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## Pattern of Parental Grief Following the Manifestation of Autism in a Progeny: Chronic Sorrow versus Determinant Grief

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PATTERN OF PARENTAL GRIEF  
FOLLOWING THE MANIFESTATION OF AUTISM IN A PROGENY:  
CHRONIC SORROW VERSUS DETERMINANT GRIEF

by  
Nancy L. Maurice

A Thesis Submitted to the Faculty of the Graduate School  
of Loyola University of Chicago in Partial Fulfillment  
of the Requirements for the Degree of  
Master of Arts  
January  
1991

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## VITA

The author, Nancy Louise Maurice is the daughter of Walter Larkin and Louise (Zieske) Larkin. She was born on June 20, 1938, in Chicago, Illinois.

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Ms. Maurice will complete a Master of Arts degree in January of 1991.

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## CHAPTER I

### INTRODUCTION

#### Purpose

Pediatric disorders, classified under the general headings of physical handicaps, developmental disabilities, and mental handicaps have engendered a great deal of research. The majority of studies concentrate on definition, diagnosis, etiology, and treatment of these afflictions. However, this research focuses only on the child's disability and fails to address the issue of the handicapped child as part of a family system. The disabled child is an integral part of a family; therefore, any disorder causing mental or physical debilitation elicits an emotional response in all members. Although all of the family members are affected, the parents experience the most devastating reaction to the handicapped child. During the past twenty years, the scientific community has virtually ignored the emotional plight of the mother and father. Consequently, there is a paucity of basic research on the emotional impact of a handicapped child on the family as well as a lack of systematic models for psychological intervention.

Grief seems to be the primary emotion associated with

the birth or diagnosis of a handicapped child (Beddie & Osmond, 1955; Kennedy, 1970; Maurice, 1984; Olshansky, 1962, 1966; Solnit & Stark, 1961; Wikler, Wasow & Hatfield, 1981). The studies which examine the parents' reaction delineate two different patterns of grieving. In some instances, parental grief is described as time-bound; the feelings of sorrow last for a short period of time. Other investigators described parental grief as "chronic sorrow"; the painful feelings never disappear completely (Olshansky, 1962, 1966).

The pattern of grieving in Olshansky's (1962, 1966) opinion, is related to the degree of retardation; the more severe the disability the greater the potential for chronic sorrow. Although severity of the disorder has a profound effect on the character of parental grief, viewing it as the only influential factor presents a limited picture of the grieving process. A perusal of the literature and parent interviews suggest several additional variables which may alter the parental affect. These include: (a) specific symptoms (i.e., deviant interpersonal relationships, speech disorders, self injury); (b) etiology (i.e., organic versus psychogenic); (c) lack of appropriate treatment; (d) inappropriate counseling for parents (i.e., focus on personality change rather than helping parents cope with the stress of having a handicapped child and/or crisis

prevention); (e) difficult and delayed diagnosis; (f) family issues (i.e., parents' personality style, number of siblings, strength of marital relationship).

As a means of acquiring a fundamental understanding of the subject, this paper will present an overview of the literature associated with the grieving process specifically focusing on parents of children diagnosed as autistic as well as those with more obvious organic disorders.

The primary research question addressed by the study is: which pattern of grieving (time-bound or chronic) typifies the experience of parents of autistic children? The second examines the differences, if any, between the grief experienced by parents of autistic children and parents of children with a clear-cut defect in the biological structure.

### Importance of the Study

One of the primary goals of social science research is the acquisition of basic knowledge such that the individual can live a life that is productive and satisfying. During the past 45 years, the autistic child has been the focus of a maelstrom of research which has moved assiduously toward this goal. Although children are the principal victims of this debilitating disease, they are not the only

participants in a tragic situation. Parents share with their children the status of victim and desperately need the empathetic support of the professional community. Constance V. Torisly (1979) the mother of an autistic child defines herself as a "Hostage Parent"; a participant in an unexpected, bewildering set of circumstances which she feels ill equipped to handle.

Help!...Our home has been hijacked!

This tiny person has us all at "gunpoint." He is demanding and we cannot even understand his demands. He is obviously desperate, he is disturbed, erratic, and often incoherent.

We feel anxious, outraged and frightened at this unexpected turn of events. This situation occurred with such suddenness that we lacked any specific preparation to be hostages. We had expected to be simply "parents"(p. 234).

Unfortunately, very little is known about the character of the emotional insult to the mother and father. The lack of knowledge has produced a void in the area of supportive counseling for parents. The current research questions are important because they seek to enhance the knowledge regarding the parent's affective plight and in turn use this knowledge to improve counseling.

### Definition of Terminology

Grief and autism are the fundamental constructs examined

in this paper; however, each has a number of synonyms which are appropriate alternate expressions. The preliminary literature search uncovered a multitude of labels attached to the personal phenomenon experienced by the individual following bereavement. Of those discovered, grief, sorrow, and sadness are the most frequently used. According to Webster's New Collegiate Dictionary, the terms grief, sorrow, and sadness are synonymous; that is to say, each uses the other as a synonym. Other important terms associated with grief are mourning and bereavement. Mourning, according to the same source, indicates an interval of time during which the emotions of grief are displayed. Bereavement, on the other hand, denotes deprivation; the loss of a valued possession or person.

The autistic syndrome, since its identification in 1943, has also been associated with a variety of names. Kanner (1973) originally named the newly discovered disorder "Autistic Disturbances of Affective Conduct;" subsequently he changed the name to "Early Infantile Autism" (p. 1, 45). However, "autism" and its' synonyms, "childhood autism," "primary autism," and "autistic child" are the most commonly used terms (Ornitz & Ritvo, 1976/1977 P. 502).

#### Summary of Chapter Contents

The principle objective of this investigation is to

glean from the current literature a clear picture of the pattern of grief experienced by parents following the discovery of autism in a progeny. The presentation of material follows a general to specific format. Accordingly, chapters II and III furnish the reader with an overview of the key constructs of grief and autism. Included in the delineation are data concerning current diagnostic criteria of both constructs. In addition, Chapter II examines the research related to the time-frame of the normal grieving process and defines pathological grief. Chapter III also contains two supplementary sections. These sections present pertinent facts regarding the etiology and epidemiology of autism.

The parent's affective response to a handicapped child is the theme examined in Chapter IV. The material is subdivided into three parts. The beginning section establishes a relationship between the birth of a handicapped child and the grieving process. A synopsis of the current theories on grief comprises the mid-portion of the chapter. The final paragraphs examine the parent's reaction to the diagnosis of a disability using stress, crisis, and coping theory as the conceptual framework.

Chapter V follows the same format as Chapter IV except it limits the study population to parents of autistic

children. The final chapter, Chapter VI, summarizes the findings of the literature search and presents some conclusions, implications, limitations, and suggestions for future reseach.

### Method of Location and Collection of Data

The information included in this thesis was obtained from six sources. Books were the first reservoir of knowledge. The library's card catalog provided the researcher with appropriate book titles. The library collections examined were those held by Loyola University, Stritch School of Medicine, West Side Veterans Administration Hospital, The American Medical Association, as well as the cities of Chicago, Skokie, Morton Grove, and Deerfield.

Professional journals also provide insight into the designated subject matter. A computer search of Medline and Psychological Abstracts databases, for a period of 10 years (i.e., 1978 through 1988), was used to locate suitable material. In addition, the catalogs listing current periodicals were individually perused. Psychological Abstracts and Medicus Index, for a period of 10 years, (i.e., 1978 through 1988), were the catalogs examined. Each article or book obtained as previously described includes a list of references which was used as another fund of



information. The final three repositories are associations devoted to helping a particular group (e.g., Autism Society of America), individuals who have conducted research in a particular area, and the thesis committee.

Grief and Autism are the two fundamental research topics examined in this thesis. However, these categories are much too broad and cannot be covered in a single investigation. In order to narrow the focus of inquiry, an outline of key concepts was constructed. The literature available was then examined in light of the thesis outline. The table of contents presents the framework of inquiry and delineates the subordinate issues discussed.

Papers categorized under other appropriate expressions were also perused and relevant findings were included in the thesis. The pertinent terms associated with grief are sorrow, sadness, mourning, and bereavement. Regarding autism, the alternate themes considered were autistic disturbances of affective contact, early infantile autism, childhood autism, infantile autism, and autistic child.

## CHAPTER II

### GRIEF: CONSTRUCT DELINEATION

#### Definition of Normal Grief

As with most aspects of modern psychiatry and psychology, it seems appropriate to begin this investigation of grief with Sigmund Freud. Freud (1917/1957) associated mourning with loss. A cherished individual or an abstract construct (i.e., country of origin or freedom) formally part of the individual's life is no longer available.

In his classic 1944 study, Lindemann associates grief with: "bereavement or the sudden cessation of social interaction..." (p. 187). Furthermore, he conceptualizes grief as having a dual nature. In Lindemann's (1944/1965) words: "acute grief is a definite syndrome with psychological and somatic symptomatology" (p. 211).

Other authors conceptualize grief differently. "In Parkes view, grief is a process of realization, of making real inside the self an event that has already occurred in reality outside" (Glick, Weiss, & Parkes, 1974, p. 8). Moreover, grief according to Parkes and Weiss (1983) is an appropriate response to loss; nevertheless, the exhibited behavior possesses a pathological character. Finally, Demi and Miles (1985) define grief: "as the multifaceted

physical, emotional, and behavioral response of an individual to the death of a significant other" (p. 399).

Loss differentiation. Unfortunately, the preparatory literature search did not yield a clear, concise definition of the construct grief. The one fact that does become obvious is grief follows loss. Peretz (1970) defines loss: "as a state of being deprived of or being without something one has had" (p. 4). He subdivides the general classification of loss into specific types: (a) the departure of a significant other; (b) the declining or disappearance of a desirable aspect of the self; (c) dissolution of worldly possessions; (d) loss associated with growth and development.

Peretz (1970) delineates the most frequently cited, grief inducing losses. However, there is a less concrete, ordinarily overlooked loss which also seems to engender grief. Tomko (1983) labels it "the dissolution of the dream" (p. 391). The construct includes personal fantasies, plans, wishes, and hopes that will never come to pass because reality has made them unattainable.

Object-relations theory. The development of "object-relations", according to Peretz, is the starting point on the loss, grief, and adaptation continuum. An infant, following the establishment of the self as autonomous and the recognition of the external world's existence, begins to

appreciate the ability of human and non-human object's to produce feelings of pleasure or pain. These insights form the foundation of object-relations. Peretz (1970) defines object-relations as a bond between certain animate and inanimate "things" found within the personal environment which the individual believes will promote psychological well being. The first relationship established by an infant is with the mother. The tie between mother and child develops because of the pleasure associated with feeding. The food satisfies a primary human drive and the relationship satisfies a secondary drive (Bowlby, 1982/1983; Peretz, 1970).

Once a relationship has been forged the possibility of loss exists followed by a dysphoric feeling state. The feelings experienced vary; however, grief is "...the most common and presumably most adaptive reaction to serious loss..." (Peretz, 1970, p. 13).

Attachment theory. Attachment theory was conceptualized by Bowlby (1982/1983) as a substitute for the object-relations theory. According to Bowlby, it provides a more accurate, empirically supported explanation of human bonding behavior.

An attachment is a bond, implying love, which one individual develops for another. Attachment behavior is any

behavior which achieves and maintains a closeness with another individual. Usually, the individual has been defined as better able to manage the vicissitudes of life. The first attachment and the prototype for all other relationships is the bond established with the mother. According, to Bowlby (1969), "... the child's tie to his mother is a product of the activity of a number of behavioral systems that have proximity to the mother as a predictable outcome" (p. 179). Included in the category of attachment behaviors are: (a) "orienting behavior" (i.e., figure discrimination and tracking people using the eyes and ears; (b) "signaling behavior" (i.e., crying, smiling, vocalizing, and gesturing; (c) "approach behavior" (i.e., searching, following, clinging, and sucking) (Bowlby, 1969,1982/1983; Ainsworth, 1973).

Attachment occurs in 4 sequential phases (Ainsworth, 1973). During the first phase labeled the "phase of indiscriminating social responsiveness", infants are capable of focusing on prominent environmental features (particularly people), they possess some discriminatory capabilities, and they can respond differentially. However, they are unable to distinguish different people; consequently infants engage in generalized social interaction. This phase lasts about 2 to 3 months. The hallmark of phase 2, the "phase of discriminating social

responsiveness", is the child's ability to discriminate between family members and strangers and to respond differently. This phase ends at about the sixth or seventh month when the child becomes mobile. A baby traversing phase 3, the "phase of active initiative in seeking proximity and contact", actively promotes proximity with the attached individuals, using more effectively all the previously described attachment behaviors. The median age of this phase is 7 months. When children reach phase 4, the "phase of goal-corrected partnership", they can anticipate their mother's behavior, adjust their own behavior to maintain proximity, and make plans to change their mothers behavior to achieve the desired closeness. This phase usually does not begin until age three.

Biologically, attachment provides protection and psychologically, it fosters a feeling of security. If the bond is broken the individual experiences grief. Bowlby (1982/1983) cites as support for his theory the works of Conrad Lorenz and Harry Harlow as well as his own research into the effect of separation, loss, and maternal deprivation in children.

Although researchers have not as yet developed an all inclusive definition of grief it is possible to construct a generic one from the material now available. Grief, it

would seem, is the physiological, affective, and behavioral response of an individual to a perceived intra and/or interpersonal loss.

### Symptomatology

Lindemann (1944/1965) studied grief using an interview format. The research subjects included 101 individuals who had experienced the death of someone close. The sessions were recorded and later analyzed with the focus on physical manifestations and alterations in the mental status of the subjects. From this investigation, Lindemann was able to develop a list of five symptoms which he believed were pathognomonic of acute grief: (a) "somatic distress" (i.e., overwhelming lassitude, visible respiratory distress, and digestive upset); (b) "preoccupation with the image of the deceased" (i.e., the external world is excluded and memories occupy the consciousness); (c) "guilt" (i.e., behaviors are examined in order to ferret out negligence); (d) "exhibits hostile reactions" (i.e., anger directed at consolers); (e) "loss of patterns of conduct" (i.e., inefficient, haphazard, ineffective, hyperactive behavior) (p. 212).

Subsequent research, most notably the works of Parkes (1972), Worden (1982), and Zisook and DeVaul (1984) has supported as well as expanded Lindemann's (1944/1965) original list of symptoms. The most comprehensive lexicon

is the one developed by Worden (1982). Research done as part of the Omega Project support the theories Worden presents in his book Grief Counseling and Grief therapy: A Handbook for the Mental Health Practitioner. His thinking was also influenced by Parkes, Weisman, Jackson, Lazare, Hackett, Klerman, and Vachon (Worden, 1982, p. X). The author grouped the characteristics of normal grief under four broad headings. The first of these headings is "feelings". This category includes: sorrow, hostility, culpability, isolation, incapacity, shock, longing, freedom, being unburdened, and "numbness". The second group of manifestations is classified as "physical sensations" and includes: abdominal distress, constriction of the chest and/or throat, intolerance of noises, loss of identity, generalized malaise, and "dry mouth." Index number three is labeled "cognitions" and it encompasses the following mental processes: doubts reality of death, disorientation, thoughts focus on deceased, deceased perceived as living, visual and/or auditory illusions. Finally, the fourth aggregate is labeled "behaviors" and includes: disrupted sleep patterns, alterations in food intake, forgetfulness, self isolation, dreams of the dead, seeking out or avoiding any type of reminder of the deceased, tears, hyperactivity, searching, and "calling out" (pp. 20-28).



Throughout the ages there have been many men and women who stood apart from society: they observed, they reasoned, and finally they commented on the human condition. However, few have done it with the depth of understanding achieved by Emily Dickinson (1980). In the poem that follows she focused her enormous talent for analysis and description on grief.

After great pain, a formal feeling comes-  
 The Nerves sit ceremonious like Tombs-  
 The stiff Heart questions was it He, that bore,  
 And Yesterday, or Centuries Before?

The Feet, mechanical, go round-  
 Of Ground, or Air, or Ought-  
 A Wooden way  
 Regardless grown,  
 A Quartz contentment, like a stone-

This is the Hour of Lead-  
 Remembered, if out lived,  
 As Freezing persons, recollect the Snow-  
 First-Chill-then Stupor-then the letting go-  
 (pp. 461-462)

Her poignant delineation of the symptoms experienced by the grief stricken individual captures the essence of this feeling state.

Factors affecting the pattern of grief. Although Lindemann (1944/1965) delineated a list of characteristics that he considers pathognomonic for grief, each individual demonstrates an idiosyncratic pattern of these behaviors. Furthermore, researchers have identified a number of factors which seem to influence a persons reaction to loss. The

most important determinants are as follows: (a) closeness of kinship; (b) type of bond (i.e., strong and loving, dependent, independent, or ambivalent); (c) circumstances surrounding the death (i.e., sudden or expected, violent or peaceful); (d) historical perspective (i.e., previous pattern of grieving, mental and physical health, number of previous crises, and thoughts regarding crises; (e) personality type (i.e., age, sex, expression or inhibition of emotions, presence of coping skills; (f) social milieu (i.e., grieving process prescribed by social, religious, and ethnic mores) (Martocchio, 1985; Worden, 1982; Volkan, (1984/1985).

### The Grieving Process

Following a loss the individual engages in the work of mourning. The tasks according to Freud (1917/1957) include acknowledgment of the loss and severance of the libidinal bond. Freud describes the process as follows:

Each single one of the memories and situation of expectancy which demonstrate the libido's attachment to the lost object is met by the verdict of reality that the object no longer exists; and the ego confronted as it were with the question whether it shall share this fate, is persuaded by the sum of the narcissistic satisfaction it derives from being alive to sever its attachment to the object that has been abolished (p. 255).

According to Lindemann (1944/1965), the bereaved individual engages in "Grief Work." The tasks comprise: (a) severance of the relational link; (b) adaptation to an altered environment; (c) establishment of new relationships.

A myriad of clinicians have subdivided the grieving process into stages; however, Kubler-Ross (1969) seems to be the most vocal proponent of this theory. During the 60's she interviewed 200 dying people and their families. From these interviews, she hoped to gain an understanding of the process of dying. Armed with the data, she believed she could help future patients and their loved ones relinquish the fear of death, attain peace of mind, and accept the impending loss.

Kubler-Ross (1969) synthesized, from the material collected during the interviews, a five stage model of the grieving process. The stages as delineated by Kubler-Ross (1969) include: (a) "denial" (i.e., rejection of the diagnosis and/or prognosis); (b) "anger" (i.e., the patient questions, "Why me?"); (c) "bargaining" (i.e., a deal struck with God to lengthen one's life); (d) "depression" (i.e., mourns past losses and impending death); (e) "acceptance" (i.e., resigned to the inevitable) (pp. 38-137). A modicum of caution must be used when applying Kubler-Ross's stage theory to individual dying patients. The stages of grieving should not be viewed as rigid and

unalterable but rather as dynamic. That is to say, each individual traverses the stages according to an idiosyncratic pattern and time table (Mauksch, 1975).

John Bowlby (1980,1982/1983) was one of the first clinicians to divide grieving into phases. Children, separated from their mothers, because of a hospitalization, were his research subjects and observation was the investigative technique he employed.

Bowlby differentiated three distinct phases which are: protest, despair, and detachment. Since that time, Bowlby (1980) has refined and extended his work on grief so that it now includes a description of adult mourning following the death of a spouse or a child. In the model of adult bereavement associated with the death of a child, Bowlby (1980) delineates four phases which commence as soon as the diagnoses is explained to the parents. The phases of grief are as follows: (a) "phase of numbing" (i.e., cognition ceases and affect is blunted, however, anger frequently overpowers the defenses); (b) "phase of disbelief and attempts to reverse the outcome" (i.e., the diagnosis and prognosis are vigorously questioned); (c) "phase of disorganization" (i.e., hope of recovery declined and grief becomes overwhelming); (d) "phase of reorganization" (i.e., the attachment to the child is relinquished, death is

acknowledged, and the parents reconstruct their lives) (Bowlby, 1980, pp. 85, 116, 120).

Other authors have found it necessary to sort the multitude of emotions associated with grief in a slightly different manner. Zisook and DeVaul (1985) have subdivided the grieving process into three partially overlapping; nevertheless, discreet stages. This model was developed following an analysis of the appropriate literature with an emphasis on their own research. The stages include: (a) "shock" (i.e., sense of incredulity or rejection of the loss); (b) "acute mourning" (i.e., included are phases of intense physical and psychological distress, self-imposed isolation, and identification with the deceased); (c) "resolution" (i.e., dysphoric feelings ameliorate and attention is externalized (pp. 171-172).

Another theoretical model of mourning was developed by Worden (1982). According to his theory, an individual, who has experienced a loss, must accomplish certain tasks in order for grief to dissipate. Worden's task theory is not a completely revolutionary conceptualization. It borrows a great deal from the stage and phase theories; however, it attempts to correct the most blatant flaws of each.

According to Worden, the stage theory suffers from two key drawbacks. First of all, people in mourning do not pass through stages in a rigidly prescribed order. Furthermore,

the neophyte counselor frequently tries to force the dying person into responding according to the model. The phase theory implies a state of inertia on the part of the bereft; the mourner is being acted upon by a set of circumstances. On the other hand, the tasks of mourning suggest a course of action; steps that can be taken by the individual to alleviate the distress engendered by the death of a loved one. The tasks can be accomplished in a pattern and over a time span idiosyncratic to the individual.

Worden (1982) conceptual framework includes these tasks: (a) "to accept the reality of the loss" (i.e., to acknowledge the end of a life and to recognize the permanence of the separation in this world); (b) "to experience the pain of grief" (i.e., to acknowledge and deal with the somatic, psychological, and behavioral concomitants; (c) "to adjust to an environment in which the deceased is missing" (i.e., the environmental modifications necessary depend on the roles the deceased played); (d) "to withdraw emotional energy and reinvest it in another relationship" (i.e., the transfer of feelings of affection to a new object) (Worden, 1982, pp.11-16).

### Time-Frame of the Grieving Process

Generally, professionals view the grief response as time

limited. The time-frame associated with resolution of grief according to Lindemann (1944/1965) is about 8 to 10 client counselor interviews. Similarly, one month post-loss, Bornstein and Clayton (1972), detected improvement in more than one half (65%) of the 92 subjects they studied. At the first anniversary of bereavement the majority (83%) expressed feelings of well being (.p 471). Moreover, if the emotion of sorrow persists for any length of time, the individual is perceived as non-accepting of the loss and experiencing an atypical grief reaction.

In recent years theorists have begun to question these and other optimistic views of recovery. A host of studies define the length of the grieving process as 2 to 4 years (Glick, Weiss & Parkes, 1974; Parkes & Weiss, 1983). A scattering of investigators have suggested a much longer period of grieving perhaps a life time of grief (Caplan, 1974). The aforementioned discrepancies spawned the research carried out by Lehman & Wortman (1985). The subjects included 39 individuals who had lost a spouse in an automobile accident, 41 parents who had lost a child in a similar manner, and 41 matched controls. The respondents were asked to participate in structured interviews. The meetings were divided into two parts. Section one was designed to access present-day functioning. The variables examined were "depression," "psychiatric symptoms," "

alcohol and drug use," " psychological well-being," (i.e., reactivity to good events and future worries and concerns), "social functioning," (i.e., in marital, parental, and work roles), and "perceived health status" (Lehman & Wortman, 1985, p. 9). The second part of the interview was composed of open-ended questions which elicited accident details, its effect on the family, and the pattern of life post-loss. The answers given by the bereaved were then compared to the control group.

When compared to the control group, the bereaved subjects exhibited a significantly higher degree of discomfort 4 to 7 years post-loss. In 30 to 85% of the cases (depending on the question asked) present ideation and affect suggest an ongoing struggle to cope with the loss. The researchers drew two conclusions from the data (previous research and current data). First of all, the individual mourns the loss of a loved one throughout their life. Furthermore, the distress is a normal response to a tragedy and not a failure to adjust (Lehman & Wortman, 1985).

Zisook, DeVaul, and Click (1982), using their newly developed "Texas Inventory of Grief", examined the prevalence and duration of grief related symptomatology. A 58 item questionnaire was completed by 211 subjects who had lost a member of their immediate family or a close friend. The



elapsed time, between the death and participation in the survey was 1 month to 22 years post-loss with the mean falling at 4.5 years.

Grief, according to the study findings, does not end following a designated interval of time; nevertheless, it reaches a zenith about one to two years post-loss and tapers off thereafter. Although, the acute dysphoria ameliorates the bereft were unable (even after a period of 10 years had elapsed) to forget the deceased. Furthermore, reminiscences are defined as distressing by more than one-third of the research subjects.

In 1976 the Home Care for the Children with Cancer Project was begun (Mc Clowry, Davies, May, Kulenkamp, and Martinson, 1987). The goals of the project were to provide support for families who had lost a child as a result of cancer and to study the grieving process over an extended period of time. The study was divided into two parts. The first section monitored bereavement during the first 2 years post-loss. Fifty-eight families participated.

Phase two of the Mc Clowry, Davies, May, Kulenkamp, and Martinson (1987) study and the most relevant to the purpose of this thesis, examined the outcome of grief 7-9 years after the death of the child. Only 49 (46 mothers, 33 fathers/step fathers and 71 siblings) of the original 58 families participated in the second study.

A semi-structured interview format was the research technique used. The questions focused on the circumstances surrounding the terminal episode, the grief experience, and the present tone of family life. The family members, even after 7-9 years were still experiencing a sense of loss accompanied by pain. According to the research subjects, the death of the child had created an "empty space" in their family's life.

### Pathological Grief

Grief is not always resolved in as orderly a fashion as described in the section entitled the "Grieving Process". Researchers estimate between 10 and 25% of the individuals, who experience bereavement, will develop an aberrant grief reaction. Atypical, pathological, morbid, complicated, absent, abnormal, neurotic, or unresolved are some of the pseudonyms used as labels for a deviant response to loss (Worden, 1982).

Definition. Pathological grief, according to Horowitz, Wilner, Marmar, and Krupneck (1980) is:

...the intensification of grief to the level where the person is overwhelmed, resorts to maladaptive behavior or remains interminably in the state of grief without progression of the mourning process toward completion (p. 1157).

Worden (1982) conceptualizes normal and abnormal grief as a continuum rather than two separate entities. An aberrant reaction is a magnification or a protraction of the normal grieving process. The all inclusive classification of pathological grief, according to Worden, can be subdivided into four distinct grief reactions which include, "chronic," "delayed," "exaggerated," and "masked" (p. 58).

If an individual succumbs to chronic grief, sorrow is interminable. Furthermore, the bereft realizes that they are enmeshed in a protracted grief state. The individual who is suffering delayed grief frequently experiences grief at the time of loss but the response is not commensurate with the loss. The residual grief is activated following some future loss making this grief reaction excessive. The heightened nature of the response is perceived by the individual as inconsistent with the importance of the present loss. Occasionally, grief takes on an exaggerated pattern and becomes incapacitating. Grief induced anxiety develops into phobias about death. Unconscious guilt and an ambivalent relationship between the bereft and the deceased seem to be the precipitating factors in phobia development. Furthermore, the depression of bereavement can turn into an unrealistic despondence. The grief stricken individual believes that he/she can not exist without the deceased. If a masked grief reaction occurs, the individual experiences

physical (i.e., symptoms manifested by the deceased), psychiatric (i.e., major depression), and/or behavioral symptoms (i.e., delinquent behavior); however, these manifestations are not acknowledged as grief (Worden, 1982).

Zisook and DeVaul (1985) conceptualize an anomalous grief reaction as the non-resolution of a particular stage of the grieving process and the development of specific clinical syndromes. The shock of stage one can lead to the perpetual denial of a loss or the unrealistic hope of an earthly reunion. Stage two, acute mourning, is subdivided into three phases. Fixation in phase one (i.e., intense feeling state) engenders depression. The individual who is unable to resolve phase two (i.e., withdrawal) can become a hypochondriac with little energy available for socialization. If stagnation occurs in phase three (i.e., identification) the mourner usually develops the symptomatology of the deceased's last illness. The individual whose grieving process stalls in the third stage (i.e., resolution) develops a state of chronic mourning. The focus of life is on the past; most particularly on events surrounding the loved one's death, rather than focusing on the future (p. 374).

Predisposing factors. A number of factors inherent within the individual and the environment were delineated as

predisposing factors in a pathological grief reaction. The general classification is subdivided into five smaller categories which are: (a) "relational factor" (i.e., dependent or ambivalent relationship, deceased considered an appendage of bereft); (b) "circumstantial factors" (i.e., loss uncertain, unanticipated death, extensive loss of life); (c) "historical factors" (i.e., history of complicated grief reaction, poor physical or mental health, early loss of parents, inadequate parent child bonding, low socioeconomic status); (d) "personality factors" (i.e., an individual who is unable to cope with strong emotions, a personality type that rejects the need for dependence, a person who conceptualizes the self as strong and will not allow emotional release); (e) "social factors" (i.e., discourse related to circumstances of death taboo, society denies the loss, lack of social support (Martocchio, 1985; Worden, 1982, pp. 53-58).

### Summary

Grief is the psychological, physiological, and behavioral reaction of humans to loss. The five pathognomonic symptoms include: (a) various somatic disturbances; (b) the focusing of conscious thought on the deceased; (c) guilt regarding treatment of the deceased; (d) anger directed toward those who try to console; (e) non-goal

oriented behavior. The amelioration of grief usually occurs over a period of time and in the majority of cases follows a predictable pattern. The mourning process includes a period of shock or denial; followed by an intense feeling state. Next, the mind realigns the environment to a new configuration which excludes the deceased. Finally, energy is reinvested in the future. Grief, according to early researchers, was thought to resolve in a very short period of time, perhaps 2 to 3 months. However, recent research has called into question this optimistic opinion. It is now thought that grief may last a life time.

## CHAPTER III

### AUTISM: CONSTRUCT DELINEATION

#### Historical Perspective in Autism

Although not labeled as such, the autistic disease process has probably always been present within the general population. Legends and antiquated medical books cite a myriad of instances of strange, aloof, non-communicative children. For example: East Indian and American lore contain stories of the "feral children." In 1807, a French physician, J.M.G. Itard studied and described Victor the "Wild Boy of Aveyron." In light of the relative advances made in contemporary psychiatry and psychology, these children would probably be diagnosed as autistic (Schopler & Dalldorf, 1980; Wing, 1972).

It was not until 1943 that Leo Kanner first differentiated autism as a distinct syndrome differing radically from other childhood psychoses and/or mental retardation. Kanner (1943/1985, 1973) came to an understanding of the disorder while observing eleven dysfunctional children. He noted a variety of behavioral features that seemed to be characteristic of all eleven children. Kanner's (1943/1985, 1973) original diagnostic criteria included: (a) deviant interpersonal relatedness

(i.e., profound self isolation); (b) absence of anticipatory posture prior to being picked up; (c) disordered speech (i.e., muteness, echolalia, pronominal reversal, impaired comprehension); (d) obsessive need for sameness; (e) limited repertoire of self initiated behavior; (f) adverse reaction to common environmental stimuli (i.e., food, loud noises, moving objects); (g) focuses attention on inanimate objects and relates to people as objects; (h) superb rote memory; (i) normal physical appearance; (j) highly intelligent extended family.

### Current Diagnostic Criteria

Kanner's discovery and delineation of the previously undefined syndrome of autism engendered a preponderance of research. These investigations supported the existence of the disorder; however, they created an enormous amount of confusion regarding the diagnostic limits of autism (Rutter, 1974/1975, 1978).

Moreover, Kanner helped to spawn a portion of the chaos associated with the diagnostic boundaries of his discovery. It seems his choice of the name autism (a term used by Bleuler to describe adult schizophrenics' withdrawal into fantasy) led to its association with adult schizophrenia and other childhood psychosis (Rutter, 1974/1975, 1978; Schopler



& Dalldorph, 1980). Another source of confusion is intrinsic in the nature of a disorder which is classified as a syndrome. There is no single lab test, x-ray, scan, or grouping of the above that can help the clinician make the diagnosis. The diagnosis depends on a specific pattern of behavior; the behavior must be observed or evidence of the behavioral pattern must come from the parents. This diagnostic procedure is fraught with difficulty and it is prone to easy error. Finally, the cause or causes of autism are still unknown (Wing, 1972).

Symptomatology. Rutter (1974/1975,1978) took upon himself the task of clarifying the diagnostic criteria for autism. He accomplished the task by doing comparative studies (controlled for sex, age, and general intelligence) on autistic and psychotic children. These studies unearthed four symptoms which Rutter (1978) thinks typify all autistic children; he called these symptoms "universal and specific." A symptom is defined as universal and specific if it is found in all or almost all children diagnosed as autistic and if it is absent in all or almost all children suffering from other psychotic disorders. Rutter's (1978) diagnostic criteria are: (a) "profound and general failure to develop social relationships;" (b) "language retardation with impaired comprehension, echolalia, and pronomial reversal;" (c) "insistence on sameness" (p. 142).

Following a perusal of the research conducted by Kolvin, Makita, and Vrono, age of onset was defined by Rutter (1978) as the fourth universal and specific diagnostic criteria. He supported his decision with the following findings. The children included in the studies were all diagnosed as childhood psychosis. However, if the children were grouped according to age of onset a bimodal distribution became apparent. All the children in the early onset group (before 30 months) demonstrated autistic symptomatology; whereas, the late onset group (post age 10) manifested the characteristic of schizophrenia (Green, Campbell, Hardesty, Grega, Padron-Gayol, Shell, & Erlenmeyer-Kimling, 1984; Schopler, & Dalldorph, 1980).

Rutter (1978) differentiated four symptoms which occur more frequently in the autistic child but are not found in all cases. These he called "common criteria" and they are: (a) "stereotypic repetitive movements;" (b) "short attention span;" (c) "self injury;" (d) "delayed bowel control" (p. 142).

The universal and specific criteria delineated by Rutter (1978) have been adapted by most authorities, including the Diagnostic and Statistical Manual of Mental Disorders Third Edition (DSM-III, 1980) and The Autism Society of America, as pathognomonic for autism. However, DSM-III adds a fifth

stipulation to its' symptom list which is the "absence of delusions, hallucinations, loosening of associations, and incoherence as in schizophrenia" (p. 90). Furthermore, several other researchers most notably Ornitz and Ritvo (1976/1977), as well as Coleman and Gillberg (1985) strongly suggest another addition to the list of symptoms; namely "abnormal perceptual responses to sensory stimuli" (Coleman & Gillberg, 1985, p.17). In behavioral terms, the child's response to visual, auditory, and painful stimuli alternates between a state of hyper- or hyporeactivity. Also peculiar to autism and associated with abnormal perceptual response is the child's preference for proximal senses (smell, touch, and taste) rather than the distal senses (sight and sound). The research of the past 10 years does not support a change in the criteria used to diagnosis autism; nevertheless, it has clarified and broadened our understanding of this severely incapacitating disorder (Rutter & Schopler, 1987).

DeMyer (1975/1976) studied 155 autistic children over a period of 12 years. The diagnosis of autism was made using the following three characteristics (a) "extreme withdrawal;" (b) "uncommunicative speech or muteness;" (c) "nonfunctional object use" (p. 400). Within the framework of the aforementioned diagnostic criteria, considerable variation among the individual autistic children was found. Three subgroups were delineated based on severity of social

isolation, the extent of the speech deficit, and the presence of "splinter skills". She defines a splinter skill as: "a skill that is considerably above the general mental age level of most other skills possessed by the child" (DeMyer, 1979, p. 5).

The group functioning on the highest level had a severely introverted type of personality although they did display some primitive social skills. The children also displayed a mixture of communicative and non-communicative speech. The middle functioning autistics were more severely regressed and only used non-communicative speech or they were mute. The lowest functioning group resembled the middle group but the children in this lowest group did not exhibit age-appropriate cognitive, motor, or intellectual skills.

Josh Greenfield (1970) is a contemporary author of some note and the father of Noah, a severely autistic child. The quote that follows is his description of his son's behavior.

At the age of 4, Noah is neither toilet trained nor does he feed himself. He seldom speaks expressively, rarely employs his less-than-a-dozen word vocabulary. His attention span in a new toy is a matter of split seconds, television only engages him for an odd moment occasionally, he is never interested in other children for very long. His main activities are lint-collecting, thread-pulling, blanket-sucking, spontaneous giggling, inexplicable crying, eye-squinting, wall-hugging, circle-walking, bed-bouncing, jumping, rocking, door-closing, and incoherent babbling

addressed to his finger-flexing right hand. But, two years ago, Noah spoke in complete sentences, had a vocabulary of well over 150 words, sang the verses of his favorite songs, identified the object's in his picture book, was all but toilet-trained and practically ate by himself (Greenfeld, 1970, p. 62).

Greenfeld's words present the human side of autism and in the process infuse life into the clinical description of the disorder.

Intellectual functioning. Kanner (1943/1985, 1973) originally thought autistic children were of normal intelligence. The child's normal physical appearance, intelligent facial expression, extensive vocabulary, superb memory for events, excellent rote memory (i.e., poems, names, intricate patterns, and sequences), he believed, supported this conclusion. The child's poor performance on standardized tests, Kanner reasoned, was due to their social withdrawal. Both DeMyer (1974/1975) and Rutter (1974/1975, 1978, 1983) found it necessary to clarify the issue of general intelligence. They accomplished the task through analysis and summarization of their own and other research projects. The authors concluded: (a) intelligence can be measured validly and reliably; (b) between 75 and 94% of autistic children are retarded; (c) verbal IQ is most severely affected; (d) IQ is stable over time; (e) IQ can be used to predict outcome; (f) lack of motivation or interpersonal relatedness does not cause low scores; (g)

treatment does not affect IQ; (h) IQ is related to severity of symptoms; (i) autism and mental retardation frequently co-exist; (j) the child's mental age is important in assessing autistic behavior.

Neurological deficit. Early theorists believed autistic children were neurologically sound and indeed some possess a normal central nervous system (CNS). However, a sizable number of the individuals suffering from this disorder exhibit neurological signs that would lead to a diagnosis of CNS dysfunction. Diagnosticians differentiate the dysfunctional CNS from the normal through a neurological work-up. The first step in the evaluation of an individual is a neurological examination. Jones and Prior (1985) used the Herzig Battery for Non-Focal Neurological Signs to evaluate the status of three groups of children. The battery assesses the presence of soft neurological signs. The functions evaluated include: "speech, balance, coordination, double simultaneous stimulation, gait, sequential finger-thumb opposition, muscle tone, graphesthesia, astereognosis and choreiform movement" (p. 42).

The 10 autistic children (5 males and 5 females) were diagnosed using DSM-III criteria. The first control group of 10 came from an inner city primary school and were

matched by chronological age to the autistic subjects. A second control group of 10 was included. This group was chosen from a class of suburban preschoolers and were matched by mental age with the autistic subjects. The autistic children, it was found, demonstrated significantly more soft signs than either of the control groups. Furthermore, all autistic children manifested choreiform movements.

Walker (1977) examined a group of 74 autistic children and a control group of 74 children (14 females and 60 males) for aberrations in their physiognomies. The autistic subjects exhibited all three of the following diagnostic characteristics: (a) onset before age 30 months; (b) deviant interpersonal relatedness; (c) language retardation. They also manifested at least two of the three behaviors listed below: (d) insistence on sameness; (e) stereotypic or abnormal movements; (f) adverse reaction to common environmental stimuli. The control group matched the autistic group on the variables of sex, age, socioeconomic level, and geographic location. This was done to control for the influence of the environment. The control group possessed a negative history and was judged free of autism.

Walker (1977) looked for abnormalities of head circumference, manageability of hair (i.e., electric hair), the eyes (i.e., epicanthial folds, hypertelorism), the ears

(i.e., placement, ear-lobe adherence, symmetry, and development), the mouth (i.e., high or steepled palate, tongue furrows), the extremities (i.e., fifth-finger curvature and/or stubbing, transverse palmier crease, syndactylia, a gap between the first and second toes, and the third toe greater than or equal to the second). Each child received a score indicating the number of stigmata present and the severity of the anomalies. The autistic group exhibited significantly higher cumulative score when compared to the control group. Furthermore, three of the anomalies, (low seating of the ears, hypertelorism, and minor syndactylia) differentiated the two groups.

The electroencephalogram (EEG) also aids in the diagnosis of CNS abnormalities. Of the 155 autistic children studied by DeMyer (1975/1976) 65% had abnormal EEG's. A second aspect of this study involved a thorough neurological exam. The autistic children, when compared with the normal control group, exhibited significantly more signs of CNS dysfunction.

Coleman and Gillberg (1985) as well as Golden (1987) summarized and analyzed every pertinent research study related to EEG abnormalities in autism. All the studies they perused, uncovered a greater incidence of abnormal EEG tracings in the affected aggregate. The EEG's, though



abnormal, did not demonstrate a distinct pattern of abnormalities unique to autism.

Seizure activity is another sign of neurological dysfunction. The incidence of seizures in autistic children ranges between 11% and 42% of those studied. Convulsions have been noted in the first year of life; however, puberty appears to be the age of highest risk to the individual (Coleman & Gillberg, 1985; Golden, 1987).

The brain imaging techniques of pneumoencephalogram (PEG) and computerized axial tomography (CT scan) have been used in an attempt to localize the CNS lesion in autism. Unfortunately, no single circumscribed lesion common to all autistic individuals has been discovered. The most consistent finding is ventricular distention, predominately in the left temporal ventricle (Coleman & Gillberg, 1985; Golden, 1987).

Research using magnetic resonance imaging (MRI), the newest form of brain scanning, has just begun. Nevertheless, a study by Eric Courchesne (1988), using this technique, has made a startling discovery. In most cases, following a comparison of the brain images of 18 autistic individuals and a normal control group, the vermis of the cerebellum was judged 25% smaller in the autistic group ("The Anatomy of Autism," 1988). If these findings can be replicated, the 50 year search for the neuropathology of

autism may be over.

### Epidemiology

Another important aspect of construct delineation is epidemiology. Lotter (1966/1985) conducted the first major epidemiological study of autism. He studied all children 8 to 10 years of age residing in the County of Middlesex England (total population 2.25 million).

A multi stage screening process was used to locate the autistic children. Two mail surveys were the components of stage one. The first letter was dispatched to all appropriate child care providers in the county to determine the total number of 8 to 10 year olds residing in Middlesex. The second mailing contained a 22 item questionnaire describing the cluster of aberrant behaviors the researchers were studying. Altogether, 2,154 questionnaires were returned. Two judges perused the questionnaires and delineated 88 possible autistic individuals. Additionally, researchers examined case records of all agencies providing care for the handicapped. They discovered 47 children who fit the study criteria raising the total number to 135 cases. The final stage of subject selection included: (a) observation of the children at school and in the home; (b) collection and analysis of parents' and teachers' behavioral

descriptions; (c) attempts at intelligence and social maturity testing; (d) medical and social histories were compiled; (e) medical records were reviewed.

Thirty-five children were diagnosed autistic; a prevalence rate of 4.5 per 10,000 children. A sub-group (nuclear autism) was defined. This group accumulated the highest scores in the behavioral categories of social withdrawal and insistence on sameness. The prevalence rate of this group was 2.0 per 10,000 children. The study produced several other major findings which include: (a) an over representation of males in the autistic group (the ratio was between 2:1 and 3:1); (b) two-thirds of the group had IQ's below 55; (c) onset before 30 months occurred in 29 of the original 35 cases.

Treffert (1970/1971) also studied the prevalence of autism. A definitional point is pertinent before further summarization. Childhood schizophrenia, according to Treffert, is a generic term which includes autism as a subdivision. The terms are used interchangeably in this study. His research subjects included all the children under age 12, residing in the state of Wisconsin, who had been diagnosed autistic or childhood schizophrenic. The list of possible subject was generated using a computer analysis of clients served by the mental health facilities in the state of Wisconsin. DSM-II criteria were used in the

diagnostic evaluation. The study discovered a prevalence rate of 3.1 per 10,000 children. Of these cases 25% or a prevalence of .7 per 10,000 were considered nuclear autism. Males outnumbered females 3.4:1 when incidence was evaluated according to sex.

Prevalence was re-evaluated during the 1980's by Steinhausen, Gobel, Breinlinger, and Wohllebed (1986). This team studied autistic children younger than 15 years old, living in West Berlin. The subjects were diagnosed cases of autism receiving services in the cities' mental health care system and children participating in programs sponsored by The National Society for Autism. The children displayed Rutter's (1978) universal and specific behavioral symptoms. Consequently, they were classified by the authors as demonstrating nuclear autism. The prevalence rate for this group was 1.9 per 10,000 children. The results obtained by Lotter (nuclear group prevalence 2.0 per 10,000) and Steinhausen et al., are very close. The study also revealed several other important facts. With regard to IQ, 2/3 of the children displayed varying degrees of mental retardation. Although all social classes were represented in the study, the middle-class was slightly more prevalent.

### Etiology

Since Kanner published his succinct description of autism a host of differing opinions have been expressed concerning the etiology of this disorder. During the 1950's and 1960's the plethora of theories focusing on causation could be subsumed into three broad categories: (a) faulty parenting (psychogenic); (b) organic pathology in the child (biogenic); (c) abnormal nature-nurture (DeMyer, 1975/1976; Morgan, 1981).

Psychogenic Theory. Tragically, for the parents of autistic children, most of the clinicians of this era ignored the physical and concentrated their attention only on the pathological parental personality, viewing this as the causative agent in the autistic syndrome (Schopler, 1971/1985). Bruno Bettelheim (1967) is one of the most influential proponents of the psychogenic theory of causation. According to Bettelheim, the infant's personality develops because of communication between the outer world (in the form of mother) and the child. If during this interaction the child experiences physical discomfort or emotional rejection he/she retreats from the trauma into a safe imaginary inner world. Personality development ceases and autism ensues.

Rimland (1964/1985) was the first clinician to question the credibility of the psychogenic theory. He discovered,

while reviewing the literature on psychogenic causation, a lack of corroborative research. On the other hand, the literature contained a number of studies which suggested an etiology due to organic neuropathology. Rimland's exposition influenced the research of the ensuing 20 years. The studies carried out during 1970's and 1980's discredited the psychogenic theory of causation and focused their efforts on finding the organic cause of autism.

McAdoo and DeMyer (1979) studied parents' personality characteristics. The purpose of the study was to determine whether or not parents of autistic children demonstrated symptoms of severe psychopathology or aberrant personality traits. The researchers were also interested in evaluating the parental stress hypothesis. According to this hypothesis, the chronic stress engendered while living with a severely behaviorally disordered individual could produce changes in the parents' personality.

The study included three groups of parents: 39 mothers as well as 37 fathers of autistic children; 100 fathers as well as 100 mothers who were parents and out-patients in a psychiatric clinic; 100 fathers as well as 100 mothers who were parents of disturbed (nonpsychotic) children being seen in a child guidance clinic. The groups were matched on age, education, number of children, and social status. The autistic children displayed social aloofness, a deviant

speech pattern or muteness, and purposeless object use. The work-up also included neurological, laboratory, and x-ray data. Finally, a staff psychiatrist taking all data into account categorized each child as organic or nonorganic autism. Goldfarb (1961) popularized the division according to the presence or absence of organicity. Parents of non-organic autistic children, he postulated, would manifest more psychopathology than did the organic group. Furthermore, the etiological agent in the nonorganic group was the parents.

The personality characteristics of the parents were evaluated by the Minnesota Multiphasic Personality Inventory (MMPI). The scores manifested by parents of autistic and child-guidance children were very similar. However, they were slightly elevated when compared to the scales of the normative group. The outpatient psychiatric group displayed scores that were significantly higher than the other research groups indicating a greater level of psychopathology. If the parents of autistic children were severely disturbed, McAdoo and DeMyer hypothesized, their scores would closely resemble the psychiatric outpatient group. The MMPI scores of the autistic parent group did not indicate severe psychopathology nor did they lend support to the psychogenic theory of causation.

Autistic children exhibit severely disordered behavior; whereas, the behavior of child guidance clients more closely resemble the norm. If the parental stress hypothesis were operative, it would be expected that the MMPI scores of autistic parents would be higher than the child guidance parents. However, the scores of both groups were essentially the same. The findings, according to the researchers, did not support the parental stress hypothesis. The final analysis entailed a comparison of the parents of organic and non-organic autistic children. This was done in order to support or negate Goldfarb's hypothesis regarding etiology in non-organic autism. If his hypothesis was valid then the MMPI scores of the non-organic group would be higher. The results showed the opposite to be the case; the parents of the organic autistic children exhibited higher MMPI profiles. Therefore, the results of the study did not support Goldfarb's hypothesis of parents as causative agent.

Biogenic. Although the previous 45 years have produced an enormous body of research, the etiology of autism, in most cases, remains a mystery. The research results have produced two universal principles related to etiology. Autism, according to the first principle, has many causes. Secondly, autism develops because of an aberration in the biology of the organism rather than faulty psychosocial interaction within the family (Folstein & Rutter, 1988).



Furthermore, research findings have uncovered a possible cause and effect relationship with infectious diseases, obstetrical trauma, and genetic abnormalities. Several of the more interesting biogenic hypotheses developed from research results are presented.

Chess (1977) examined a cluster of 243 children who suffered from congenital rubella. Each child underwent extensive physical, neurological, psychiatric, and psychological testing. Ten of the children, using Kanner's (1943/1985, 1973) list of symptoms, were diagnosed as autistic (nuclear autism). Another eight demonstrated most of the symptom complex; however, these children occasionally seemed to recognize other people. The prevalence rate for the first group would equal 412 per 10,000 and the rate for the second group equals 329 producing a combined prevalence rate of 741 per 10,000. The incidence of autism in the congenital rubella aggregate is excessively high when compared to Lotter's (1966), Trefferet's (1970), and Steinhausen et al's., (1986) epidemiological survey results (2.1 per 10,000, .7 per 10,000 and 1.9 per 10,000 respectively). The data, according to the authors, suggests a causal relationship between the rubella virus and autism in which the virus attacks the CNS. It is further "hypothesized that the course of autism was that of a

chronic infection in which recovery, chronicity, improvement, worsening, and delayed appearance of the autistic syndrome all were found" (p.69).

Cytomegalovirus (CMV) has also been associated with autism. However, the causal relationship between this virus and the disorder is not as clearly defined as it is with rubella and autism. In a total clinic population of 76 autistic children, Stubbs (1978) and Stubbs, Ash, and Williams (1984) discovered 3 children with the dual diagnosis. Ornitz and Ritvo's (1976/1977) list of pathognomonic symptoms was used to make the diagnosis of autism. This constitutes approximately 4% of the clinic's autistic clients. The authors did not draw any conclusion from their findings but suggested further research.

Research findings have also implicated physical trauma in the etiology of autism. Finegan and Quarrington (1979/1980) examined the pre-, peri-, and neonatal histories of 23 autistic children searching for evidence of obstetrical trauma. The autistic children exhibited aberrant social relatedness, compulsive ritualistic behaviors, abnormal response to sensory stimuli, absent or deviant speech, cognitive deficits, and onset of symptoms before age 30 months. The control group was made up of 15 apparently normal siblings of the autistic children. The rate of unfavorable obstetrical factors in the autistic

sample was compared with the rate in the general population and in the sibling control group. The autistic children experienced a greater number of birth traumas than did the general population. The most frequent complications included breech birth, low birth weight, Apgar less than 6, hemolytic disease, hyperbilirubinemia, Respiratory Distress Syndrome, cephalic forceps in breech births, and primary apnea. The autistic and sibling control groups were also compared on total number of obstetrical complications. The autistic aggregate experienced significantly greater numbers of untoward birth events. The single most significant event was amniotic meconium.

Gillberg and Gillberg (1983) also examined the incidence of obstetrical complication in a group of 25 Swedish autistic children. This sample constituted the total autistic population of the region of Goteborg, Sweden. The pediatricians and psychiatrists practicing in the area were asked to provide names of possible subjects. One of the authors examined the designated children diagnosing cases of autism using Rutter's (1978) criteria. The authors assembled a control group of normal children (N=25) matched for sex, hospital of birth, and time of birth. Each child's pre-, peri-, and neonatal history was examined in order to determine the optimality or reduced optimality of the

respective periods.

A total of 725 non-optimal points were possible for the autistic and normal aggregates. The autistic group earned a score of 137 non-optimal points (18.9%) where as the control group's score was 53 (7.3%). When compared, the totals exhibit a statistically significant difference. The authors then differentiated the total score into pre-, peri-, and neonatal periods and again compared the totals. In this instance, the autistic children accumulated significantly higher non-optimal scores during the pre- and neonatal time-frame. Mother's age greater then 35, dysmaturity (low birth weight), bleeding during pregnancy, and pre/post-maturity were the individual complications found significantly more often in the autistic group. More common but not significantly higher in prevalence were the traumatic events of maternal infection, generalized edema, medication greater then 1 week, and a low Apgar for the child.

In the opinion of the authors obstetrical complication are not necessary and sufficient conditions for autism; however, they do contribute to the development of the disorder. Gillberg and Gillberg present two possible causal hypotheses. In the first they propose a link between non-optimal condition during gestation and delivery and a genetic defect in the child. Whereas, in the second

hypotheses, a genetically dysfunctional fetus is the precipitating factor of the adverse obstetrical events.

Research results have indicated a robust cause and effect relationship between autism and obstetrical trauma as well as autism and CNS infections; however, there still remains an enormous aggregate of individuals who suffer from idiopathic autism. The most fruitful area of investigation in these cases seems to be genetics. The influence of heredity must be seriously considered because " the 2% rate of autism in siblings is 50 times that of the general population and a family history of speech delay is found in about a quarter of families" (Folstein & Rutter, 1977/1985 p. 321). Twin studies and familial aggregation studies form the foundation of this type of research (Folstein and Rutter, 1988).

British scientists, Folstein and Rutter (1977/1985) were not the first researchers to study autism in twins; however, they were the first team to use systematic methods of sample selection. With the help of the appropriate mental health care providers, the National Society for Autistic Children (NSAC), and two hospital twin registries a roster of possible candidates was developed. The authors, using Kanner's and Rutter's diagnostic criteria, identified 21 pairs of twins, one or both of the set exhibited the

distinctive autistic symptom complex (individual cases. N=25). The larger group was subdivided into 11 monozygote (MZ) and 10 dyzygote (DZ) twin pairs. Four of the MZ and none of the DZ twins were concordant for autism. All concordant pairs were male. According to the authors, "the MZ concordance rate is equivalent to a very high correlation in liability (over 0.9) using the multifactorial model" (Folstein & Rutter, 1977/1985, p. 322).

If the aberrant tendencies seen in autism were viewed as linear (mild abnormalities on one end of a continuum and autism on the other) the authors hypothesized a less severe cognitive deficit in the non-autistic co-twins. In fact, five MZ and one DZ co-twins demonstrated the hypothesized cognitive deficit. To reiterate, "9 (82%) of the 11 MZ pairs were concordant for cognitive disorder/autism compared with only 1 (10%) of the DZ pairs ( $p=0.0015$ )" (Folstein & Rutter 1977/1985 p. 322).

Twins, because of the existence of two fetuses in the uterus, are more likely to experience complications during delivery. Therefore, it was hypothesized, concordance could be due to a birth injury rather than to a genetic defect. With this possibility in mind, the researchers examined the obstetrical histories of the sibling dyads. A perusal of the records did not produce evidence of birth injuries in both twins, of the 4 pairs concordant for autism.

Furthermore, the twins who exhibited the milder cognitive disorder did not suffer a birth trauma. Nevertheless, perinatal complications were evident in the group with one autistic child and a normal/cognitive deficit child. In 12 of the 17 pairs of twins discordant for autism the autistic, but not the non-autistic co-twin, experienced a birth trauma. The recorded perinatal hazards included: kernicterus (i.e., bilirubin deposits on the basal ganglia and brain stem nuclei), apnea greater than 6 minutes, neonatal seizures, numerous birth defects, delayed second birth greater than or equal to 30 minutes, dysmaturity greater than or equal to 1 pound, hypoplastic umbilical cord, and infection with fever.

From these data the authors drew three conclusions regarding the etiology of autism: (a) for some cases genetic factors are the necessary and sufficient cause of autism; (b) on other occasions brain damage appears to be the causative agent; (c) in still other instances autism develops because an inherited cognitive defect and a perinatal trauma occur together.

More recently the scientists at University of California Los Angeles (UCLA) initiated another twin study examining the possibility of genetic causation in autism (Ritvo, Freeman, Mason-Brothers, Mo, & Ritvo, 1985). Forty pairs of twins,

with one or both children exhibiting autism, met the research criteria and were included in the project. Of the total, 23 sets of twins were MZ and 17 were DZ. The diagnosis of autism was made using DSM-III and NSAC's standards of evaluation. The study uncovered a MZ rate of 95.7% or 22 of 23 subject pairs demonstrated autism. The DZ concordance rate equaled 23.5% or 4 of 17. Ideally, the MZ concordance rate should be 100% and the DZ rate 25%. Nevertheless, the results, according to the authors supports an autosomal recessive pattern of inheritance.

Additional support for the genetic transmission hypothesis is found in multi incidence families. Ritvo, Spence, Freeman, Mason-Brothers, Mo, & Marazits (1985) studied 46 families, 41 with 2 affected members and 5 with 3. The subjects were gleaned from the research records of UCLA, through referrals, and from an advertisement in the NSAC newsletter. The 97 autistic probands were diagnosed using DSM-III's list of pathognomonic symptoms. Four methods (x linked recessive, multifactorial or polygenetic, autosomal dominant, and autosomal recessive) of genetic transmission were considered possible in the families examined. The authors rejected all forms of heritability except autosomal recessive.

Still other probes have uncovered a relationship (stronger than a chance relationship) between autism and



several single gene disorders. The first occupant of this category is Phenylketonuria. This disorder is an inborn error of metabolism and it is transmitted as an autosomal recessive trait. The child is unable to metabolize phenylalanine. If the disorder goes untreated, with a phenylalanine-free diet, mental retardation is the result (Folstein & Rutter, 1988).

Tuberous Sclerosis and neurofibromatosis are both neurocutaneous disorders which are inherited as an autosomal dominant trait. Children with tuberous sclerosis suffer from epilepsy, a progressive mental retardation, and a gradually worsening butterfly shaped skin eruption. The degeneration in the CNS is due to growths called tubers which usually effect the gyri of the cortex but can also be found in the thalamus or caudate. The children display an EEG pattern called hypsarrhythmia. Researchers believe that autism is associated with the aberration in the electrical impulses of the brain rather than tuberous sclerosis (Coleman & Gillberg, 1985; Folstein & Rutter, 1988). Neurofibromatosis causes freckle-like lesions of the skin and cranial nerves as well as malformation of the subcutaneous and bony tissue (Folstein & Rutter, 1988).

Most recently autism has been associated with a genetic disorder called the fragile x syndrome. Microscopic

examination of the affected x chromosome reveals a narrowing of the long end of the chromosome. The clinical features are post pubital mental retardation, testicular enlargement, lack of muscle tone, an elongated face, and oversized ears (Folstein & Rutter, 1988).

### Summary

Autism is a rare (4-5 per 10,000 children) developmental disorder that probably begins at birth. The universal and specific symptom which must be manifested before the age of 30 months include: (a) absence of interpersonal relationships; (b) muteness or retarded language development, with faulty comprehension, echolalia, and pronomial reversal; (c) compulsive need for sameness. The etiology of autism, in most cases, is still unknown. However, it has been associated, in a cause and effect relation with several infectious diseases, pre-, per-, and neonatal complications as well as abnormal genes.

## CHAPTER IV

### PARENTS AFFECTIVE RESPONSE TO A HANDICAPPED CHILD

How should parents respond to the birth of a handicapped child? Society, in general, has not provided the mother and father of the handicapped with a prescribed ritual to help them deal with the tragedy they face. Death would be easier because the sustaining rituals support the bereaved and allow them to mourn their loss. Furthermore, the dead child is not a visible reminder of the tragedy (Beddie & Osmond, 1955).

If she were dead, there would be condolences, flowers, the priest or parson, the neighbors' sympathy-- "poor little thing, perhaps she's better dead." ...Although each death reminds us always that we cannot escape yet and at the same time we rejoice that this time we have escaped. We do this by mourning (Beddie & Osmond, 1955, p. 168).

Beddie and Osmond, it seems are the first authors to associate grief with the birth of a handicapped child and to suggest professional help as well as societal support for the bereaved parents.

#### Determinant Grief

Loss of the idealized child. Solnit and Stark (1961) also believe parents, particularly the mother, grieve

following the birth of a handicapped child. They base this hypothesis on their knowledge of Freud's (1917) and Lindemann's (1944) theory of grief as well as observations of parents encountered in their clinical practice.

According to Solnit and Stark (1961), the grieving process proceeds in the following manner. Pregnancy activates the imagination and creates for the parents a picture of the expected baby. Frequently, this representation attains a perfection far beyond that which reality can provide. If a normal child is born, the parental adjustment to reality is usually accomplished rapidly and more or less effortlessly. This is not the case if a handicapped child is born. The parents are faced with an overwhelming dilemma which has two facets. The mother and father have been deprived of the idealized child. They must not only cope with this loss, but also with the loss of a normal child. The parents of a disabled child truly have suffered a loss both symbolic and actual.

The grieving process. In Solnit and Stark's (1961) opinion, the process of grieving begins at the time of birth and continues through separate, distinct stages; the final stage is acceptance and amelioration of grief. If sorrow persists beyond two to three months the grief is labeled pathological.

Kennedy's (1970) research examined empirically the

reaction of mothers following the birth of a physically or mentally impaired child. The mother, he hypothesized, passes through specific phases and upon completion of the phases, grief is attenuated. Kennedy (1970) used John Bowlby's work on mourning as the theoretical framework for his study. Bowlby (cited in Kennedy, 1970) delineated a three phase process. The grieving individual experiences a period of "protest, despair, and finally detachment" (Kennedy, 1970, p. 411). Kennedy's findings support this three phase, time-bound grieving process. However, the phases are not as circumscribed as those described in Bowlby's work. Between one and four weeks, Kennedy's 17 subjects exhibited, in rotation and concurrently, behaviors related to protest, despair, and detachment. The observed timetable for an uncomplicated grief reaction was 4 to 6 weeks.

In 1986 Nicholas and Lewin studied the reaction of 40 couples to the birth of a handicapped child. The tools used included: a family information sheet, an unresolved grief inventory, and a semi-structured interview. The authors drew several conclusions from the test results. In the first place, parents, following the birth of a handicapped child experience, an intense grief response. Furthermore, the pattern of grief, the author's judged, was "reactive and

time-related rather than endogenous and chronic" (p. 295).

Using Irvin, Kennell, and Klaus's work as a foundation Benkendorf (1987) presents an overview of the parental reaction to the birth of a handicapped child. Grief seems to be the typical response. The grieving process is subdivided into five stages, included are: (a) "shock" (i.e., emotionally numb, incoherent, rejects truth, a desire to escape, feeling helpless, and/or tears); (b) "denial" (i.e., disbelief, anxiety, disorientation); (c) "anger" (i.e., guilt, sadness, and depression); (d) "equilibrium" (i.e., dysphoric feelings ameliorate, life normalizes); (e) "reorganization" (i.e., depression abates, attention focuses outward and guilt dissipates) (pp.28-31).

The literature also contains another category of research which closely resembles the conceptualization of determinant grief; however, these theories are not labeled grief. Table 1 presents an outline of a representative sample of these models.

Blacher (1984) examined a substantial number of research papers delineating the stage theory of parental adjustment to the birth of a handicapped child. She uncovered a number of methodological and practical problems. In the first place, the stages were not derived following the analysis of data gathered by studies using appropriate scientific methods. Furthermore, the results were based primarily on

Table 1

Parental Reaction to a Handicapped Child

Study	Subjects	Etiology	Stages
Cohen 1977	Parents	Disabled children	1. Numbness and shock 2. Guilt and inferiority 3. Denial 4. Self isolation 5. Resolution
Drotar, Baskewicz, Irvin, Kennell, & Klaus 1975	Parents	Congenital defect	1. Shock 2. Denial 3. Sadness, anger, & anxiety 4. Adaptation (i.e., strong emotions abate & self confidence returns) 5. Reorganization (i.e., child care becomes rewarding)
Hall Richard 1984	Not specified	Handicapped children	1. Shock 2. Anger (i.e., Why me?) 3. Denial & rejection 4. Blame & guilt

Table continues

Study	Subjects	Etiology	Stages
			5. Overprotection (i.e., parental care stifling)
			6. Cognitive versus emotional acceptance (i.e., accept diagnosis but refuse remediation)
Eden-Piercy Blacher Eyman 1986	Parents	Handicapped children	1. Emotional turmoil 2. Refusal- denial 3. Adjustment- recovery- acceptance

parents preconceived notion of a particular handicap rather than the child's aberrant physiognomy and/or behavior. A substantial number of the studies used only one family or a very small group of subjects. Not only were the sample sizes small, the fathers' reaction to the event were not studied. Most studies did not allow for a social desirability factor when evaluating the parents' answers to the questionnaires. Moreover, there were inconsistencies in the definition of the key constructs. Finally, many projects did not include an assessment of the child's actual limitations. In light of the research deficiencies listed



above the author believes the primary research question (i.e., are stages of adjustment a fact?) still remains unanswered.

Additional support for Blachers (1984) position is offered by Allen and Affleck (1985). According to the authors certain intrinsic theoretical assumptions (i.e., rigid order of stages, stage specific behavior, and an interdependence of stages) are not supported by empirical data. Moreover, the stage theory of adjustment is not validated by data acquired in studies examining the individuals reaction to other life crises. In fact a number of studies suggest a chronic, episodic form of distress. Finally, Allen and Affleck's (1985) own research findings negate the stage theory.

### Chronic Sorrow

The majority of clinicians conceptualize parental grief, following the diagnosis of their child's disability, as time-bound. Olshansky (1962, 1966) vehemently and vociferously disagrees with the bulk of his peers. In his opinion, parents experience, "a pervasive psychological reaction, chronic sorrow" (Olshansky, 1962, p. 190). This type of grief does not represent in parents a maladjusted personality; it is a normal response to an unending,

horrible calamity. The intensity of feeling is not constant; it varies with time, situation, personality, ethnic group, religion, and social class. Olshansky's (1962) hypothesis emerged as a result of his work with clients in his clinical practice and was supported by the experience of his staff.

Wikler, Wasow, and Hatfield (1981) designed a study, employing suitable research procedures, whose findings they hoped would test the theory of chronic sorrow in situations where a child has been diagnosed as disabled. Consequently, the research question asked; is sorrow chronic in such cases or is it time-bound?

The subjects include 32 individuals who were parents of handicapped children and 32 social workers. The two groups were asked to respond to a mailed questionnaire. The research material was divided into three parts: a free-form graph and a structured graph which depicted visually the parental adjustment pattern. The third component was a direct question: do you experience chronic sorrow? The instructions differ slightly for each group. The social workers were asked to depict the parent's adjustment patterns; whereas the parents were asked to indicate their own feelings. Three quarters of the social workers and parents drew free-form graphs which demonstrated chronic sorrow. On the structured graph, parents again drew graphs,

which illustrated chronic sorrow; however, social workers depicted time-bound grief. In response to the direct question, 63% of the parents and 65% of the social workers defined sorrow as chronic.

Distinctive features. A review of the literature describing chronic sorrow was completed by Copley and Bodensteiner (1987). Their work uncovered five defining characteristics. First of all, parents experience, throughout the child's life, periodic inevitable exacerbations of grief. These reoccurrences are usually precipitated by: (a) a missed or delayed developmental milestones (i.e., normal rights of passage); (b) milestones associated with the disorder (i.e., residential placement, acquisition of specialized equipment); (c) individually significant events (i.e., hearing a particular song, seeing a movie) (Davis, 1987). Furthermore, denial can foster mood swings; feelings fluctuate back and forth between happiness and profound sadness. Moreover, the bereft parents mourn the loss of the idealized normal child. Chronic sorrow is thought to be a normal reaction whose severity changes from time to time and with differing situations. The presence of chronic sorrow does not preclude a sense of joy when the child achieves a particular goal. Finally, those who suffer chronic sorrow may pass through phases which include:

denial, developing awareness, and restitution (i.e., adaptive and/or maladaptive coping).

Factors affecting the character of grief. Researchers have identified a number of factors which seem to influence a parent's reaction to the birth of a handicapped child. The most important determinants are as follows: (a) professional's attitudes (i.e., expect parents to be super parents, blame parents for disorder, exhibit disdain for parents or the handicapped, manner in which the diagnosis presented; (b) interminable burden of care (i.e., child reminder of loss, remediation progresses slowly, lack of definitive prognosis); (c) social milieu (i.e., parents socioeconomic status, societies negative attitudes, social and professional support system, religious mores, lack of prescribed rituals for mourning, societal expectations of mourning and an end to mourning); (d) family characteristics (i.e., spouse and other children in home, presence of physical and behavioral anomalies) (Blacher, 1984; Copley & Bodensteiner, 1987; Hillyer-Davis, 1987; Kornblum & Anderson, 1982; Wright, 1976).

The grieving process. According to Wright (1976), the grief parents experience following the diagnosis of a handicapped child, is chronic. Although grief is chronic the painful emotions do ameliorate with the passage of time. The easing of the dysphoric state occurs in six distinct

psychological stages, The stages are not traversed in sequence; parents may skip a stage, regress, or fixate in any of the six. Stage one is labeled "Shock". The purpose of shock is to allow the parents time to prepare for the protracted period of emotional distress that follows. Shock lasts for several hours to several days. As shock dissipates it is replaced by fear; fear on the part of the parents that they will be unable to cope with the burdens engendered by a handicapped child. "Denial", the second stage, insulates the parents against the dysphoric feelings of guilt and anger. It also provides them with a spark of hope. At first parents hope that the diagnosis is inaccurate and later on they hope for a cure. Denial can become dangerous if it is prolonged because the parents, by deceiving themselves, delay recovery.

The truth usually seeps into consciousness braking down the defense of denial. When this occurs "guilt and anger", stage three, takes its' place. At first parents blame themselves for the tragedy, believing that it is punishment for some long forgotten transgression. As time passes, guilt becomes intolerable and parents search for others to blame. They strike out in anger at those around them. The hostility towards others can lead family and friends to avoid the parents of a handicapped child. Parents attribute

the avoidance behavior of others to a loss of respect. The imagined diminution of status engenders the stage of "shame and martyrdom". Along with the perceived loss of status parents who have reached this stage feel disgraced in the eyes of the world and inferior to other people. These beliefs propel the mother and father toward the role of martyr. Martyrdom temporarily alleviates the psychological distress they feel. A cure, control of dysphoric emotions, and escape have eluded the parents. These failures push parents into the fifth stage "depression". The feelings of hopelessness and helplessness are the hallmark emotions. With time and the emotional support of others parents realize that there is treatment for their child's disorder. The new insight fosters the emergence of the strength necessary to achieve stage six "recovery". Recovery is divided into three sub-stages: (a) "acceptance" of the child, others, and the self; (b) "reconstruction" of life so that it supports all family members; (c) "reorientation" of energies and attention outside the self (pp.161-168). Although parents have recovered from grief it does not mean that they will never experience sorrow again.

Other authors have found it necessary to sort the multitude of emotions associated with the diagnosis of a handicapped child in a slightly different manner. Copley and Bodensteiner (1987) using Fortier and Wanless' (1984)

crisis model as their theoretical framework, developed a five stage two phase conceptualization of chronic sorrow. Phase I includes the three stages of "impact" (i.e., numbness, shock, agitation, and confusion); "denial" (i.e., incredulity, cognitive deafness, fantasies related to causation, unrealistic expectations for outcome); and "grief" (i.e., agitation, anger, guilt, and depression) (p. 69). The bereaved parent moves in a circular pattern among these stages. The authors longitudinal, clinical observation of parents offered support for the circular pattern of bereavement. Moreover, this phase, which can last for years, has been characterized as an "emotional roller-coaster ride" (Copley & Bodensteiner, 1987, p.68).

Parents progress to phase II when they recognizes the presence of the child's handicap and the impact it will have on family life. Chronic sorrow in this phase of bereavement is episodic and time-limited. The quality of the sorrow also changes; rather than excruciating pain it becomes a gnawing ache. Phase II is subdivided into the stages of "focusing outward" (i.e., parents cope adequately with the child as well as the handicap) and "closure" (i.e., the family function as a cohesive unit) (p.69-70).

Stanford Searl (1978) is the father of a mentally retarded individual. The quote that follows is his

description of the pattern of grief he experienced while coming to terms with his daughter's retardation.

Underneath my well-adjusted surface, shock, denial and fear remained, though they were buried and sublimated. At times these feelings found their way into the world again. Once it happened when Parnel and I were shopping for presents for Diana's fifth birthday.

After we left the toy store, Parnel burst into tears. "I don't want to buy those infant toys for her. I want her to go to first grade this year like everyone else."

"So do I, Parn. So do I," I answered.

Neither of us ever "got over" the fact of Diana's severe retardation. To that extent we never really "adjusted" to it, in spite of our usual appearance of calm and acceptance (Searl, 1978 p. 28).

Searl(1978) believes that parents would be better served by the professional community if they cast-off the stage theory of grieving and accepted the existence of chronic sorrow.

### Pathological Reaction

The enormous task of parenting a handicapped child can be overwhelming and lead to a pathological reaction. Nevertheless, there is a paucity of research in this area. One of the few brief discussions of this topic was presented by Solnit and Stark (1961).

The authors conceptualize a pathological reaction as a continuum with rejection of the child at one end and parental martyrdom at the other end. If the child is



rejected, parents experience a compelling desire to repudiate the natural parent-child bond. The rejection is behaviorally manifested, shortly after birth, by institutional placement of the child. Martyrdom is precipitated by guilt and is manifested in the exclusive, unrelenting care given the handicapped child.

Kennedy (1970) defines a pathological response as one that lasts more than two or three months. The response he believes, is due to a desire on the part of the mother to maintain a tie to the lost perfect child.

### Stress, Crisis, and Coping Theory

Parental reaction to the diagnosis of a disabled child has also been studied using stress, crisis, and coping theory as the conceptual framework. Reuben Hill (1958/1965) was one of the first theorists to develop a model describing the families reaction to normative and non-normative stress producing events. The model is made up of three primary constructs. The first factor is the "family", which Hill defines as "an arena of interacting personalities, intricately organized internally into positions, norms, and roles" (p. 34). Assessed from the outside the family is seen as an ordered group interacting with other aggregates. Throughout its life, the family is beset with problems that could destroy its structure. In order to maintain the

integrity of the family the members develop problem solving abilities. These acquired skills are labeled the families "crisis-meeting resources." Construct number two, "the crisis-provoking event or stressor," is an unexpected, disconcerting incident the family is ill equipped to handle. Accompanying the event are certain hardships; these complications are a product of the event not the family. Loss of income, need for home care of a disabled person, or the illness of other members of the family are examples of hardships.

The final factor needed to complete the schematic is the "meaning attached to the event" (p. 32-36). The meaning is the subjective definition a family gives an event (i.e., a stressor is a crisis if defined as such by the family). Hill's (1958/1965, p. 36) ABCX model of family crisis is as follows: "A (the event)---> interacting with B (the family's crisis-meeting resources)---> interacting with C (the definition the family makes of the event)---> produces X (the crisis)."

The pattern of adjustment to a crisis, according to Hill, resembles an abbreviated roller-coaster. The family members initially experience a overwhelming sense of numbness. As the numbness abates the individual's ability to organize his/her life plummets. Following a period of

disorganization the recovery process begins. Adjustment culminates with reorganization. In Hill's opinion, the stages of adjustment to a crisis are analogous to the stages of bereavement resolution.

The Vietnam War generated a study, conducted by McCubbin and Patterson (1983), which broadened our knowledge of families in crisis. They observed 216 families whose husband/father was absent (a prisoner of war or missing in action) for an average of 6.6 years. Originally, the Hill ABCX model was used as the conceptual framework for this longitudinal study. However, four additional factors came to light which also seemed to influence the families progress towards an adaptive termination of the crisis. The additional constructs discovered were: (a) "pile-up" (i.e., an accumulation of stressors); (b) "existing and new resources" (i.e., available capabilities); (c) redefinition of the situation; (d) adaptive coping strategies (p.10). McCubbin and Patterson added the new factors to Hill's schematic and developed the "Double ABCX Model."

In the augmented framework pile-up is labeled aA and includes five types of stressors; (1) the initial insult; (2) normal growth and development; (3) pre-existing problems; (4) side effects of coping strategies; (5) social and familial uncertainty. The designation for existing and new resources is bB and this segment includes the problem

solving capabilities of each member of the family, the family as a group, and the community. Taking into consideration all pertinent stressors, the available resources, and the hypothesized action necessary to return the family's equilibrium, the crisis is then redefined. The redefinition is labeled cC. To achieve adaptation balancing when faced with a crisis, the family initiates coping procedures. Coping is defined as an interplay among capabilities, perceptions, and actions. These procedures may focus on (1) the eradication and/or circumventing of the stressors; (2) dealing with the tribulation; (3) fostering family continuity and a positive outlook; (4) acquisition of needed skills; (5) altering the anatomic configuration of the family to meet new requirements. Family adaptation balancing, labeled xX, is the key outcome concept of the Double ABCX model. The authors conceptualize the construct as a continuum with "bonadaption" at one end and maladaption at the other. If bonadaption occurs, a balance is achieved between the crisis demands and the capabilities of the individual, the family, and the community. Maladaption ensues if the imbalance between demands and capabilities is not equalized.

According to McCubbin and Patterson (1983), crisis precipitates change in a family. The process of adaptation

occurs in three stages, Initially, the members "resist" any permanent disruption of the precrisis structure and/or operation of the family. However, once a crisis situation is defined, "restructuring" becomes necessary so that family integrity can be maintained. Transfer of some parental responsibility to children, the acquisition of additional education, or re-entering the work force are examples of restructuring. The changes instituted in the restructuring stage create turmoil in the family. In order to return the family to a state of equilibrium additional changes are initiated. This stage is called "family consolidation" (p. 20).

Fortier and Wanlass (1984) perused the literature on the families reaction to a handicapped child. Using the data collected in the review as support, they differentiated a five stage model of family crisis. Before presenting the stages the authors offer several caveats to the potential user. To begin with, the length of each stage and the stage sequence are idiosyncratic to the individual. Furthermore, not everyone will experience every stage. Finally, the type of reaction experienced by one family member can effect the reaction of other members.

The first of the five stages is "impact" which usually occurs at the time of diagnosis. The impact stage is marked by feelings of anxiety and a sense of turmoil in the family.

" Denial" is second in line. The characteristic manifestations are: rejection of the diagnosis and shopping for another, pipe dreams related to a miracle cure, or refusing to see the child. Stage number three is "grief" defined by feelings of anger (i.e., parents question, "Why me?"); guilt (i.e., related to acts of commission and omission or define retardation a punishment); and sadness (i.e., perception of loss). Parents also feel unacceptable as human beings. The mother and father's struggle to cope realistically with the dilemma originates in stage four, labeled "focusing outward." The parents give up the dreams of a cure and start to develop plans for the future based on the reality of the situation. Family solidarity is the hallmark of stage five, labeled "closure". Life is reordered so that it includes the irreversible changes that have occurred and hope, that the family can flourish in spite of adversity, is ignited.

Stress documented. The existence of stress in the families of handicapped children has been empirically documented by a number of researchers. A representative sample of the study results will be presented in the following paragraphs.

In 1966 Cummings, Bayley, and Rie conducted a study which examined the effect a disabled child had on the

mother. They compared the level of psychological stress in mothers of normal, mentally retarded, chronically ill, and neurotic children. Each group contained 60 mothers making a total of 240 research subjects. These groups completed a battery of five tests which included: (a) "the Shoben Parental Attitudes Inventory;" (b) "the Self-Acceptance Scale of the Berger Acceptance Inventory;" (c) a 46-item Sentence Completion Test;" expressly designed for the study (i.e., to elicit feelings associated with interpersonal satisfaction as well as those related to maternal role capability); (d) "a Family Drawing Task" (i.e., to discover the mother's views on family unity, feelings of role adequacy, and level of contentment with family life); (e) "the Edwards Personal Preference Schedule" (i.e., a standardized personality inventory) (pp. 598-599). The data accumulated in the study supports the hypothesis that having a retarded, chronically ill, or neurotic child is a psychologically stressful experience for the mother. Mothers of neurotic children experience the most stress, while mothers of retarded children occupy the middle position. Finally, mothers of the chronically ill are the least troubled.

The impact of a disabled child on the father was also studied by Cummings (1976). The format of the current study was generally the same as the 1966 one, using mothers as

research subjects. The total of 240 fathers was divided into four groups of 60 fathers of handicapped, chronically ill, neurotic, and normal children. They completed a series of four self-administered tests which included: (a) "the Edwards Personal Preference Schedule" (i.e., a standardized personality inventory); (b) "a 46-item Sentence Completion Test," especially developed for the research project (i.e., to ascertain the level of interpersonal satisfaction as well as paternal role adequacy); (c) "the Self Acceptance Scale of the Berger Inventory;" (d) "the Shoben Parental Attitudes Inventory" (p. 248). The researchers concluded from the test data that both fathers of mentally retarded and chronically ill children experience psychological stress; however, fathers of the mentally retarded are the most severely effected group. The results also indicate a long term personality change in fathers of the mentally retarded children which is suggestive of a neurotic-like constriction.

Stress, using families of the handicapped as subjects, was studied by Friedrich and Friedrich (1981). The examinees totaled 68 families, 34 with one handicapped child living at home and 34 controls. The two groups did not differ in mean age of the child, family income, mothers age, and total number of children. The mothers of each family



were asked to complete five tests including: (a) "The Questionnaire on Resources and Stress" (i.e., a measure of parent's personal difficulties, malfunction in the family, and anticipate hardships for the child); (b) "The Locke Wallace Marital Adjustment Inventory;" (c) "Psychological Well-Being Index;" (d) "a social-support index;" (e) "a religiosity index") (pp. 551-552). The test data demonstrates a higher level of stress in parents of disabled children, reduced levels of marital fulfillment, decreased contentment, limited community support, and diminished religiousness. In other words, the parents of handicapped children experience more stress and are bereft of the usual psychosocial supports needed to attenuate the effects of stress.

Factors effecting stress. Gallagher, Beckman, and Cross (1983) conducted an extensive literature review focusing on the factors which seem to enhance the parents level of stress. These characteristics can be found in the disabled child, the parents, the family as a whole, and society in general. The features intrinsic to the child are: advanced age, diagnosis, sex, aberrant behavior, limitations in mobility and need for assistance, slowed maturation, socially aloof nature, and need for the specialized care. The parental attributes which influence their ability to cope with stressors are: income level, IQ, years of

education, language skills, frame of mind, personality type, previous contact with stress, age, occupation, view on causation, mental or physical disability, attitude towards life, and single parent status. Characteristics of the family as a unit also influence the degree of experienced stress. Included in this category are the socioeconomic status of the family and the number of normal siblings. The final classification focuses on social influences. Society as a whole has a very condescending attitude towards the handicapped which can extend to the parents. The internalization of this fallacious conclusion can cause an elevation of parental stress. The current educational policy of deinstitutionalization and mainstreaming is also a source of parental stress.

Stress unique to families of the retarded. Wilker (1984) delineated four stressors which are characteristic of families with a retarded child. The first is "stigmatized social interaction." Mankind is ill prepared to deal with the mentally retarded. The handicapped are shunned because society feels uneasy in their company. People in general, and sometimes even parents, see the retarded as incapable of participating in any meaningful activity. Not only do parents cope with these difficulties, they also are faced with a variety of thoughtless, angry, pitying, impertinent

and disparaging remarks.

"Prolonged burden of care" is the second stressor described by Wikler. Retardation by its nature involves a protracted period of dependency for a child. Moreover, the burden of care is continuous because there is a paucity of any type of respite care. A variety of physical limitation can add to the management problems already present.

Stressor number three is "lack of information." Ordinarily, parents have three sources of information on child care: (a) nonprofessionals (i.e., early personal experience, extended family, and peer group); (b) child care experts; (c) professional and nonprofessional literature. These sources are frequently inadequate when one is dealing with a mentally retarded child. The most helpful source of information is a parent or a group of parents facing the same dilemma.

The final category is "grieving." Parents emotional reaction to the birth of a handicapped child is overwhelming grief. The hypothesized cause is the loss of the idealized perfect child. As time passes, the intensity of the grief reaction abates and homeostasis eventually return. However, grief can reappear during moments of particular significance to the parents (pp. 58-60). Although these stresses are ever present, the level of awareness is elevated to crisis proportions when the child's development and/or the

parenting experience differs from what was anticipated.

### Summary

The parent's reaction to the birth of a handicapped child has been conceptualized in a number of different ways. Beddie and Osmond (1955) as well as Solnit and Stark (1961) defined it as grief. Solnit and Stark described a time-bound, stage process which was engendered by the loss of the idealized perfect child. Olshansky (1962, 1966) rejected the time limits his colleagues placed on the process. He believed parents experienced a non-neurotic everlasting form of grief which he called chronic sorrow. More recently, the parent's reaction has been examined in light of stress, crisis, and coping theory. The theoretical framework used was Hill's (1958/1965) ABCX model and McCubbin and Patterson's (1983) Double ABCX model.

## CHAPTER V

### PARENT'S AFFECTIVE RESPONSE TO AN AUTISTIC CHILD

#### Determinant Grief

Until recently, parents have been the neglected victims in the tragic situation engendered by the autistic syndrome. Early on, one of three fates befell them: a handful of clinicians ignored the mother and father completely and concentrated on treatment of the child, others accused the victims of perpetrating the disorder and prescribed psychotherapy, and still others trained the parents as co-therapists. None of these early professionals examined the emotional devastation experienced by parents following the diagnosis of autism. In 1979 DeMyer made an attempt to correct this oversight. Her study examined the deleterious effects of the autistic child's symptoms on the family unit. Although DeMyer did not label the parent's reaction to the child as grief, it bears a striking resemblance to this dysphoric state. Both parents and siblings were studied; however, the researchers concentrated on the mothers emotional state because she usually is the primary care giver. The data were gleaned from controlled studies; however, the total number of parents and siblings studied as well as pertinent demographic information were not provided

by the author.

Family life, in general, according to the parents studied, is somewhat tarnished by the child's handicap. More specifically, 65% of the mothers and an unspecified percentage of fathers experienced feelings of guilt related to acts of omission or commission. The guilt led 33% of the mothers to question their parenting skills. The aberrant behavior of the autistic child generated feelings of anger in 30% of the mothers and an unspecified percentage of fathers. A scant number of fathers became angry at fate, questioning, "Why me!" Both parents experienced elevated levels of anxiety, created by the autistic symptomatology (e.g., the need for constant watchfulness, incessant screaming, or restlessness). Furthermore, the emotional distress experienced by the mother and her intense devotion to the autistic child generated additional stress and worry in about 45% of the fathers.

DeMyer's study also compared the incidence of psychopathology in the parents of autistic children and a matched control group. The groups differed on only one aspect. About one third of the mothers whose children were autistic experienced a reactive depression. In all cases, the depression was attributable to the vicissitudes of life with an autistic child. Moreover, a little less than one half (42%) of the mothers expressed a desire to escape the

burdens of coping with their child's problems. The desire to escape, the authors believe, was engendered by the irreconcilable nature of autism.

The development of autism in a progeny not only adversely affects parents individually but it also places an additional strain on a marriage. As a means of determining the effect an autistic child has on a marriage, the happiness or unhappiness of each couple was evaluated. Although the difference was not significant, it was found that the normal control group had more extremely happy marriages (autistic 30%, controls 42%) whereas the autistic group had more extremely unhappy marriages (autistic 30%, controls 18%). Furthermore, the affectional bond between couples was weakened in 51% of the autistic marriages as compared to 21% in the control group.

DeMyer (1979) has delineated a number of factors which seem most destructive to the autistic marriage. Included in the list are: a morbid concern for the child; frustration generated by the symptoms; diminished communication which isolates the partners from each other; lack of moral support and encouragement for each other; disordered household; additional financial burdens; sadness; depression; restriction of social activities; and diminished sexual contact between partners.

As with the parents of an autistic child, the siblings also experience elevated levels of stress. In 30% of the families studied one or more of the autistic child's sibling felt that their parents did not attend to their needs or parents described themselves as inattentive to the non-index child. About 18% of the parents reported inordinate worry expressed by a child over the autistic siblings disorder. Another 15% of the non-autistic children regressed to a lower level of development. In addition, one or two families reported excessive teasing by peers, elevated levels of jealousy in siblings, and avoidance of the autistic child by normal siblings. Tragedy does not always have an adverse effect on the family or its members. The truth of this statement was born out by the data in the DeMyer study. In 54% of the families studied one or more of the normal siblings provided physical as well as psychological care, education, and entertainment for the autistic child. Moreover, a surprising number of the non-autistic children chose careers in the professions of health care and education.

Research focusing exclusively on the parental grief reaction following a diagnosis of autism is almost non-existent. Most authors refer to grief only superficially. They recognize the existence of grief and acknowledge the parents need to verbalize the sorrowful feelings to a



compassionate listener. Nevertheless, they do not dissect the dysphoric emotion into its fundamental parts (Marcus and Schopler, 1987).

### Chronic Sorrow

There is also a dearth of research examining the concept of chronic sorrow in parents of the autistic. One of the few studies available is an unpublished thesis (Maurice, N., 1984). The results obtained lend support to the Wikler et al. (1981) study and to Olshansky's (1962,1966) theory of chronic sorrow.

The N. Maurice (1984) investigation was inspired by and is heavily dependent on the work of Olshansky (1962, 1966) as well as that of Wikler, et al. (1981). However, it differs in the following ways: (a) the study population was limited to parents of autistic children; (b) the graphs were a design developed by the current researcher rather than copies of those used in the Wikler et al. study; (c) a personality style index was included; (d) also a questionnaire based on Rutter's (1974/1975,1978) universal and specific criteria of autism (i.e., to limit the study population). The primary research questions were: (a) do parents of autistic children feel chronic sorrow or determinant grief; (b) does parental stress vary during the

child's life; (c) does personality style (i.e., extrovert/reactive versus introvert/reflective) influence the grieving process; (d) does the sex of the individual effect the grieving process.

The test material used was divided into five parts. The first portion was a letter introducing the author and the research project. The second component was a scaled chart on which the parents could plot a free-form graph. The subjects were instructed to graph the changes in their feelings beginning at a time before they knew they were to be parents and ending with the present. The third part was a structured graph. Twelve critical developmental milestones were listed (beginning with early happenings and ending with current events) each was followed by a scaled chart. The parents were asked to graph the intensity of their feelings at these critical stages. The structured graph permitted the development of a "Total-Distress" measure and it facilitated a comparison of the grief felt at early milestones and present events. The fourth component was a personality style index. The fifth and final section was as a questionnaire. Question one asked the parents if indeed they did experience "chronic sorrow". The remainder of the questionnaire sought information related to demographics and diagnosis.

A total of 14 people were asked to participate in the

study. Four people, (i.e., two couples) after seeing the test material, elected not to take part in the study. The 10 subjects who agreed to participate included 5 women and 5 men. Two additional demographic facts seem pertinent to the study. In the first place, the individuals represent five married couples. In addition, their children exhibited Rutter's (1974/1975,1978) universal and specific criteria of autism.

The resultant free-form graphs (70%) and the answers to the direct question (80%) lend empirical support to Olshansky's (1962, 1966) theory of chronic sorrow and corroborate the findings of Wikler et al. (1981). However, the structured graphs suggests time-bound grief. Regarding the differences in the sexes, the findings indicated a more intense grief response in women. Finally, the subjects personality type (i.e., reflective/introvert versus reactive/extrovert) also seemed to have an impact on the grieving process. The reactive (extrovert) personality type, expressed a more profound feeling of grief then did the person with a reflective (introvert) personality style.

### Personal Account

The final category and the largest body of material is the personal account. These stories contain a wealth of

information, regarding the parents emotional state. The excerpt that follows was taken from Josh Greenfeld's Life article, "A Child Called Noah."

But I still don't know exactly what's wrong with Noah. I only know something is profoundly wrong with him. I still don't know what to do- I only know I must do whatever I possibly can. Although Noah is too young for an institution now, I know I must still accept the very real possibility of his eventual institutionalization. I also know I must try not to feel more sorry for myself then, for Noah, but some days I forget (Greenfeld, 1970, p. 72).

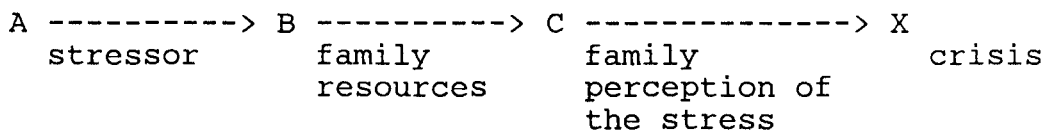
Grief is not limited to the parents of autistic children; siblings also experience severe emotional pain. The following passage was written by the 17 year old brother of an autistic individual.

From my own life, I had a miserable example of suffering. It happened to my oldest brother Sam; he is retarded and mute. It hurts me because if he was not this way, I would have two brothers teaching me the facts of life, about high school, college, girls, etc. Unfortunately, I only have one brother who gives me advice on life. I do not understand why he (Sam) is this way. I pray to God asking him, "Why did you make him different from us?" I never get an answer. It hurts me to see him this way, but there is one most important thing; I love my brother very much no matter what handicap he has (Maurice, G., 1987).

### Stress, Crisis, and Coping Theory

For a period of 10 years or more Bristol and Schopler (1983) have been studying the reaction of parents to the presence of an autistic child in a family. The information

presented by the authors in "Stress and Coping in Families of Autistic Adolescents" was gathered from three sources: the professional literature, their clinical experience, and a study whose subjects were families with an autistic child. The study data were obtained from 40 mothers with children ranging in age from 4 to 19 years. The theoretical model they used as a foundation for their research was Hill's theory of stress, crisis, and coping. A reiteration of Hill's ABCX model as it appears in Bristol and Schopler's (1983, p. 261) article follows:



The stressors (A) which mediate the development of a crisis in an autistic family are the child's perverse personality traits (i.e., difficult to supervise, incapable of independence as well as the need for aid with "self-help skills") and the lack of programmed remediation.

The broad category of "family resources" (B) can be subdivided into personal capabilities, the skills of the family as a unit, and the active coping tactics employed by the parents. The attributes included under the heading of personal resources are: sufficient wealth, good health, an average or better intellect, a better than average

education, adequate self-esteem, and a sense that one is controlling one's own life. The authors uncovered one exception to the findings stated above. Occasionally, more intelligence and a better education can produce stress rather than alleviate the distress. This situation occurs because parents who possess these characteristics sometimes have very high vocational expectations for their children. When the child cannot meet these expectations parental stress is produced. The resources of the family unit include: the ability to adapt, a moderate amount of family cohesiveness, the capacity to laugh, the ability to see beyond the autistic child to the outer world, and previous success in dealing with stress.

Although the research into active coping tactics has not been completed the initial findings suggest a number of behaviors which, at certain times and under certain circumstances, are effective in alleviating stress. Coping behavior is subdivided into "instrumental and palliative" measures. To reduce stress, using instrumental strategies, the parents must change the child or the environment. For example parents can: acquire information as well as learn new skills so that they can participate in the child's treatment; petition authorities for needed services; initiate changes in school or job training programs; and be

consistent in carrying out the treatment plan at home. Parents using "palliative or intra psychic strategies" attempt and sometimes fail to cognitively reduce, endure, or disregard the stress produced by life with a autistic individual. These goals are more readily attained if the parents have a philosophy of life which allows them to be thankful for and to find fulfillment in other aspects of their life. Furthermore, it is important for parents to hold certain positive tenets related to the etiology and prognosis of autism. Finally, medications, such as antidepressant, are also an appropriate palliative measure.

The third aspect of Hill's model (C) examines the subjective definition and/or beliefs which the family attributes to the experience of having an autistic member. A stressful event is less likely to become a crisis if causation is defined as an entity outside the family rather than a failure from within and also the knowledge that others share the same problem. A look at the early research on autism shows that most theoreticians labeled parents as the causative agent; furthermore, because of the rarity of autism there is a paucity of families similarly afflicted. Religious beliefs also help parents cope with the problems engendered by the autistic child. In some cases, parents believed that God would give them the strength to deal with

the problems and that he had a purpose for the trauma. Others believed that God would cure the child. Whatever the sustaining belief parents: "feel that they are 'not alone' and that having an autistic child has a higher meaning and an ultimate reward" (p. 266). As part of Bristol and Schopler's (1983) research, parents were asked to define the experience of having an autistic child. In some instances the child's problem was defined as a burden; a situation that would prevent the family from reaching its full potential. Others felt that the child was a punishment; possibly for a delinquent member's misdeeds or deficient parenting skills. Finally, some parents saw the child's handicap as a challenge; a chance to learn new skills.

Bristol's (1987) research project tests the efficacy of using a modified version of the Double ABCX model when assessing the ability of families to adapt to a child with autism or other severe communication disorders. The definition of the original components was modified slightly for the study. The redefinitions are as follows: "severity of handicap (A)"; "pile-up of other stresses (aA)"; "family resources-cohesion (B)"; "social support (bB)"(i.e., informal-formal); "externalization of blame (C)"; "definition of handicap as a family crisis (cC)"; "pattern of coping (BC)"; "family adaptation (X)" (i.e., depression,



marital adjustment, quality of parenting) (pp.471, 473).

Four hypothesis were tested: (a) the modified Double ABCX model will determine those families who have achieved a healthy adjustment; (b) the variables of a close knit family, an extensive professional and non-professional support system, and superlative coping skills will positively predict family adaptation; (c) positive adjustment would be negatively forecast by pile-up of other traumas, paternal self recrimination, and a maternal definition of a tragedy; (d) pile-up, family capabilities, beliefs, and coping strategies would explain more of the variance in successful family adjustment then severity of the handicap.

The mothers were recruited from consecutive referrals to the Division for the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH). The children ranged in age from 2 to 10 years and the group included 27 autistic children and 18 with a non autistic communication disorder. Before the initial diagnostic work-up was begun the mothers were asked to complete a number of self-report measures; following this a home visit was scheduled. During the visit the completed questionnaires were picked up and a structured interview was carried out. The observer blind to the results of the self-assessment measures then rated the families ability to function.

The results of the study indicated that the modified Double ABCX model is capable of predicting the healthy adaptation of a family to an autistic child. Hypothesis number two was upheld by only two of the predictor variables. The variables that offered support were more readily available non-professional help and better than average coping skills. Greater family cohesion was found to be associated with negative family adaptation and formal support was not predictive. Regarding hypothesis number three, additional family stress, maternal recrimination, and the label of a family disaster, forecast inadequate family adaptation. Contrary to the stated hypothesis, the severity of the child's handicap was not a significant negative predictor of adjustment. In fact, with regard to marital adjustment the more severe the handicap the better the adaptation. Hypothesis number four was not supported by the results of the research. To be more specific, the severity of the handicap was not predictive of maternal depression or quality of parenting. With regard to marital adjustment, greater severity was associated with better adjustment.

Stress documented. The Questionnaire on Resources and Stress was used by Holroyd and McArthur (1976) to compare the level of stress experienced by mothers of autistic children, Down's syndrome children, and children who were

outpatients in a neuropsychiatric clinic. The research hypotheses were: (a) mothers of autistic children will report more disruptions in family life than mothers of Down's syndrome children or mothers of clinic clients; (b) mothers of Down's syndrome children will report more disruptions than out patient subjects.

The data obtained supported the first hypothesis; in fact the autistic group scored higher than both comparison groups on all scales except financial problems. The seven highest scores suggested the areas of greatest stress for mothers of autistic children and differentiated them from the Down's syndrome group. The scale content suggests that mothers of autistic children experience: (a) more negative feelings towards the child; (b) elevated stress levels generated by greater caretaker demands; (c) greater concern over the effect of the child on the well being of other members and concern for the continuity of the family unit; (d) the need to cope with more physical limitations; (e) distress related to the lack of appropriate services and vocational training; (f) a more acute awareness of the child's maladaptive behavior and aberrant personality traits. The second hypothesis was not supported by the findings. Specifically, mothers of Down's syndrome children did not experience more distress than the clinic mothers.

The study conducted by Bebko, Konstantareas, and

Springer (1987) assesses the severity of the stress generated by certain characteristic of the autistic child. The project sought the answers to the following four questions: (a) what symptoms do parents define as most severe; (b) are the most maladaptive symptoms the most stress producing; (c) do parents and professionals agree on the harshest symptoms; (d) are professionals accurate in their definition of the most stress producing symptoms.

The 40 subject parents came from all parts of Ontario and were participating in a program conducted by the Geneva Centre for Autism, Communication, and Language Disorders. The professionals were 20 caseworkers who had worked with the research families from 3 to 12 months. The mothers and fathers were asked to fill out a modified version of the Childhood Autism Rating Scale (CARS). The adaptation reworded the scale so that it was appropriate for self-administration to non-professionals. The parents were instructed to rate the severity of each symptom and the amount of stress it caused. The professionals were asked to rate the severity of the child's symptoms and to estimate the amount of stress the symptoms produced in the parents.

The child's deficiencies in verbal expressive language and the inconsistencies in intellectual abilities (i.e., splinter skills combined with retardation) were defined by

both parents as the most significantly deviant symptoms. The third most abnormal characteristic defined by both parents was the child's inability to form relationships. The symptom rated least abnormal was the child's difficulty in dealing with environmental change.

The ratings given by the professionals were similar to those of the parents. According to the professionals, the most abnormal symptoms were defined as the child's inability to communicate nonverbally (i.e., employment of and reaction to gestures and facial expressions) and the cognitive deficits. The professionals ranked verbal expressive language as the fourth most abnormal characteristic and emotional appropriateness as number three.

Table 2 presents the whole list of symptoms studied and the rating given to each by the research subjects. Each participant was asked to use a 4-point rating scale in which 1 represented the normal range and 4 severely abnormal. The symptoms are ordered by mean score from the most abnormal to the least. The data are a product of the Bebko et al. research project; however, the table was developed by the current author. The results also demonstrated a significant correlation between the mother and father's rating total. Professional and parent rating totals also agreed; however, a closer correlation was found between the father's and the professional's ratings.

Table 2

Symptoms Rated from Most Abnormal to Least

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Mean Symptom Rating

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Mother		Father		Professionals	
Intellectual abilities	3.50	Intellectual abilities	3.24	Nonverbal communication	2.95
Verbal communication	3.25	Verbal communication	2.89	Intellectual abilities	2.90
Relate to others	2.70	Relate to others	2.84	Emotions inappropriate	2.75
Activity extremes	2.60	Emotions inappropriate	2.42	Verbal communication	2.68
Body movements	2.50	Activity extremes	2.26	Relate to others	2.65
Emotions inappropriate	2.45	Imitation	2.21	Body movements	2.65
Imitation	2.40	Visual information	2.21	Relate to objects	2.65
Nonverbal communication	2.30	Body movements	2.16	Anxiety reaction	2.65
Visual information	2.25	Relate to objects	2.16	Activity extremes	2.65
Response to sound	2.15	Other senses	2.08	Imitation	2.55
Relate to objects	2.10	Nonverbal communication	2.00	Visual information	2.50

Table continues

Mother		Father		Professionals	
Other senses	1.95	Anxiety reaction	1.89	Environmental change	2.45
Anxiety reaction	1.85	Response to sound	1.84	Other senses	2.25
Environmental change	1.75	Environmental change	1.79	Response to sound	2.20

Parents rated verbal expressive abnormalities and cognitive irregularities as the most stressful characteristic of the child. The least stressful symptom was the child's inability to cope with change. Factors examined which were found to be unrelated to parental stress were, the child's sex, number of siblings, ordinal position, socioeconomic status, and mothers working situation. Table 3 lists all the characteristics studied. Subjects rated the stressfulness of each symptom using a 4-point scale; a score of 1 meant the symptom was not stressful where as a symptom with a score of 4 was considered extremely stressful. The symptoms are ordered according to the mean score from most stressful to least stressful. The authors concluded, after reviewing the results, that the more aberrant the child's symptoms the more anxiety it produced in the parent. Furthermore, the overall severity of the disorder (as delineated by the sum of all symptoms ranking) was related

Table 3

Symptoms Rated from Most Stressful to LeastMean Stress Rating

Mother		Father		Professionals	
Verbal communication	2.80	Verbal communication	2.58	Verbal communication	3.30
Intellectual abilities	2.50	Intellectual abilities	2.16	Intellectual abilities	2.90
Emotions inappropriate	2.20	Relate to others	2.11	Activity extremes	2.70
Activity extremes	2.20	Emotions inappropriate	1.95	Relate to others	2.60
Body movements	2.10	Activity extremes	1.95	Body movements	2.60
Relate to others	1.95	Body movements	1.92	Emotions inappropriate	2.55
Imitation	1.95	Other senses	1.89	Anxiety reaction	2.50
Nonverbal communication	1.95	Imitation	1.74	Nonverbal communication	2.40
Other senses	1.89	Visual information	1.68	Relate to objects	2.35
Anxiety reaction	1.75	Nonverbal communication	1.68	Environmental change	2.20
Visual information	1.60	Relate to objects	1.58	Other senses	2.00

Table continues



Mother		Father		Professionals	
Response to sound	1.55	Response to sound	1.58	Imitation	1.95
Relate to objects	1.53	Anxiety reaction	1.58	Visual information	1.95
Environmental change	1.30	Environmental change	1.42	Response to sound	1.55

to the parents' level of stress.

Professionals were very accurate when estimating the most stressful of the aberrant traits. They defined as most stressful the child's verbal expressive impairment and cognitive limitations. Wide fluctuations in the child's level of activity was also seen as distressing for parents. However, the professionals felt that parents were experiencing more overall stress than families themselves reported.

Factors effecting stress. Families vary in their ability to cope with stress. At the negative end of the continuum a family becomes overwhelmed and disintegrates, while at the positive end another family, in spite of adversity, functions in a continuous and harmonious manner. Bristol (1981) compared the high stress families with the low stress families in order to determine the factors which influenced the outcome. The research subjects were 40

mothers of autistic children, who were participating in the TEACCH program. The ten mothers experiencing the most stress and the ten experiencing the least were delineated. The demographic variables of family income, mothers age, family size, and number of working mothers were parallel. All the index children had been diagnosed as autistic and the groups contained comparable numbers of mild and severe manifestations of the disorder.

The factors which differentiated the high stress group from the low stress group were found in the child and in the environment. Factors related to the child included: abrasive character traits; an inability to care for one's personal needs; more dependent; and a paucity of remedial services, leisure activities, as well as opportunities to live independently. The environmental factor which influenced the parents level of stress was the adequacy of informal support. The informal support net work includes: the mate, extended family members, friends, and self help groups.

The study conducted by Siu (1982) also tried to determine the variables which influenced the parents' emotional reaction to the autistic child. The 27 subject families were gleaned from the files of a state institution, day schools, and parents associations. Questionnaires and

semi-structured interviews were the methods used to gather data. The author constructed the following five composite indices from the interview data: "Summated Family Problem Score", "Summated Negative Impact Score", "Parents' Self-Assessment Index Score", "Researcher's Assessment Index Score", and "Total Parental Coping Index Score" (pp. 171, 173, 176, 178, 181).

Three factors were found to be significantly related to outcome: (a) the extent of the child's aberrant personality traits; (b) the magnitude of the maladaptive behavior; (c) whether parents define the diagnosis of autism as an opportunity for growth or a catastrophe. Several additional factors were strongly associated with the outcome. Included in this group of factors are: ordinal position, age, the time elapsed between diagnosis and the research interview, parents perception of the future, and adequacy of informal as well as formal social support.

Stress unique to families of the autistic. Parents of autistic children experience all the stresses related to retardation and a number of additional ones specifically associated with autism. Schopler and Mesibov (1984) as well as Wing (1985) have described some of these problem areas. The diagnosis of autism is difficult and usually does not occur until after the age of two. The child's physical appearance is normal, the developmental mile stones occur at

the appropriate intervals, and splinter skills are frequently present; these circumstances make it hard for parents to accept the fact that there is something very wrong with their child. The diagnostic delay also fosters the development of secondary behavioral problems which could have been avoided with early remediation. The child's normal physical appearance associated with the aberrant behavior frequently sparks criticism from strangers and extended family alike. The onlookers believe the child is just spoiled and not handicapped.

Autism is a rare disorder which occurs in about 4 to 5 per 10,000 children. The rarity of the disorder limits the number of remedial programs as well as social services designed specifically for the autistic child and the family. Moreover, it restricts parent to parent contact which is the best source of informal social support. Parents are also frustrated by their inability to penetrate the child's isolation and/or stop the disruptive behavior (e.g. screaming). Finally, all parents feel some guilt and shame related to their child's handicap; however, these feelings are intensified in parents of the autistic because early theoreticians falsely labeled parents as the causative agents. In recent years parents have been exonerated by most but not all professionals and the etiology has been

defined as a biological defect.

### Summary

The parents emotional reaction to the diagnosis of autism in a child has received very little attention. In 1979 DeMyer made an attempt to correct this oversight. She found that parents in her study experienced guilt, anger, anxiety, depression, and diminished marital happiness. Although not labeled as such, these feelings resemble the symptoms experienced by a grieving individual. The results of the Maurice (1984) project demonstrated the existence of chronic sorrow in parents of autistic children. More recently, the parent's reaction has been examined in light of stress, crisis, and coping theory (Bristol & Schopler, 1983; Bristol, 1987). The theoretical frameworks used by these studies were Hill's (1958/1965) ABCX model and a modified version of McCubbin and Patterson's (1983) Double ABCX model. The results of Bristol's (1987) study indicates that the modified Double ABCX model is capable of predicting the healthy adaptation of a family to an autistic child.

## CHAPTER VI

### CONCLUSION

The principal purpose of this research was to discover the answers to two questions. The primary research question addressed the following: which pattern of grieving (time-bound or chronic) typifies the experience of parents with an autistic child. The second examined the differences, if any, between the grief experienced by parents of autistic children and by parents of children with a clear-cut defect in their biological structure. A supplemental body of material, an overview of autism and grief associated with death, was included in order to provide pertinent background material for the investigation.

Unfortunately, there is so little research specifically focused on the autistic parent's affective plight that it is impossible to draw any definitive conclusions using only this research. However, if the data obtained from autistic parents are combined with the data on grief in general and the grieving pattern experienced by parents of children with other types of biological handicaps, a preliminary understanding can be gained.

Parents of an autistic child like all other parents never expect to produce a handicapped child. They dream about and make plans for the baby who is about to enter

their lives; however, the child of their imaginings is always perfect. Following the diagnosis of a handicap, the parents experience a sense of loss; hypothetically the loss of the dreamed of perfect child. The one fact most generally supported by the research findings is that grief follows loss. The parents of an autistic individual have experienced the loss of their perfect child; therefore they should experience the symptoms of grief. In 1979 DeMyer found that the autistic parents in her study suffered feelings of guilt, anger, anxiety, depression, and diminished marital happiness. Although not labeled as such, these feelings resemble the symptoms encountered by the grieving individual. However, DeMyer did not uncover a pattern associated with these dysphoric feelings.

The literature on grief following death and grief associated with the more obvious biological handicaps describes three patterns of grief. A small group of researchers believe the individual passes through distinct, sequential capsules of time (i.e., stages, phases) and ultimately achieves a state of acceptance, when grief has abated. This form is called determinant grief (time-bound grief). Other practitioners describe parental grief as chronic sorrow; the dysphoric (non-pathological) feelings are a permanent aspect of the individual's affective state.

Still others hypothesize a pathological form of grief in which the individual becomes completely enmeshed in the handicapped child's life or conversely denies the child's existence. Unfortunately, the supplemental body of research does not provide a definitive answer regarding the pattern of grief either. Therefore, the question still remains: which pattern of grief typifies the emotional experience of the parents whose child suffers from autism?

Although researchers have not as yet developed an all inclusive theory of grieving, it is possible to construct one with the information now available. In order to fit the pieces of the puzzle together, it is necessary to conceptualize the parental grieving process as a continuum. Following this, determinant grief is then renamed acute grief. The symptomatology is initiated by loss. The client experiences an acute grief reaction similar to the time-bound grief described in Chapter II. The bereft moves down the continuum and the quality of grief begins to change. At some point (different for each individual) one of three outcomes occurs: (a) grief abates; (b) grief becomes a non-pathological chronic sorrow; (c) grief takes on a pathological character. The N. Maurice (1984) study supports the existence of (a) and (b).

Acceptance of the theory on parental grieving does not automatically exclude the use of all other conceptual



models. Stress, crisis, and coping theory is also an acceptable conceptual framework for studying the emotional reaction of parents to an autistic child. It delineates the conditions necessary for a crisis to occur. In this model the stressor interacting with family resources and the families perception of the stress produce a crisis. The pattern of adjustment to the crisis occurs in three stages: numbness, disorganization, and reorganization. In Hill's (1958/1965) opinion, the stages of adjustment to a crisis are analogous to the stages of bereavement resolution.

Bristol and Schopler's (1983) and Bristol's (1987) research projects tested the efficacy of using the ABCX and the Double ABCX models of stress, crisis, and coping when assessing the ability of families to adapt to a child with autism. The results of the studies indicated that both models were applicable when studying families afflicted with this disorder. Two studies, the one carried out by Holroyd and McArthur (1976) as well as Bebko, et al's (1987), empirically support the presence of stress in parents of autistic children.

The answer to the second research question is even more allusive than the first. Only one project has attempted to compare the parents of autistic children with parents of obviously biologically impaired children. Holroyd and

McArthur (1976) found the parents of the autistic experienced more stress than did parents of Down's syndrome and normal children. Not only do parents of the autistic experience a greater level of stress, they also are subject to certain stresses that are unique to autism. Included in this category are: (a) difficult and/or delayed diagnosis; (b) normal appearance, developmental milestones occur at appropriate intervals, and splinter skills facilitate denial of the problem and peer criticism; (c) limited number of remedial programs and social services; (d) lack of informal social support; (e) parental frustration related to control of aberrant behavior; (f) intense guilt and shame because parents were labeled causative agent. How these factors effect the grieving pattern is unclear. It may intensify the grief reaction or increase the number of episodes of chronic sorrow experienced by parents. However, these factors do not seem to cause the expression of a specific pattern of grief.

### Limitations

The conclusions drawn from the data uncovered during the literature search are only preliminary. The tentative nature of their presentation is due to the nature of the data and the methods of data collection which supports them. They were developed using data collected from (a) groups of

parents whose children had disorders other than autism; (b) the groups of appropriate subjects were small; (c) the research method was usually clinical observation; (d) the number of appropriate studies was meager. .

### Future Research

The possibilities for future research are almost unlimited because so little work has been done using the autistic parent as a subject. Studies which will determine the pattern or patterns of grief following the birth of an autistic child are needed. There are several ways that this can be accomplished.

1. The N. Maurice (1984) study could be replicated using a larger group of subjects. Furthermore, the addition of a semi-structured interview, in which the questions focused on the parents experience with grief, could provide support for the results of the graphs. In addition the interview could expand the understanding of the pattern of grief as well as provide information needed for the construction of a definition for acute grief, chronic sorrow, and pathological grief.

2. Although more costly and time consuming, a longitudinal study is also an appropriate research tool. The testing would be begin following the diagnostic work-up, at 3 months, 6 month, 12 months, and every year for a

total of 10 years. The information gathering instruments for this piece of research could be the same as those used in example one or a standardized inventory (e.g. "Texas Inventory of Grief" (Zisook, DeVaul & Click, 1982)) could be substituted for the graphs. The type of information gathered would be the same as in example number one.

3. Research is also needed to determine whether the grief experienced by parents of the autistic differ from parents of other more obvious biological handicaps and if it does how and why it differs. This task could be accomplished in the following manner. The study design would resemble the two research projects described above with the addition of a second group of subjects alike in all ways except that their children were the victims of Downs Syndrome. The pattern of grief experienced by each group would then be compared to determine the difference if any.

4. A survey is needed to determine the types of information that would be most helpful to parent of the autistic.

5. A research project which would determine the effect of personality style, socioeconomic status, and marital status on the pattern of grief is also important.

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APPROVAL SHEET

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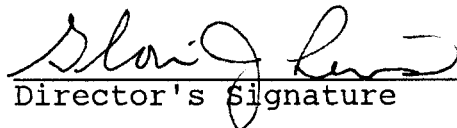
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The final copies have been examined by the director of the thesis and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the thesis is now given final approval by the Committee with reference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

The thesis is therefore accepted in partial fulfillment of the requirements for the degree of Master of Arts.

12-7-90  
Date

  
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