment was family income (partial correlation=.55). The variables of age of the child and family income were then partialled out. No other non-experimental variables' second-order partial correlations reached significance. Therefore, the variables representing age of the child and family income were considered significant covariates for further analyses.

8

Schopler and his colleagues at the TEACCH program at the University of North Carolina have begun to successfully use parents as "co-therapists" and "co-teachers" in attempts to treat their autistic children. While their programs do not directly address the issue of control, certainly many of the behavior management and educational components are at least theoretically related to the issue of control.

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APPENDIX A

FAMILY INFORMATION QUESTIONNAIRE

PART I

Autistic child's age _____; sex _____

Age at which your child was diagnosed as autistic _____

Is your autistic child receiving any special services (outside of school) from any agency? _____ If yes, please describe these services:

Is your family receiving any special services to help you in parenting and managing your autistic child? _____ If yes, please describe these services: _____

What school is your autistic child now attending?

Please list the age and sex of any other children in the family:

Mother's

Age _____

Race _____

Occupation _____

Highest Educational Grade Level Attained _____

Annual Income _____

Father's

Age _____

Race _____

Occupation _____

Highest Educational Grade Level Attained _____

Annual Income _____

PART II

Using the following scale, please indicate who in your family is primarily responsible for helping your autistic child complete the following daily tasks. Please assign one of these numbers to each of the following tasks:

- 1 = Only Dad helps the child on this task
- 2 = Dad helps the most, but other family members help too
- 3 = Dad and Mom help equally
- 4 = Mom helps the most, but other family members help too
- 5 = Only Mom helps the child on this task
- 6 = Neither Mom nor Dad are involved in this
- 7 = The child needs no help in doing this task

- _____ Helping the child with toileting
- _____ Helping the child with eating
- _____ Helping the child with bathing
- _____ Helping the child with dressing
- _____ Helping the child with undressing
- _____ Teaching your child language skills at home
- _____ Playing with your child at home
- _____ Teaching your child daily living skills at home
- _____ Working with your child's school(i.e. talking to teachers)
- _____ Working with your child's medical doctor
- _____ Working with other agencies helping your child
- _____ Working with/talking to other parents of autistic children
- _____ Contacting politicians and legislators to encourage laws and funding which might benefit autistic children.

PART III. CHILD BEHAVIOR RATING SCALE

Since autistic children often act quite differently, it is important for us to get a sense of the behaviors your child demonstrates at home. I have listed several behaviors below. Using the following scale, please indicate how frequently you observe your autistic child behaving in the following ways.

- 1=very rarely
- 2=seldomly
- 3=sometimes
- 4=often
- 5=very often

_____ The child behaves as if no one else is present. That is, he appears oblivious to other people, avoids direct eye contact, does not respond to others.

_____ The child withdraws from others or resists interaction. That is, he responds to either physical or verbal contact from others by turning away, struggling to pull away, or verbally expressing a desire to withdraw.

_____ The child engages in non-verbal interaction. That is, he makes eye contact with others, smiles at others, cuddles up to others, gestures for food, or clings to others.

_____ The child relates to individuals by engaging in questions or conversations unrelated to the immediate situation, by seeking reassurance, comfort, sympathy, and approval verbally or non-verbally, and by angry or aggressive actions if attention is withdrawn.

_____ The child demonstrates sensory problems which include chewing inedible objects, rubbing hand over objects repetitively, twirling objects in front of face, sniffing objects, or licking objects.

_____ The child does not respond to auditory stimuli. That is, the child disregards a person talking to him, and is not responsive to loud noises such as hand clapping, objects dropping, or people screaming.

_____ The child is not responsive to pain. That is, the child fails to show a painful reaction to physical injuries such as burns, cuts, falls, or head banging.

_____ The child does not produce clearly recognizable words.

_____ The child produces clearly recognizable words but does not employ them for the purposes of communication.

Continue to use this scale:

1=very rarely

2=seldomly

3=sometimes

4=often

5=very often

_____ The child, either immediately or after some delay, repeats words, phrases, or sentences spoken by others.

_____ The child demonstrates an inability to sustain or focus his attention when given tasks or activities to perform.

_____ The child demonstrates problems in coordination. That is, he has trouble manipulating familiar objects, holding food in his mouth, button his clothes, zipping his clothes, or tying his shoes.

_____ The child demonstrates overactivity. That is, the child jumps up and down excessively, twirls around, or rocks.

_____ The child demonstrates underactivity. That is, the child shows long periods of passivity and immobility.

_____ The child demonstrates repetitive movements. That is, the child flaps his hands, flicks his fingers, or demonstrates writhing motions with his head, face, and neck.

_____ The child reacts with expressions of panic or rage when change is introduced into his environment.

_____ The child demonstrates persistent attachments to unusual objects, particular articles of clothing, or types of textured items.

_____ The child engages in preoccupation with simple objects.

_____ The child demonstrates other ritualistic behaviors such as touching certain objects prior to beginning an activity, arranging his toys in a certain manner, walking in a specific pattern upon entering a room, or repeating a TV or radio commercial or popular song.

_____ The child demonstrates eating difficulties. That is, the child has strong aversions to certain textured foods, has a narrow range of food preferences, refuses to eat outside the home, has specific rituals associated with eating.

Continue to use this scale:

- 1=very rarely
- 2=seldomly
- 3=sometimes
- 4=often
- 5=very often

_____ The child demonstrates sleeping difficulties. That is, the child has difficulty falling or remaining asleep, or the child appears to need very little sleep.

_____ The child demonstrates toileting difficulties which include either wetting and or soiling during the day or night.

_____ The child engages in self injurious behaviors such as head banging, biting of the hands and arms, hitting the body with a clenched fist, face scratching, or hair pulling.

_____ The child engages in destructive activities directed against other people or objects, such as hitting, pinching, punching, pulling hair, and breaking objects.

_____ The child engages in temper tantrums which include long periods of screaming, screeching, crying, and kicking.

_____ The child demonstrates anxieties or fears, such as fear of being physically harmed, fear of abandonment.

_____ The child demonstrates special abilities. The special abilities could include capacities for gross and fine motor coordination, language usage, vocabulary, memory, music, geography, or arithmetic.

APPENDIX B

ATTRIBUTIONS QUESTIONNAIRE

PART I. CAUSES QUESTIONNAIRE

Many, if not all, parents who have an autistic child develop some idea about how their child developed autism. That is, even though we do not know the causes of autism specifically, many people have a hunch or theory about why their child is autistic. I have listed some reasons, or causes, that parents commonly give for why their child is autistic. I would like you to consider each possible cause below, and rate how important you feel each cause was in determining your child's autism. Please rate each possible cause using the following scale:

- 1= this cause was not a factor at all in causing my child's autism
- 2= this cause was a very minor factor in causing my child's autism
- 3= this cause was a somewhat minor factor in causing my child's autism
- 4= this cause was a somewhat major factor in causing my child's autism
- 5= this cause was a very important factor in causing my child's autism
- 6= this cause was completely responsible for my child's autism

- ___ Disease in mother during the pregnancy
- ___ Some behavior of mother during pregnancy like smoking, drinking, or poor eating
- ___ Genetic inheritance
- ___ Injury to the child during birth
- ___ Premature birth
- ___ Disease in the child after birth
- ___ Accident which injured the child after the birth
- ___ Doctor's mistake before, during, or after the birth
- ___ Mother's interactions with the child after the birth
- ___ Father's interactions with the child after the birth
- ___ Mother's personality
- ___ Father's personality
- ___ Chance, a random event
- ___ Other: (please explain and give a number rating)

Part II

Parents sometimes have said that at times they find themselves blaming either themselves or someone else for their child's handicap, even though they are not sure about the specific causes. I would like you to please rate how often you blame each of the following factors by circling the number that applies.

1.) I blame my personality for causing my child's autism:

1	2	3	4	5	6
never	rarely	occasionally	often	very often	always

2.) I blame my behavior for causing my child's autism:

1	2	3	4	5	6
never	rarely	occasionally	often	very often	always

3.) I blame chance for causing my child's autism:

1	2	3	4	5	6
never	rarely	occasionally	often	very often	always

4.) I blame someone else for causing my child's autism:

1	2	3	4	5	6
never	rarely	occasionally	often	very often	always

5.) I blame something else for causing my child's autism:

1	2	3	4	5	6
never	rarely	occasionally	often	very often	always

APPENDIX C

CONTROL QUESTIONNAIRE

Many parents worry about controlling various aspects of their autistic child's life and their own lives. Sometimes parents worry about controlling the child's behavior or his learning, other time parents worry about controlling whether they might have another autistic child. Both of these concerns are understandable worries for parents to have. I'd like to ask you a few questions about any worries you might have over controlling your child's and your own lives. Please respond to the following scale by circling how much control you feel you have over each situation:

1.) How much control do you feel you have over your child's autistic behavior in terms of being able to modify it now?

1	2	3	4	5	6
almost no	little	limited	some	much	almost
control	control	control	control	control	complete
					control

2.) How much control do you feel you have over your child's autistic behavior in terms of being able to influence his or her future behavior?

1	2	3	4	5	6
almost no	little	limited	some	much	almost
control	control	control	control	control	complete
					control

3.) How much control do you feel you have over your child's language development in terms of being able to modify it now?

1	2	3	4	5	6
almost no	little	limited	some	much	almost
control	control	control	control	control	complete
					control

4.) How much control do you feel you have over your child's language development in terms of being able to influence his or her future language development?

1	2	3	4	5	6
almost no	little	limited	some	much	almost
control	control	control	control	control	complete
					control

5.) How much control do you feel you have over your child's learning ability in terms of being able to modify it now?

1	2	3	4	5	6
almost no control	little control	limited control	some control	much control	almost complete control

6.) How much control do you feel you have over your child's learning ability in terms of being able to influence his or her future learning ability?

1	2	3	4	5	6
almost no control	little control	limited control	some control	much control	almost complete control

7.) How much control do you feel you have over the outcome of any future pregnancies in terms of preventing autism in any future children?

1	2	3	4	5	6
almost no control	little control	limited control	some control	much control	almost complete control

APPENDIX D

ON
RESOURCES AND STRESS
(ORS)

Jean Holroyd

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INSTRUCTIONS

This questionnaire deals primarily with your thoughts and feelings regarding your disabled child. Each question contains a blank. Each time you see a blank, imagine your child's name in the blank.

For every question, you need to answer either "True" or "False". Simply put a "T" or an "F" in front of each question to indicate whether the statement is true or false for you. Please answer every question.

1. _____ demands that others do things for him/her more than is necessary.
2. _____ understands the idea of time.
3. Because _____ is the kind of person he/she is, he/she can handle his/her situation better than another person could.
4. _____ is cared for equally by all members of our family.
5. It will take us three years or more to pay off our debt.
6. A member of my family has had to give up education (or a job) because of _____.
7. One of the things I appreciate in _____ is he/she is independent.
8. Members of the family share in the care of _____.
9. _____ would not resent being left at home while the family went on vacation.
10. Members of our family praise each other's accomplishments.
11. _____ has a pleasing personality.
12. I do not attend very many meetings (PTA, church, etc.).
13. I know _____'s condition will improve.
14. _____ does not have problems with seeing or hearing.
15. Even if people don't look at _____, I am always wondering what they might think.
16. I take on responsibility for _____ because I know how to deal with him/her.
17. _____ has some unusual habits which draw attention.
18. In our house the whole family eats dinner together.
19. The doctor sees _____ at least once a month.
20. I usually do not have to take _____ with me when I go out.
21. There is more than one wage earner in our family.
22. _____ is a very capable, well-functioning person despite his/her other problems.
23. I always watch to make sure _____ does not do physical harm to himself/herself or others.
24. The special opportunities needed by _____ are available in our community.
25. Our house is comfortably arranged to meet _____'s needs without making it difficult for other members of the family.
26. Money from the government or an organization pays for part of our medical costs.
27. _____ would be in danger if he/she could get out of the house or yard.
28. I feel that our family situation will get better.
29. Medicine does not have to be given to _____ at a set time.
30. _____ doesn't communicate with others of his/her age group.
31. People who don't have the problems we have don't have the rewards we have either.
32. Other members of the family have to do without things because of _____.
33. _____'s problems or illness do not stand in the way of our family progress.
34. When others are around _____ I cannot relax; I am always on guard.
35. If _____ were more pleasant to be with it would be easier to care for him/her.
36. Thinking about the future makes me sad.
37. Much of the time I think about _____ dying.
38. If I knew when _____ would die I wouldn't worry so much.
39. I don't worry too much about _____'s health.
40. Our family agrees on important matters.
41. Professionals (nurses, etc.) in an institution would understand _____ better than I do.
42. When _____ is not well, I can't go out.

43. I am afraid that by limiting _____'s activities he/she will not develop on his/her own.
44. Our family's income has dropped over the past 5 years.
45. The constant demands for care for _____ limit growth and development of someone else in our family.
46. _____ feels that I am the only one who understands him/her.
47. In his/her own way _____ brings as much pleasure to our family as the other members.
48. I worry about what will happen to _____ when I can no longer take care of him/her.
49. I think in the future _____ will take up more and more of my time.
50. I am able to leave _____ alone in the house for an hour or more.
51. I fear the day when other members of the family leave home and I am left alone with _____.
52. It would be better for _____ if our house could be remodeled.
53. A counselor or a teacher sees _____ at least once a month.
54. I get out of the house to do something interesting at least once a week.
55. I am very careful about asking _____ to do things which might be too hard for him/her.
56. The attitude of our family makes it impossible for _____ to live with us any longer.
57. I would rather be caring for _____ than doing some other kind of work.
58. _____ is limited in the kind of work he/she can do to make a living.
59. I have accepted the fact that _____ might have to live out his/her life in some special setting (i.e., hospital, institution, foster home).
60. I have given up things I have really wanted to do in order to care for _____.
61. My family argues about how to care for _____.
62. _____ is able to fit into the family social group.
63. Some members of my family don't like the way I do things.
64. I would not want the family to go on vacation and leave _____ at home.
65. At times I fear _____ will not be able to function in society if he/she is out of our house.
66. It is difficult for me to stand back and watch _____'s condition get worse.
67. In the future our family's social life will suffer because of increased responsibilities and financial pressure.
68. It doesn't make any difference to _____ if he/she is at home or in a hospital.
69. _____ knows the difference between strangers and friends.
70. I am afraid that other members of the family will be hurt because they are related to _____.
71. There is no way we can possibly keep _____ in our house.
72. People should take care of their own.
73. One of us has had to pass up a chance for a job because _____ could not be removed from a clinic or a special school, etc.
74. I would rather help _____ do something than have him/her fail and feel badly.
75. _____ has always lived with our family.
76. I cannot manage _____.
77. Sometimes I avoid taking _____ out in public.
78. _____ is on a special diet.
79. Many people simply don't understand what it is like to live with _____.
80. Every member of our family has had to do without things because of money spent on _____.
81. _____ can feed himself/herself.
82. I tend to do things for _____ that he/she can do himself/herself.
83. When we go on vacation, I'm not afraid to leave _____ for any length of time.
84. As the time passes I think it will take more and more to care for _____.

85. I belong to organizations which help with problems I have with _____.
86. There have been serious emotional problems for someone in our family.
87. Our relatives have been very helpful.
88. We have discussed what will happen when _____ dies.
89. It is easier for me to do something for _____ than to let him/her do it himself/herself and make a mess.
90. _____ is easy to manage most of the time.
91. I don't think that _____ depends too much on me or other members of the family.
92. It is not necessary for _____ to go up or down steps in our house.
93. I feel that I must protect _____ from the remarks of children.
94. We can afford to pay for the care _____ needs.
95. Just talking about problems with close friends makes life easier.
96. I can never leave the house because of _____.
97. I am happy when I watch the development and achievements of _____.
98. It bothers me that _____ will always be this way.
99. No one in our family drinks alcohol too much.
100. The community is used to people like _____.
101. _____ uses special equipment because of his/her handicap.
102. _____ has a handicap which prevents him/her from improving.
103. _____ is sometimes too sexual.
104. _____ has a lot of pain.
105. I feel tense whenever I take _____ out in public.
106. _____ is easy to live with.
107. The doctor sees _____ at least once a year.
108. _____ eats his/her meals with other members of the family.
109. Wheelchairs or walkers have been used in our house.
110. An electricity failure would endanger _____'s life or health.
111. Caring for _____ has been a financial burden for our family.
112. _____ made a good income at one time.
113. Some friends are very helpful when it comes to _____.
114. I worry that _____ may sense that he/she does not have long to live.
115. _____ will not do something for himself/herself if he/she knows someone will do it for him/her.
116. I can go visit with friends whenever I want.
117. Members of the family show no interest in what happens to _____.
118. We enjoy _____ more and more as a person.
119. We have changed our house because of _____.
120. Taking _____ on a vacation spoils pleasure for the whole family.
121. The family does as many things together now as we ever did.
122. _____ knows his/her own address.
123. _____ gets along very well with others.
124. _____ is aware of who he/she is (for example, male 14 years old).
125. _____ prevents any communication within our family.
126. Someone in our family turns against _____ when his/her friends are around.
127. Sometimes I need to get away from the house.

128. I get upset with the way my life is going.
129. Sometimes I feel very embarrassed because of _____.
130. Having to care for _____ has enriched our family life.
131. Neighbors want us to move because of _____.
132. I respect _____'s judgment about what he/she can do.
133. _____ doesn't do as much as he/she should be able to do.
134. Our family has been on welfare.
135. We have discussed what will happen if _____ lives longer than we do.
136. _____ is truly accepted by the family.
137. A bed that raises and lowers has made things easier.
138. We take _____ along when we go out.
139. It makes me feel good to know I can take care of _____.
140. Others do for _____ what he/she could do for himself/herself.
141. Because of _____ our family has never enjoyed a meal.
142. I hate to see _____ try to do something and fail.
143. _____ is accepted by other members of the family.
144. I fear _____ might get hurt while playing games or sports.
145. It is difficult to communicate with _____ because he/she has difficulty understanding what is being said to him/her.
146. _____ spends time at a special day center or in special classes at school.
147. _____ is very anxious most of the time.
148. _____'s health is not getting worse.
149. There is no special government program to help _____.
150. I have no time to give the other members of the family.
151. Our family is quite religious.
152. In our family _____ takes an active part in family affairs.
153. There are many places where we can enjoy ourselves as a family when _____ comes along.
154. It is hard to think of enough things to keep _____ busy.
155. _____ is overprotected.
156. Our family income is more than average.
157. Some of our family do not bring friends into the home because of _____.
158. I try to get _____ to take care of himself/herself.
159. Caring for _____ gives one a feeling of worth.
160. We have discussed his/her death with _____.
161. _____ is able to take part in games or sports.
162. One of us has had to pass up a chance for a job because _____ could not be left without someone to watch him/her.
163. We think _____ will live longer in an institution.
164. _____ has too much time on his/her hands.
165. There is an organization for families who share our problems.
166. I am disappointed that _____ does not lead a normal life.
167. We spend up to 25 percent of our income on medical care (or care for _____).
168. Time drags for _____, especially free time.

169. I worry about how our family will adjust after _____ is no longer with us.
170. The part that worries me most about _____ going on his/her own is his/her ability to make a living.
171. _____ resents being treated as a handicapped person.
172. _____ can't pay attention very long.
173. I worry about what will be done with _____ when he/she gets older.
174. If _____ were healthier it would be easier to go away for a holiday.
175. Compared to others, we spend a lot of money on medical costs.
176. I get almost too tired to enjoy myself.
177. _____ has things to entertain him/her (TV, radio) in his/her room.
178. We owe a great deal of money.
179. _____ is depressed most of the time.
180. If I were healthier, it would be easier to care for _____.
181. Most persons in public places indicate they don't want _____ around.
182. _____ can get around the neighborhood quite easily.
183. _____ wants more freedom than he/she has.
184. One of the things I appreciate about _____ is his/her confidence.
185. I don't mind when people look at _____.
186. Whenever I leave the house I am worried about what's going on at home.
187. In our family _____ plays as important a role as other members.
188. _____ will never be any brighter than now.
189. One of the things I appreciate about _____ is his/her ability to recognize his/her own limits.
190. I believe _____ should go places as often as others in the family.
191. I am not embarrassed when others question me about _____'s condition.
192. There is a lot of anger and resentment in our family.
193. If _____ could get around better we would do more as a family.
194. Our family has managed to save money or make investments.
195. We own or are buying our own home.
196. Information and encouragement is available to those who seek it.
197. We get special funds because of _____'s problem.
198. One of the things I enjoy about _____ is his/her sense of humor.
199. We can have no luxuries.
200. I have enough time to myself.
201. _____ is able to go to the bathroom alone.
202. I am afraid _____ will not get the individual attention, affection, and care that he/she is used to if he/she goes somewhere else to live.
203. I have too much responsibility.
204. No member of the family pities _____ too much.
205. _____ cannot remember what he/she says from one moment to the next.
206. _____ is better off in our home than somewhere else.
207. _____ can describe himself/herself as a person.
208. Others in the family should help care for _____.
209. A nurse sometimes works in our home.
210. Relatives have done more harm than good when it comes to _____.

211. I am afraid that as _____ gets older it will be harder to manage him/her.
212. It is easy to keep _____ entertained.
213. It makes me feel worthwhile to help _____.
214. _____ wants to do things for himself/herself.
215. In the future _____ will be more able to help himself/herself.
216. _____ needs a walker or a wheelchair.
217. I have become more understanding in my relationships with people as a result of _____.
218. The constant demands to care for _____ limit my growth and development.
219. _____ cannot get any better.
220. _____ is very tense in strange surroundings.
221. It is easy to communicate with _____.
222. I feel sad when I think of _____.
223. Our family should do more together.
224. I have had to give up a chance for a job because of _____.
225. _____ accepts himself/herself as a person.
226. Outside activities would be easier without _____.
227. Our relatives give us much help.
228. I enjoy church.
229. Caring for _____ puts a strain on me.
230. I often worry about what will happen to _____ when I no longer can take care of him/her.
231. _____ can use the bus to go wherever he/she wants.
232. People can't understand what _____ tries to say.
233. If it were not for _____ things would be better.
234. I feel that _____ would prefer a professional (nurse, day care helper, etc.) to care for him/her rather than a member of our family.
235. Some members of the family resent _____.
236. Members of our family get to do the same kinds of things other families do.
237. _____ embarrasses others in our family.
238. My happiness goes up and down with _____'s behavior.
239. _____ uses the phone frequently.
240. _____ has many things to keep him/her busy.
241. Sometimes the demands _____ makes drive me out of my mind.
242. I had high hopes for _____'s future.
243. _____ could do more for himself/herself.
244. My family understands the problems I have.
245. It is easy to do too much for _____.
246. _____ appreciates the interest others show in him/her.
247. It is easier for our family to do things with people we know than with strangers.
248. I am pleased when others see my care of _____ is important.
249. We can hardly make ends meet.
250. _____ rarely has nightmares.
251. I don't try to shelter _____ from life's difficulties.
252. Members of my family are able to discuss personal problems.

253. I often have the desire to protect _____.
254. I am as healthy as I ever was.
255. _____ does not dress right.
256. Most of _____'s care falls on me.
257. No one can ever understand what I go through.
258. We have household help (cleaning woman, nurse, etc.).
259. It is fortunate how _____ has adjusted to life.
260. _____ accepts his/her handicap.
261. _____ has his/her own room.
262. _____ is very irritable.
263. We have lost most of our friends because of _____.
264. _____ has an attractive, clean appearance.
265. _____ can ride a bus.
266. _____ will always be a problem to us.
267. _____ is able to express his/her feelings to others.
268. It is easy for me to relax.
269. _____ has to use a bedpan or a diaper.
270. I rarely feel blue.
271. We have good laundry facilities at home.
272. _____ can walk without help.
273. _____ needs help in the bathroom.
274. I have chances to carry on interests outside the home.
275. It bothers me to see _____ in pain.
276. Every cloud has a silver lining.
277. I like myself as a person.
278. I am worried much of the time.
279. _____ has a strongly defiant personality.
280. Because _____ uses special equipment and facilities, it is difficult to take him/her out.
281. One of the things I appreciate about _____ is his/her sensitivity to others.
282. Others have offered to share the load in caring for _____.
283. _____ likes to follow the same schedule all the time.
284. _____'s needs come first.
285. _____ attracts attention.

APPENDIX E

NAME _____

DATE _____

IDENTIFICATION

Below are words that describe feelings and moods people have. Please read EVERY word carefully. Then fill in ONE space under the answer which best describes how you have been feeling DURING THE PAST WEEK INCLUDING TODAY.

Suppose the word is happy. Mark the one answer which is closest to how you have been feeling DURING THE PAST WEEK INCLUDING TODAY.

The numbers refer to these phrases:

- 0 = Much unlike this
1 = Slightly unlike this
2 = Slightly like this
3 = Much like this

MARKING DIRECTIONS

- USE A NO. 2 PENCIL ONLY.
- MAKE NO STRAY MARKS.
- ERASE CLEANLY.

CORRECT MARK

0 1 2 3

INCORRECT MARK

X O /

0	1	2	3	0	1	2	3	0	1	2	3
0	1	2	3	0	1	2	3	0	1	2	3
0	1	2	3	0	1	2	3	0	1	2	3
0	1	2	3	0	1	2	3	0	1	2	3
0	1	2	3	0	1	2	3	0	1	2	3
0	1	2	3	0	1	2	3	0	1	2	3
0	1	2	3	0	1	2	3	0	1	2	3
0	1	2	3	0	1	2	3	0	1	2	3
0	1	2	3	0	1	2	3	0	1	2	3
0	1	2	3	0	1	2	3	0	1	2	3
0	1	2	3	0	1	2	3	0	1	2	3
0	1	2	3	0	1	2	3	0	1	2	3

<p>MUCH UNLIKE THIS SLIGHTLY UNLIKE THIS SLIGHTLY LIKE THIS MUCH LIKE THIS</p> <p>1. Composed .. 0 1 2 3</p> <p>2. Angry 0 1 2 3</p> <p>3. Cheerful 0 1 2 3</p> <p>4. Weak 0 1 2 3</p> <p>5. Tense 0 1 2 3</p> <p>6. Confused 0 1 2 3</p> <p>7. Lively 0 1 2 3</p> <p>8. Sad 0 1 2 3</p> <p>9. Friendly 0 1 2 3</p> <p>10. Tired 0 1 2 3</p> <p>11. Strong 0 1 2 3</p> <p>12. Clearheaded . 0 1 2 3</p> <p>13. Untroubled .. 0 1 2 3</p> <p>14. Grouchy 0 1 2 3</p> <p>15. Playful 0 1 2 3</p> <p>16. Timid 0 1 2 3</p> <p>17. Nervous 0 1 2 3</p> <p>18. Mixed-up 0 1 2 3</p>	<p>MUCH UNLIKE THIS SLIGHTLY UNLIKE THIS SLIGHTLY LIKE THIS MUCH LIKE THIS</p> <p>19. Vigorous 0 1 2 3</p> <p>20. Dejected 0 1 2 3</p> <p>21. Kindly 0 1 2 3</p> <p>22. Fatigued 0 1 2 3</p> <p>23. Bold 0 1 2 3</p> <p>24. Efficient 0 1 2 3</p> <p>25. Peaceful 0 1 2 3</p> <p>26. Furious 0 1 2 3</p> <p>27. Lighthearted .. 0 1 2 3</p> <p>28. Unsure 0 1 2 3</p> <p>29. Jittery 0 1 2 3</p> <p>30. Bewildered 0 1 2 3</p> <p>31. Energetic 0 1 2 3</p> <p>32. Lonely 0 1 2 3</p> <p>33. Sympathetic .. 0 1 2 3</p> <p>34. Exhausted 0 1 2 3</p> <p>35. Powerful 0 1 2 3</p> <p>36. Attentive 0 1 2 3</p>	<p>MUCH UNLIKE THIS SLIGHTLY UNLIKE THIS SLIGHTLY LIKE THIS MUCH LIKE THIS</p> <p>37. Serene 0 1 2 3</p> <p>38. Sad Tempered. 0 1 2 3</p> <p>39. Joyful 0 1 2 3</p> <p>40. Self-doubting... 0 1 2 3</p> <p>41. Shaky 0 1 2 3</p> <p>42. Perplexed 0 1 2 3</p> <p>43. Active 0 1 2 3</p> <p>44. Downhearted .. 0 1 2 3</p> <p>45. Agreeable 0 1 2 3</p> <p>46. Sluggish 0 1 2 3</p> <p>47. Forceful 0 1 2 3</p> <p>48. Able to concentrate 0 1 2 3</p> <p>49. Calm 0 1 2 3</p> <p>50. Mad 0 1 2 3</p> <p>51. Jolly 0 1 2 3</p> <p>52. Uncertain 0 1 2 3</p> <p>53. Anxious 0 1 2 3</p> <p>54. Muddled 0 1 2 3</p>	<p>MUCH UNLIKE THIS SLIGHTLY UNLIKE THIS SLIGHTLY LIKE THIS MUCH LIKE THIS</p> <p>55. Ready-to-go ... 0 1 2 3</p> <p>56. Discouraged ... 0 1 2 3</p> <p>57. Good-natured . 0 1 2 3</p> <p>58. Weary 0 1 2 3</p> <p>59. Confident 0 1 2 3</p> <p>60. Businesslike ... 0 1 2 3</p> <p>61. Relaxed 0 1 2 3</p> <p>62. Annoyed 0 1 2 3</p> <p>63. Elated 0 1 2 3</p> <p>64. Inadequate 0 1 2 3</p> <p>65. Uneasy 0 1 2 3</p> <p>66. Dazed 0 1 2 3</p> <p>67. Full of pep 0 1 2 3</p> <p>68. Gloomy 0 1 2 3</p> <p>69. Affectionate.... 0 1 2 3</p> <p>70. Drowsy 0 1 2 3</p> <p>71. Self-assured ... 0 1 2 3</p> <p>72. Mentally alert... 0 1 2 3</p>
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BE SURE YOU HAVE ANSWERED EVERY ITEM

APPENDIX F

Semistructured Interview

(NOTE: DUE TO THE RECRUITMENT OF SUBJECTS FROM OUT OF STATE, THIS INTERVIEW WAS NOT ADMINISTERED TO ALL SUBJECTS. IN ADDITION, ALL INTERVIEWS WHICH WERE COMPLETED WERE DONE BY PHONE. BECAUSE OF THESE EXPERIMENTAL CONSTRAINTS, THIS INTERVIEW WAS NOT USED VERBATIM WITH ANY SUBJECTS. RATHER, THE INTERVIEW WAS CHANGED TO REFLECT THE REVISED EXPERIMENTAL PROCEDURE.)

Introduction and Overview. [Informal introduction of interviewer as a graduate student at Loyola University working on this project in order to complete my degree in psychology.]

First of all Mr. and Mrs. (name), I want to thank you for agreeing to participate in this project and talk to me about your thoughts and experiences regarding raising (Child's name). I'd like to start by giving you a short overview of what I'd like to do today. As you know there are two parts to this project. You have already completed the first part which included the questionnaires. The second part involves me interviewing each of you separately. In this interview, I'd like to talk to you about your thoughts, feelings, and experiences regarding raising (Child's name). I will ask some specific questions, but I also want to try to understand it from your point of view. Every parent is going to answer these questions somewhat differently, and that is fine.

As you know, the questions and the interview are part of my dissertation work. I want to assure you that what we talk about together in the interview will remain confidential. I would like to tape record our conversation. Tape recording would make it easier for me to focus on our talk, instead of concentrating on writing things down. Would that be okay with you? Again I want to assure you that no one besides myself will be listening to the tape. I would listen to it and write down the information which I need. Then the tape will be erased.

Because this is a research project, I will be reporting the results of the project. Let me assure you once again that no names will ever be used in any report. In fact, no one's individual responses will be presented in the report. Instead of individual responses, I will be looking more generally at the types of thoughts, feelings, concerns, and experiences that many parents of autistic children have in common. Do you have any questions about this?

Now before we begin let me go over how I would like to work this. I'd like to interview you first Mr./Mrs.(name). (Order will be determined randomly before the interview begins.)

Demographic Data and Warm-up. [Although demographic data will be collected on the questionnaires, some limited demographic information will be collected here in order to

ease the parent into the interview process. Therefore, parents will be asked questions about their autistic child, including his age, his current schooling, as well as several questions designed to give a sense the child's adaptive behavior and the level of care needed.]

I'd like to change the topic a bit for a few minutes and talk about some of your thoughts and feelings. Maybe we could start by your telling me some of the things that you find particularly stressful in raising an autistic child. (Parent answers and follow-up if necessary.) Sometimes when parents have a handicapped child they mention both good things about the experience as well as things that are difficult for themselves and the family. I wonder if you could share with me some of your thoughts about either the positive things or the hard things involved in raising (child's name)? (Answer and follow-up. Interviewer here will continue to briefly discuss these issues with the hope of allowing the parent to feel comfortable in the interview. When the interviewer judges that the parent is feeling comfortable enough that he might probe into some thoughts and feelings, he will continue with the following:)

Control Cognitions. As you have said, and other parents have said, there are a lot of different aspects to autism that cause concern, including the child's behavior, his language development, his education, and his future. I'd like to ask you a few questions about each of these areas by asking you to think about how much control you feel you have over these areas. I'm going to ask you to use this scale for all the questions, so let's just go over it for a minute. (Interviewer presents the following scale to the parent on a piece of paper and explains the scale):

1	2	3	4	5	6
almost	very	limited	some	much	almost
no	little	control	control	control	complete
control	control				control

You mentioned (Child's name) behavior in terms of (give examples from parent). If I asked you to rate on a scale of 1 to 6 how much control you feel you have over (name's) behavior, what would you say? (Answer) Okay, you said that you feel you have _____ control over his behavior. Can you tell me why you chose _____ control. (Follow up)

Now, in general, I'd like you to rate how much control you feel you have over (name's) autistic behavior in terms of being able to influence it or modify it now? (Rate and follow-up)

How much control do you feel you have over your child's autistic behavior in terms of being able to influence his future behavior? (Rate and follow-up)

We also talked about (name's) language development. How much control do you feel you have in terms of being able to influence his language development now? (Rate and follow-up)

How much control do you feel you have in terms of being able to influence his future language abilities? (Rate and follow-up)

We also talked about (name's) education and learning. How much control do you feel you have in terms of being able to influence his current learning? (Rate and follow-up)

How much control do you feel you have in terms of being able to influence his future learning abilities? (Rate and follow-up)

One final question about control I'd like to ask you is a little bit different. Sometimes another thing that many parents of handicapped children worry about is the possibility of having another handicapped child. In your case this would involve having another autistic child. Have you ever worried about that? (Follow-up) One final question about control then, using the same scale is : How much control do you feel you have over the outcome of any future pregnancies in terms of preventing autism in any future children? (Rate and follow-up)

Causal Attributions. We have been talking about some things that may be rather stressful for you in terms of raising (name). Your comments have been very helpful in terms of giving me a sense of some of your thoughts and feelings. I wonder if I might switch for a second and ask you about some of your thoughts about autism and how it develops. Many, if not all, people who have had an autistic child develop some theory about how their child developed autism. That is, even though we do not know the causes of autism specifically, many people have a hunch or theory about why their child is autistic. I wonder if you would mind sharing your hunch or hunches with me if you have any?

(Follow up on the response, pursuing the issue in such a manner that when proximate causes are given as the reason, more distal causes are inquired into. For example, if the individual cites "brain damage" as the cause, the interviewer asks, "And what do you suppose might have caused that?")

Sometimes when we talk about what caused something, the issue of responsibility and blame comes up. Do you ever think about responsibility or blame? (Answer and follow-up). If you had to make a choice, which of these factors would you say you blame the most for your child's autism: your behavior, your personality, the environment, other people, or chance. Which factor do you blame second most? Do you blame any of the other factors at all? Okay, let me go back for a second, you said you blame () the most, can you tell me in what way do you blame (). (Similar follow up on other factors.)

I'd like to thank you Mr./Mrs. (name) for taking the time to talk with me about your thoughts and feelings regarding autism. Your information has been very helpful to me. Do you have any questions about anything I asked you?

Okay then, I'd like to interview your husband/wife now.
Thank you again.

(Follow same procedure for interview with other
parent.)

APPENDIX G

INFORMED CONSENT

Dear Parent:

Thank you for volunteering to participate in our research project.

We are going to ask you to fill out five questionnaires as part of this project. These questionnaires ask about your thoughts and feelings regarding raising your autistic child. Some questions ask for your thoughts regarding what caused your child's autism. Other questions ask for your thoughts regarding how well you feel you can manage your child's behavior. And finally, some questions ask more generally about your thoughts and feelings. These questionnaires are included in this packet.

In addition, after you have completed this packet and have mailed it back to me, I may be contacting you for a very brief phone conversation in which I could follow up on a few of the questions from the questionnaires. This would be scheduled at your convenience.

I want to assure you that every parent is going to answer these questions somewhat differently, and that is fine. I am just trying to get an understanding of your experiences.

I also want to assure you that all of the information I will collect will remain confidential. This means that it will only be seen by myself and other qualified researchers, and will be used for research purposes only. Also, all information is anonymous. Your name will not appear on any of the data. You need not put your name on any of the questionnaires at all.

Finally, should you decide at any point to discontinue your participation in the project, for whatever reason, please feel free to do so. Though we do not expect that this will happen, we want you to know that you are free to leave the study at any point without incurring any penalty.

Please feel free to ask any questions along the way. I can be reached at (312) 445-4648. Once again, thank you for participating in our project.

Sincerely,

Edmund M. Kearney, M.A.
J. Clifford Kaspar, Ph.D.
Loyola University of Chicago

I have read the above and understand it.

SIGNATURE

DATE

APPENDIX H

October 20, 1989

Dear Parent:

I am truly grateful that you have chosen to donate a bit of your time and energy to a project I consider to be extremely important. I feel that this project is important for three reasons. First, within the "scientific world", there is currently little documentation of the stresses parents of disabled children experience. This is unfortunate in that, without a documented need, it becomes more difficult to procure both public and private funding and support. True, we can all describe and imagine the need, but such anecdotal evidence is not sufficient in our world of limited mental health funding.

Secondly, I feel it is important to document this need by asking parents directly. This study is one of the first to attempt to answer the question of need by asking those who are truly experts in the field--the parents. By asking parents who are currently parenting an autistic child, we hope to begin to gather information around which we can build specific programs to address your needs.

The third reason is, in some ways, a bit more selfish. I have worked with seriously disabled children (autistic and pervasively developmentally disabled) throughout my 6 year training to become a child-clinical psychologist. During that time I have learned much from my supervisors, my child-clients, and parents with whom I have been in contact. This dissertation study constitutes the final phase of my formal education. I need your help, however, to complete this project and formally enter the professional world. Unfortunately, I am not in a position to compensate you monetarily for your time. I can offer you only my genuine thanks and my assurance that because of your assistance, I will enter that professional community dedicated to working diligently to serve families such as yours, and children such as your sons and daughters.

Once again, thank you.

Sincerely,

Edmund M. Kearney, M.A.
Ph.D. Candidate
Loyola University of Chicago

APPENDIX I

GENERAL INSTRUCTIONS

Dear Parent:

Thank you for agreeing to participate in this study. Enclosed in this package are several questionnaires and forms for you to complete. Your package should contain the following:

- 1 Informed Consent Letter
- 1 Family Information Questionnaire
- 1 Control Questionnaire
- 1 Attribution Questionnaire
- 1 Mood Questionnaire
- 1 Questionnaire on Resources and Stress

Please read and examine the Informed Consent letter first. If you agree to participate in the study as explained, please sign this letter first. If you have any questions about the study, please call me at (312) 445-4648 before signing.

After you have signed the Informed Consent Letter, you may fill out the remaining questionnaires in any order. You need not put your name on any questionnaire, and you can use any writing implement to fill out the forms. Moreover, please do not feel that you must complete all the questionnaires in the same sitting. Feel free to work on the questionnaires at your convenience, although we would like to have them returned within three weeks of the time you receive them (November).

When you have completed the questionnaires, place all the forms in the enclosed large envelope. This envelope is pre-addressed and stamped, so please just deposit it in any U.S. mail box.

Once again, thank you for your help. I will be calling you within the next few weeks to answer any questions and talk briefly about the project.

Sincerely,

Edmund M. Kearney, M.A.
Loyola University of Chicago

APPENDIX J

Dear Parent:

Thank you for participating in this study. Your participation has allowed us to learn more about the experience of parenting an autistic child.

In this study we have several goals. The first goal involves beginning to gather information in order to better understand the unique thoughts and feelings experienced by parents such as you. Unfortunately, very few scientific investigations have asked the question, "What is the experience of parenting an autistic child like?" This study is an attempt to begin to answer this very general question.

More specifically, we are trying to get a sense of your thoughts and feelings regarding the parenting experience by asking questions about your thoughts concerning how your child developed this disorder, and how well you feel you can control and influence your child's autistic behaviors. We plan to examine whether there exists a connection between parents thoughts and feelings regarding control over behavior and causation, and the stress they often report experiencing. Some scientists have argued that thinking and feeling about control and causation in certain ways may lead to experiencing more stress. Our study is designed to see if these patterns apply to families with an autistic child.

We are hoping that as we gain more knowledge about these two crucial components of the parenting process we will begin to have a better understanding of how to help and provide support for families such as yours. It is this goal that must remain most important for all of us. Your participation in this study has allowed us to get closer to the goals of understanding and helping.

We will be interviewing other similar families for the next several months. After completing the interviews, we will be compiling our findings in a report and would be glad to share this information with you. If you would like, I could send you a brief report summarizing the important findings from this research. In addition, I will be organizing a few small group parent meetings to discuss the results and allow parents to share their experiences. If you are interested in either of these options, please let me know.

Once again, thank you for sharing your valuable time and information with us.

Sincerely,

Edmund M. Kearney, M.A.
Department of Psychology
(312) 508-3001

APPROVAL SHEET

The dissertation submitted by Edmund Martin Kearney has been read and approved by the following committee:

Dr. J. Clifford Kaspar, Director
Associate Clinical Professor, Psychology
Loyola University of Chicago

Dr. Jill Nagy Reich
Associate Professor, Psychology
Loyola University of Chicago

Dr. John Shack
Associate Professor, Psychology
Loyola University of Chicago

Dr. John Paoletta
Clinical Assistant Professor, Psychology
Loyola University of Chicago

The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

4/10/90
Date


J. Clifford Kaspar
Director