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UNIVERSITY OF ALBERTA

THE EXPERIENCE OF PARENTING
AN ADOLESCENT WITH AUTISM

BY

K. LAYNE (MACKEIGAN) FONG

A thesis submitted to the Faculty of Graduate Studies
and Research in partial fulfillment of the requirements
for the degree of MASTER OF EDUCATION

IN

SPECIAL EDUCATION - SEVERE DISABILITIES

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UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled THE EXPERIENCE OF PARENTING AN ADOLESCENT WITH AUTISM submitted by K. LAYNE (MACKEIGAN) FONG in partial fulfillment of the requirements for the degree of MASTER OF EDUCATION in EDUCATIONAL PSYCHOLOGY (SEVERE DISABILITIES).

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Abstract

This study used phenomenological research methodology to investigate the experiences of parents of adolescents with autism. Eight parents, representing six separate family units, were interviewed regarding their experiences as parents of teenagers with autism. The study had two primary objectives: (1) to understand the phenomenon in the lives of the parents interviewed, and (2) to identify needs of adolescents with autism, making recommendations for service provision. In addition, the results of the study were compared to the existing literature on families of individuals with autism, and to the experiences of families of children who have other types of disabilities.

Six consistent themes emerged from the interview data, including: (1) behavioral concerns, (2) social and communication concerns, (3) family-related concerns, (4) education and related services, (5) relationships with professionals, and (6) independence and future concerns. Responses to probe questions on adolescent issues, coping strategies, and support systems were also presented. The results of the study were discussed in terms of the objectives of the study, and in terms of limitations and personal implications.

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As the mother of two children, one of whom is autistic, I have come to rely on a very extensive social support system. I would like to acknowledge the contributions of the following special individuals, without whom this thesis would have never reached completion:

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TABLE OF CONTENTS

CHAPTER 1

Introduction

Autism is a severe, life-long, developmental disability, which affects an individual's behavior, communication skills, cognitive abilities and social relationships. It is often identified by the presence of a set of behavioral symptoms that include the failure to develop normal social relationships; abnormalities in speech, language and communication; abnormal relationships to objects, events and sensations; and a pattern of developmental delays or differences (Powers, 1989). Rutter and Schopler (1978) defined the syndrome according to four essential criteria: (1) onset before age 30 months, (2) impaired social development, (3) delayed and deviant language development, and (4) insistence on sameness, including stereotyped play, obsessions, and resistance to change. Autism occurs in about four or five births out of ten thousand, making it the fourth most common developmental disability. The disorder is four times more common in boys than in girls.

Kanner (1943) was the first to identify autism as a unique disorder. He described his clinical experiences with a group of eleven children, who shared several common characteristics. These children had difficulty relating normally to other people from a very young age. As infants, they often did not anticipate being picked up by their parents, and seemed content to be left alone. All of the children exhibited delayed or disordered language development. Some of the children were mute. Those who did speak tended not to use language for communicative purposes. Instead, their speech was characterized by delayed echolalia, literalness, and reversal of personal pronouns. The children also tended to have excellent rote memory skills, and a rigid insistence on sameness in their routines and activities.

Kanner (1943) also observed a tendency for these children to come from highly intelligent, achievement-oriented families. In Kanner's opinion, the parents, most of whom were professionals,lacked genuine interest in people, and were obsessively pre-occupied with intellectual pursuits. However, Kanner suggested that, because autism began so early in the children's lives, the disorder could not be attributed solely to parental pathology. Instead, he postulated that these children had an innate inability to form normal social relationships.

Although Kanner did not directly imply that parents had caused autism in their children, other theorists used his observations about parents to develop a psychogenic theory of autism. For example, Bettleheim (1967) theorized that children with autism were actually withdrawing from what they perceived to be a hostile and rejecting environment, created by cold and distant parents. Parents, especially mothers, were seen as the cause of the disorder. Treatment involved separation of the child from the parents, followed by intense psychotherapy for both the mother and child. However, usually this treatment produced no noticeable improvement.

Much of the early research on mothers and fathers of children with autism focused on the possible etiological effects of various parental factors, in an attempt to either support or refute the psychogenic theory. According to Cantwell and Baker (1984), primarily three aspects of family functioning have been investigated as possible etiological agents. These include: (1) severe early stress experienced by the infant, (2) deviance in parent-child interactions, and (3) deviance in parental personality. In reviewing the research concerning families of children with autism, they found little current support for any of these factors as the cause of autism. In particular, Cantwell and Baker (1984) suggested that studies that implicated deviance in parental personality as the cause of autism were mostly written prior to 1970 and often suffered from methodological flaws. The authors concluded that "the literature does not support the hypothesis that parents of autistic children are excessively cold, introverted, undemonstrative, or mentally disordered." (p.43). At present, there is general agreement that autism is caused by biological rather than psychological factors (Ritvo & Freeman, 1984). For this reason, it has become more productive to study the impact of autism on the family, focusing on the chronic stress caused by the child's disability and on the resources available to the family to help family members cope (McAdoo & DeMyer, 1978).

Much of the general information on stress and coping in families of children with disabilities is applicable to the family of a child with autism. However, there may be some unique characteristics of autism that result in different or more profound effects on the family when compared to families of children with other types of disabilities. For example, Holroyd and McArthur (1976) found that mothers of children with autism experienced more stress and interference with personal and family functioning than did mothers of children with Down Syndrome. Because autism is a less visible type of handicapping condition, many of these children are not actually diagnosed until age three or four, when normal communication and social relating should have started to develop. By this time, the family may have realized that the child is not developing normally, and family members may blame themselves for the child's lack of development. Because of the difficulty in positively identifying autism and the reluctance to label the child prematurely, parents may often visit a series of doctors and other professionals, before securing an appropriate diagnosis.

The fact that children with autism often exhibit severe behavior problems, such as temper tantrums and aggression, may also make coping very difficult for the family. According to Chetwynd (1985), children with disabilities who exhibited a greater number of social and behavioral problem were associated with increased maternal stress. Stress levels were reported to be the highest among mothers whose children: (1) were overly active or inactive, (2) were difficult to manage behaviorally, (3) could not occupy themselves for at least an hour, and (4) were unable to play with other children. Of course, most children with autism, by definition, exhibit all of the characteristics listed above.

While it is plausible that families of children with autism may experience considerable stress and difficulty coping with their child's disability, very little research has been done in this area. Most of the information available is based on quantitative data from questionnaires and surveys administered to groups of parents of children with autism (Bristol, 1979; DeMyer, 1979). While this information is useful for our understanding of the issues affecting families and the relationships among the different variables, it does not explore the meaning of the experience to families with a member who is autistic.

The importance of exploring the meaning of an experience in an individual's life is related to the fundamental differences in perspective between natural science (quantitative research) and human science (qualitative research). Natural science is rooted in physics, chemistry and other investigations in the natural world. The underlying assumption is that there is a split between the body and the mind. Thus, we learn about objective reality by making observations and measurements in the physical world. Subjective interpretations are to be avoided. Quantitative methods seek objectivity and attempt to control and predict the relationships among variables.

On the other hand, human science (qualitative research) contends that, according to the principle of co-constitutionality (Valle & King,1978), the human mind and the outside world are inseparable. Human science also contends that the human consciousness is always directed toward something in the outside world (Osborne, 1989). Therefore, all knowledge must be attained through human understanding and all knowledge is subjective.

Osborne (1989) stated that the focus of the qualitative research approach is "the understanding of persons' experiences of their world(s) and not the generation of explanatory laws" (p.6). Anderson (1991) further stated that in qualitative research "the world is not just waiting to be discovered; the 'facts' cannot be taken for granted; it is the task of the social scientist to explicate how meanings in every day life are constituted and maintained" (p.29). Meanings, according to Anderson (1991), are generated by humans as they interact with one another and with their world(s). According to Berg (1989, "qualitative techniques allow the researcher to share in the understandings and perceptions of others and to explore how people structure and give meaning to their daily lives" (p.6).

We can begin to understand the meaning of the experience of parenting a child with autism by reading some of the excellent personal accounts that have been written by parents (Beavers, 1982: Lovell, 1978; Morphett,1986; Park, 1972). While these personal accounts provide valuable insight as to what it must be like to parent a child with autism, they have not been analyzed thematically and therefore the commonality of experience cannot easily be determined.

Phenomenological research methodology, explained more fully in the Methods chapter, is one type of qualitative methodology that seeks to illuminate the meaning of a certain phenomenon or experience in the lives of individuals, using thematic analysis. Data in phenomenological research is usually derived from open-ended interviews with individuals, called co-researchers, who have experienced the phenomenon in question and are able to clearly describe their personal experiences. Using certain procedural steps, interview data are then analyzed into themes or meaning clusters (Colaizzi, 1978), which describe the essential elements of the experience.

Recently, a series of masters' theses have used the phenomenological approach to study the experiences of families with a variety of different handicapping conditions. Morgan (1987) studied the experiences of mothers of adolescents with hearing impairments, and Hancock (1988) described the experience of parenting a child with visual impairments. Adams (1987) documented the experiences of families of children labelled "dependent handicapped", and Waggoner (1988) discussed the concerns of families of children with learning disabilities.

To date, a comparable study of families of children with autism has not been conducted. In fact, qualitative research with families of children who are autistic is extremely limited. Only one study has attempted to thematically analyze the experiences of mothers of children with autism from a phenomenological perspective (Dudziak, 1982). However, Dudziak's study contains only limited information about the feelings experienced by the mothers and fails to give a comprehensive description of how mothers have coped and adapted to their child's disability. Clearly, there is a need for additional qualitative research that describes the experiences of families of individuals with autism from a phenomenological perspective.

Hopefully, understanding the phenomenon of parenting a child with autism will lead to greater empathy on the part of professionals toward the families with whom they are in contact. It will also provide important information to families of children who have been newly diagnosed with autism regarding what they may expect to encounter. Eventually, understanding the experiences of families of children with autism may also lead to better service provision for families and individuals, as needs are identified and addressed.

Statement of the Problem

This thesis endeavors to describe the experience of parenting an adolescent with autism, using phenomenological methodology. There are two primary objectives of this study: (1) to understand the meaning of the phenomenon in the lives of the parents interviewed, and (2) to identify needs of adolescents with autism and their families, making recommendations for service provision. In addition, the results of the study will be compared to the existing literature on families of individuals with autism, and to the experiences of families with children who have other types of disabilities.

The experiences of families of adolescents with autism have been selected as the phenomenon in question for a number of reasons. First, many families are now able to keep their children at home for longer periods of time, rather than resorting to other residential options. This is partly due to the wide-spread acceptance of the principles of normalization and integration and also due to the availability of better services for individuals with disabilities and their families. Thus, there are more families who are endeavoring to provide care at home to their adolescents with autism.

Second, adolescence, a difficult period even for so-called "normal" children, may be particularly volatile for some individuals with autism. This may be due partially to hormonal changes during puberty and partially to increased physical size, which may make existing behavioral problems more difficult to manage. Bristol (1979) suggested that dealing with older children with autism might be more stressful for parents than dealing with younger children.

Third, there is relatively little research available on adolescents and adults with autism, as compared with the information available on younger children with autism. Therefore, this study explores the experiences of parents of adolescents with autism to hopefully fill in some of the gaps identified in the existing literature.

A phenomenological methodology has been chosen because it is the most consistent with the purpose and objectives of the study. In most cases, the parents involved in the study as co-researchers were mothers, because they were usually the primary caregivers. However, the father's experience was also included in cases where the father was involved in direct care of the child and was willing and able to participate in the study.

Overview of the Thesis

Chapter 1 has described background information, stated the research problem, and outlined the objectives of the study.

Chapter 2 consists of a review of the literature, which is divided into three parts: (1) a general review of the literature on families of children with disabilities, (2) a review of the literature specific to families of children with autism, and (3) a review of the literature pertaining to adolescents with autism and their families.

Chapter 3 consists of an overview of the phenomenological research methodology used in this study. It also describes the specific methods used, such as the selection of co-researchers, the interviewing process and the analysis of data. Bracketing, the reduction of the presuppositions and biases held by the researcher, is also discussed.

Chapter 4 describes the results, and specific themes which have emerged from the parent interviews. Results and discussion are presented simultaneously due to the nature of the data and the interpretation process.

Chapter 5 discusses conclusions and implications, which have been drawn from the analyzed data. These conclusions reflect the stated objectives of the study, namely (1) to understand the meaning of parenting an adolescent with autism in the lives of the parents interviewed, and (2) to identify needs of adolescents with autism and their families, making recommendations for service provision. Comparisons are also made with the existing literature on families of individuals with autism, and with the experiences of families of children with other types of disabilities.

CHAPTER 2

Literature Review

The material in this literature review is comprised of three broad areas of research: (1) general information about families of children with disabilities, (2) more specific information about families of children with autism, and (3) information about autism in adolescence. Each of these areas will be considered separately.

Families of Children with Disabilities

This overview of families of children with disabilities is categorized into six sub-headings, including: (1) historical perspectives, (2) stress, (3) coping strategies, (4) family systems theory, (5) family life cycles, and (6) parental experiences.

Historical perspectives are considered first in order to provide a social context for the research on families with disabilities. In the past, parents of children with disabilities were often viewed from a standpoint of assumed pathology. The major focus was often on the influence of the parents on the child.

Later, research began to focus on the impact of the child with disabilities on the parents and other family members. In particular, the aspects of stress and coping have been investigated. Results of studies on stress and coping in families of children with disabilities will be summarized. Earlier studies on stress and coping were often univariate studies, which considered the effect of one variable upon another, for example the effect of the severity of the disability on maternal perceptions of stress. However, such research was simplistic because it did not consider the extremely complex, interdependent nature of the family unit. It also did not take into consideration the development of the family over time.

Most recently, research has emphasized a family systems perspective, which takes into account the complexities of family life. The family life cycle has also been investigated in order to understand the developmental changes experienced by families over time. The literature on both of these aspects of family functioning will be reviewed.

Finally, a review of the descriptive literature on families of children with disabilities will be presented, because it is most relevant to the present investigation. Both personal accounts written by parents and results of the few existing qualitative studies will be reviewed.

The same format will also be used in a later section to review literature specific to families of children with autism.

Historical perspectives

Turnbull and Turnbull (1986) described eight historical roles that parents of children with disabilities have held. While these roles represent a progression over time, there is considerable overlapping of the roles and their historical time periods. Parents have been viewed as: (1) the source of the problem, (2) organization members, (3) service developers, (4) recipients of professional decisions, (5) learners and teachers, (6) political advocates, (7) educational decision makers, and (8) family members. The authors suggested that the last role is perhaps the most important, because successful family life requires that the needs of all family members, including the parents, must be met.

According to Paul and Beckman-Bell (1981), research on families of children with disabilities has historically emphasized the parents' impact on the child's behavior, rather than the impact of the child with special needs on the parents. More recently, however, the perspective of the parents and other family members has been considered.

McClellan (1990) observed that the early literature on families of children with disabilities tended to assume that pathology in these families was almost inevitable. In general, this literature has focused on the significant costs to the well-being of the parents as individuals, and to the family as a whole. However, more recent studies have indicated that there is much variability in the way families respond to the presence of a member with a disability. Caution must be exercised to ensure that there is a balance between outlining the potential stressors faced by families, and delineating coping strategies and other factors, which might help to mediate stress. The literature on stress in families of children with disabilities will be reviewed in the following section.

Stress in Families of Children with Disabilities

Stress was defined by Beckman-Bell (1981) as "a set of circumstances that requires change in the individual's ongoing life pattern" (p.46). Donovan (1988) defined stress as " the individual's response to lifestrains, demanding events, or crises consisting of a pattern of physiological and psychological reactions that can be both immediate and delayed" (p.502).

Kazak and Marvin (1984) supported the generally accepted notion that families of children with disabilities typically experience more stress than do other families, with the mother typically being most directly affected by stressors.

Reddon (1989) and McClellan (1990) both provided comprehensive reviews of the literature on stress and coping in families of children with disabilities. Reddon (1989) stated that, despite improved service provision, many families of children with disabilities continue to experience varying degrees of stress. Other families of children with special needs seem to be functioning reasonably well, despite the presence of numerous stressors. Reddon suggested that a complex array of variables, which can potentially affect the experience of stress in these families, must be considered. These factors may include: (1) child-related variables, such as birth-order, gender, age and type of handicap; (2) demographic variables, such as socioeconomic status, parental age, family size and family composition; and (3) parent-related variables, such as cognitive variables, personality variables and coping strategies.

McClellan (1990) reviewed the literature on the effects of parenting children with special needs pertaining to mother-father differences, marital adjustment and parent-child interactions. Generally, mothers and fathers tend to be affected differently by the presence of a child with disabilities, with the mother often assuming most of the child-related stress. Marital satisfaction and stability may be affected by the presence of the child with disabilities, but other factors, such as the characteristics of the parents and the child, and the strength of the marital bond must be considered. Stress may also impact on the relationship between the parent and child. The effect of child-related variables, such as gender, residence, age, difficulty of care and diagnostic category, must be considered when evaluating the parenting stress related to caring for children with disabilities. For example, Beckman (1983) found that child-related characteristics, such as unusual caregiving demands, reduced social responsiveness, more difficult temperaments and repetitive behavior patterns, were associated with maternal reports of stress.

Having a child with a disability does not necessarily predispose a family to the experience of stress. Reddon (1989) stated that, while some families of children with disabilities do experience significant levels of stress, other families appear to be functioning effectively. Our attention now turns to a discussion of coping strategies, which are used by families of children with disabilities to mediate the presence of stressors in their lives.

Coping in Families of Children with Disabilities

A coping strategy may be any method a family uses to help the members to adapt and function in response to stress. Pearlin and Schooler (1978) described three general categories of coping strategies that may be used by families: (1) changing the stressful experience, (2) controlling the meaning of the stressful experience, and (3) controlling the stress itself.

McCubbin and Patterson (1981) differentiated between internal and external coping strategies. Internal coping strategies involve changing one's thinking in order to view a situation as being less stressful, while external coping involves using outside resources to reduce stress. Examples of internal coping strategies,identified by Olson, McCubbin, Barnes, Larsen, Muxen and Wilson (1983), included: (1) ignoring the problem (passive appraisal), (2) changing one's thinking about the problem (cognitive reframing), and drawing on one's spiritual beliefs (spiritual support). Examples of external coping strategies, identified by the same authors, included: (1) relying on help from agencies and professionals (formal support), and (2) relying on help form family and friends (informal or social support).

Unger and Powell (1980) suggested that there appears to be a strong relationship between a family's social support network and it's adaptation to stress. Social support networks may function to meet the following three areas of need for families of children with disabilities: (1) instrumental support - provision of goods and services to reduce financial needs, (2) emotional support - communication that an individual is loved, valued and needed, and (c) referral and information - provision of information to assist in locating other sources of help.

Kazak and Marvin (1984) found that families of children with disabilities tend to have smaller social support networks. Social support networks were also more dense, that is the members of the support system tended to know and interact with one another. The authors stressed that families do have successful coping strategies and should be viewed in terms of strengths and existing patterns of adaptation.

Crnic, Friedrich and Greenburg (1983) reviewed the research on adaptation of families of children with mental handicaps, concluding that the results of studies were generally inconsistent, contradictory and tended to anticipate pathology. The authors viewed these shortcomings as the result of methodological inadequacies, a narrow focus on uni-dimensional rather than multi-dimensional variables, and a failure to consider a longitudinal perspective of families over time. Family systems theory, which has addressed some of these shortcomings by taking a broader viewpoint of the family, will now be discussed.

Family Systems Theory

Seligman (1991) discussed the family of a member with a disability in terms of family systems theory. He stated that since the family is an interacting unit, what affects one family member affects all of the family members, as well as their relationships with one another.

Both Reddon (1989) and McClellan (1990) suggested the need to adopt a multi-variate approach to studying families of children with disabilities. Reddon, in particular, stressed the need to adopt a family systems perspective and to consider the stresses facing the family throughout it's developmental history. Hill's ABCX family crisis framework (Hill, 1949) and the Double ABCX Model of Family Adjustment and Adaptation (McCubbin & McCubbin, 1987; Patterson & McCubbin, 1983) are two examples of attempts to study the family from a family systems perspective.

In the T-Double ABCX model, for example, the AA factor refers to the accumulation or "pile-up" of stressors, both those related to the child, and those resulting from general family living. The BB factor refers to family resources, or factors which help the family function in the presence of stress. The CC factor refers to situational appraisal, or the degree to which the family views the situation as a threat. The PSC factor refers to the family's problems solving skills and coping strategies, and the T factor refers to the family type. Finally, the XX factor refers to family adaptation, or the family's ability to maintain a balance between the stresses and demands facing it, and it's resources and coping abilities.

The Double ABCX model is useful because it explains the variability in adaptation observed in families of children with disabilities. It considers a variety of factors which may either contribute to or mediate the stress experienced by families. It can be used to predict which families are likely to experience stress and which families are likely to cope effectively.

Another family systems framework which applies to children with disabilities and their families was discussed by Turnbull and Turnbull (1986). Four major concepts were discussed: (1) family resources, (2) family interaction, (3) family functions, and (4) family life cycles. This framework includes some of the same factors as the T-Double ABCX model, such as family resources and the adaptation of families over time. It also discusses some additional concepts not included in the Double ABCX model, such as family interactions and family functions.

In the Turnbull model, family resources are defined as the unique characteristics which describe the family, including membership characteristics, personal characteristics of individual family members and the characteristics of the child with disabilities. This is similar to the BB factor in the Double ABCX model, but may also encompass aspects of the family type or T factor.

Another different aspect of family functioning considered by Turnbull and Turnbull (1986) is family interaction, the relationships between family members and subsystems on a daily basis. The authors identified four family subsystems, which may be present: (1) the marital subsystem, (2) the parental subsystem, (3) the sibling subsystem, and (4) extra-familial subsystems. The needs of each of these subsystems must be addressed. A change in any one of these subsystems may be expected to affect the other subsystems.

Two components of family interaction which were considered by Turnbull and Turnbull (1986) are cohesion and adaptability. Cohesive, or well-functioning families maintain a balance between the two extremes of enmeshment and disengagement. An enmeshed family has weak boundaries between subsystems and is often over-protective and over-involved, while a disengaged family has rigid boundaries between subsystems, and is often minimally involved (Minuchin, 1974: Seligman, 1991). Adaptable families are readily able to change when confronted with a difficult situation. Other families may be either chaotic or rigid, and thus not be able to adapt easily.

The Turnbull model also considers the various family functions that may be affected by having a child with disabilities in the family. The authors identify seven functions, which must be addressed by families, including: (1) economic needs, (2) domestic/health care needs, (3) recreation needs, (4) socialization needs, (5) affection needs, (6) self-identity needs, and (7) educational / vocational needs. The presence of a child with disabilities may affect the family's ability to meet these needs in a negative, positive or neutral way depending on the situation.

The T-Double ABCX model and the Turnbull model both emphasize the importance of considering the family's adaptation to the child with disabilities over time. Family life cycles refer to the normal developmental stages through which families progress, including marriage, child-birth and rearing, the school years, adolescence and the departure of older children from the home. As will be discussed in the following section, the a family's progression through the various life cycle may be affected by the presence of a child with disabilities.

Family Life Cycles

Simeonsson and Simeonsson (1981) have suggested a developmental approach, which focuses on the needs of families at various stages of their development. Two elements of this approach particularly relevant to children with disabilities and their families are the successful resolution of developmental tasks and developmental stages. Developmental tasks must be mastered by the family before they can proceed to a further stage of development. In addition to the tasks faced by other families, families of children with disabilities must also face other tasks, such as assisting the child with therapy and programs, dealing with added stress and managing additional financial demands. Many of these children do not reach developmental milestones at the usual times. Farber (1959) described the life cycle of the family and suggested that the presence of a child with disabilities may contribute to an arrest in that life cycle, perhaps because normal developmental milestones are not reached.

Turnbull and Turnbull (1986) identified four major life cycle stages through which all families, including those of individuals with disabilities, must pass. Helping professionals must develop sensitivity to the differing needs of families during each of these life cycle stages, which include: (1) birth and early childhood, (2) elementary school years, (3) adolescence and (4) young adulthood.

At birth or during early childhood, an important issue for parents is that of dealing emotionally with the initial diagnosis. Several "grief models" have been proposed, which theorize about the various emotional stages through which parents may pass, in order to come to terms with the loss of their "perfect" child (Bristor, 1984; Fortier & Wanlass, 1984). However, other authors (Allen and Allfleck, 1984; Blacher, 1984) caution against the application of stage theories to families of children with disabilities.

During the elementary school years, parents of children with disabilities may experience a period of relative calm, especially if their child is well-served in an appropriate educational program. However, as children with disabilities grow older and reach adolescence and adulthood, a balance must be found between the parent's needs for protection and shelter of the person with disabilities, and the individual's need for independence and freedom of choice, especially in areas such as social relationships, sexuality, residential placement, and employment.

Turnbull and Turnbull (1986) listed some of the important issues of adolescents with disabilities as: (1) emerging sexuality, (2) developing a peer group, (3) social stigma, and (4) increasing physical care needs. These issues must all be addressed at the same time parents may be facing their own mid-life issues. Parents may begin to be more anxiously concerned about the future. Pearlman and Scott (1981) stated that planning for the future involves a great deal of uncertainty, because families must make guesses based on both the past and the future. An inadequate question is, "What will happen to my child as an adult?". A more productive question, according to Pearlman and Scott, would be "How can I prepare my child for adulthood?" The authors have discussed two general areas of preparation that families need to consider: (1) practical or financial preparation, such as vocational training, residential accommodation and long-term financial planning; and (2) social preparation, such as social skills training and opportunities to form friendships. Adolescent and adult issues, as they relate more specifically to individuals with autism, will be explored in greater detail in a later section.

While the previous sections have reviewed the research and theories regarding families of children with disabilities, it is also important to consider the experiences of the family members themselves. The following section will review some of the personal accounts written by parents of children with disabilities, as well as the results of qualitative studies that have attempted to understand the experience of parenting children with special needs.

Parental Experiences

Taylor (1988) advocated the use of descriptive data and qualitative methods to understand the experiences of parents of children with disabilities. This material can be used to complement data from empirical research to help us understand the meaning of the experiences in the lives of parents. Several authors have presented detailed personal accounts of parents of children with disabilities, and/or results of qualitative research based on interview data.

Pivato (1990) has compiled a collection of poignantly written personal accounts by parents and siblings of children with severe disabilities. These stories give the reader a glimpse of what life must be like for these family members. Pivato stated that attempts to provide a normalized home environment for children with severe disabilities, may have caused a de-normalization of the family, by limiting the opportunities of other family members. Greater emphasis must therefore be placed on providing adequate support to these families to ensure that the needs of all members are met.

Paul and Beckman-Bell (1981) included written accounts of personal experiences of several parents of children with various disabilities. These parent accounts are presented with little editing and few comments, and are arranged into six sections: (1) impact on self, (2) impact on marriage, (3) impact on relationships with the larger social community, (4) interactions with schools and school officials, (5) interactions with professionals outside the school system, and (6) parent views of normalization and de-institutionalization.

Hannam (1988), himself the parent of a child with Down Syndrome, conducted a qualitative study, based on interviews with families of children with mental handicaps. He described his own personal experiences, and also discussed ten themes, based on interview data with other families. These ten themes include: (1) how the parents were told, (2) the effect on family life, (3) parents and other people, (4) two women coping on their own, (5) brothers and sisters, (6) bringing up the child with a disability, (7) the next child, (8) the child grows up, (9) the school and social education centre, and (10) the future. Regarding the effects on families, Hannam stated that families cope differently with disasters, and identified two extreme types of families: (1) the "solids", who have adequate personal resources for coping and can rely on family members to help, and (2) the "brittles", who fall apart and require considerable support from outside agencies. Most families function somewhere in between these two extreme types. Hannam also discussed some of the problems encountered by families as the child becomes an adolescent, such as dealing with increased physical size, mood swings and emerging sexuality.

Naseef (1989) conducted a qualitative study of successful coping in families of children with different handicapping conditions. The author suggested that his identity as the parent of a child with special needs had facilitated the open and candid responses of his co-researchers. The results indicated that members of these functional families had a broad repertoire of coping strategies, including spousal support, relying on other parents of children with disabilities, and maintaining family stability. As well, parents tended to agree on the strategies that they used to cope, and siblings felt free to discuss their brother or sister's disability. The author also noted that families had learned how to cope successfully over a period of years. They appreciated professionals who were empathetic, involved siblings and had developed support groups for parents.

A series of Masters' theses have also used qualitative research methods to explore the experiences of parents of a variety of different handicapping conditions. Morgan (1987) studied the experiences of mothers of adolescents with hearing impairments. She identified the following six themes: (1) personal development, including the assumption of new roles, improved decision making ability and career development; (2) relationship with the child,including viewing the child as an individual, emotional reactions regarding the child and the issue of separation; (3) parent-professional relationships,including both negative and positive experiences; (4) educational program considerations, including the availability of program alternatives, mainstreaming, and the quality of education; (5) communication,including the mode of communication and the fluency of communication; and (6) support, including assistance from the spouse, family members, support groups, friends and professionals.

Hancock (1988) described the experience of parenting a child with visual impairments. The three dominant themes which emerged were: (1) emotional issues, especially those pertaining to the initial diagnosis of the visual impairment; (2) coping strategies, including those related to the mother's personality, the child's attitude toward the disability, the child's accomplishments and the mother's support networks; and (3) problems and concerns, including relationships with professionals, educational issues, other people's attitudes and time involvements.

Waggoner (1988) discussed the concerns of families of children with learning disabilities, discovering seven main themes: (1) parental involvement in the child's education as teachers, advocates and stimulators of the system; (2) parents in relationship with the school, including both negative and positive experiences; (3) support for the parents from spouses, family members, friends and professionals; (4) social concerns for the child, including concerns about low self-esteem, embarrassment and frequent school changes; (5) emotional strains of parenting, including personal stress and dealing with the child's frustrations; and (7) family life, including time involvement and reactions of siblings.

Finally, Adams (1987) documented the experiences of families of children labelled as "dependent handicapped". His five dominant themes included: (1) pre-dominant influences on the mother's life-world, including physical and mental strain, life restrictions and personal development; (2) feelings about the assistance received from agencies and professionals, including frustration over inadequate service provision, and gratitude toward helpful professionals; (3) concerns about the future, including the availability of services and the child's adaptation to those services; (4) ongoing stress and anxiety, involving lack of support, and caregiving demands; and (5) influence of the child on other family members, including the effect on fathers and siblings. No similar study has been conducted with families of individuals with autism.

In summary, the general literature on families of children with disabilities has been reviewed with respect to historical perspectives, stress and coping, family systems theory, family life cycles and parental experiences. The literature specific to families of children with autism will now be reviewed in a similar manner.

Families of Children with Autism

Historical Perspective

Parents of children with autism have assumed two major historical roles. Psychoanalysts have viewed them as the cause of the child's autism, based on a psychogenic viewpoint. Alternatively, behaviorists, adopting a biogenic theory of autism, have viewed parents as therapists, responsible for conducting intensive behavioral programs with their children. Only recently have parents of children with autism come to be viewed primarily as family members, who are affected by the stress of raising children with pervasive developmental and behavioral needs.

According to Bristol and Wiergerink (1979), early research on children with autism and their families consisted primarily of measuring the personality characteristics and attitudes of parents, in order to refute or support the psychogenic theory. The parent's role varied depending on how much they were thought to be the cause of the child's autism.

Cantwell and Baker (1984) provide an extensive review of the literature on families of children and adolescents with autism. Regarding the family's role as a possible etiologic agent of autism, the authors found that three aspects of family functioning had primarily been studied: (1) severe early stress, (2) deviant parental personality, and (3) deviant parent-child interactions. Most of the studies implicating the family as the cause of autism had been written prior to 1970, while more recent studies have not supported family factors as the cause of autism.

Unfortunately, several authors have continued to study parental characteristics from a psychoanalytical perspective. For example, Narayan, Moyes and Wolff (1990), found a high incidence of "schizoid personality" in their sample of parents of 21 children with autism. Their research seems to have involved subjective clinical judgement, and considers only a very limited range of literature on the topic of parental characteristics of children with autism.

Whelan and Hudson (1987) wrote about the "plight" of the family of the child with autism. While not actually blaming the parents as the cause of their children's autism, these authors presented two case histories, which they feel illustrate how parents internalize the child's autism, and begin to live in a distorted reality. The authors do not cite any of the recent research on family systems theory, fail to mention any type of positive adaptation on the part of the parents, and reference articles written primarily in the 1960's and 1970's. Even in recent times, parents of children with autism are sometimes viewed from a standpoint of assumed parental pathology.

Donnelan and Mirenda (1984) discussed some of the historical roots of negative parent-professional relationships, as they relate to individuals with autism. Although parents may not currently be viewed as the cause of the problem, several negative assumptions about families of children with autism are still made by professionals. For example, the family is seen to be at fault if interactions are not productive, or if the needs of the child with autism are not given priority over the needs of other family members. Based on these assumptions, parents may be negatively labelled as unco-operative, unrealistic, or over-protective.

Recently, parents have assumed a more therapeutic role in the treatment of autism, due to three major trends: (1) lack of evidence for a psychogenic basis of autism, (2) evidence for a biological basis for autism, and (3) the success of behavioral intervention (Bristol & Wiegerink, 1979). For example, Kozloff (1984) and Groden & Baron (1988) recommend the use of behavioral training to assist parents in teaching their children with autism.

According to Bristol (1984), a biological basis for autism often suggests that parents should be involved in teaching their children with autism. However, the author recognizes the limitations of this approach, if the broader needs of the family are not considered. She prefers to adopt an ecological family systems approach, which sees the goal of intervention as not only improving the child's behavior, but also facilitating the adaptation of the family as a whole. However, she cautions that the family should not once again be placed in the role of the patient. While parents may assume the roles of learner, teacher and team members with their children, they must primarily be viewed as parents and as people (Bristol & Wiegerink, 1979). Marcus (1977) further suggests that a meaningful way to study families of children with autism is to examine the stresses with which they are faced, and the coping strategies they employ.

Stress in Families of Children with Autism

Most studies have documented the presence of stress in families of children with autism. Bristol and Schopler (1983) suggested that parents of children with autism may have a characteristic profile of stress. Holroyd and McArthur (1976) investigated the stress experienced by parents of children with autism and Down Syndrome. They found that mothers of children with autism reported more difficulty in personal and family functioning than did mothers of children with Down Syndrome. Similarly, Donovan (1988) compared maternal perceptions of stress in families of adolescents with autism and mental retardation. Mothers of adolescents with autism reported more child-related stress than did mothers of adolescents with mental retardation.

DeMyer (1979) found that the stresses facing families of children with autism over a long period of time had significant effects on the parents as individuals, on the marriage, and on the other children. Mothers of children with autism were the most directly affected by their children's problems, with about one third reporting reactive depression regarding their child. All thirty-three mothers of children with autism reported increased physical and psychological tension. Other reported effects of the child's symptoms on the mothers included guilt, doubts about mothering abilities, anger, hurt, physical exhaustion, feelings of being trapped, and fear of the next pregnancy.

Fathers were also affected by their child with autism although, for many, an important effect was their reaction to the mother's depression and preoccupation with the child's autism. The stress of parenting a child with autism seemed to have strengthened some marriages, but weakened others. Many mothers wanted more support from their husbands in dealing with their child's disability, while many fathers found it difficult to deal with their wives' emotional pain. Siblings reacted to their brother or sister's autism by becoming more helpful, although some also felt that they had been neglected by their parents because more time was devoted to the child with autism.

Bristol (1979) found that mothers of older children with autism reported more stress and coping difficulties than did mothers of younger children. Autistic boys, and children who were more dependent, also had a more adverse effect on their parents. The author concluded that child-related characteristics play a significant role in the stress and coping responses of families of children with autism.

Bristol (1984) cited several risk factors, common to families of children with autism, which may increase stress. These include the ambiguity, severity and duration of the stressor, and the lack of congruence with norms in the community.

Morgan (1988) reviewed the literature on the effects of the child with autism on his or her parents, siblings and the family as a whole. Regarding the psychological functioning of the parents, he concluded that while parents are faced with numerous situational stresses pertaining to raising the child with autism, there is not typically a high incidence of psychological problems in these parents. The research on the effect of the child with autism on the marital relationship is inconclusive. In some cases, having a child with autism draws a couple closer together, while in other cases, the presence of a child with autism will contribute to marital problems, separation and divorce. Siblings may also be affected by the presence of their brother or sister with autism. However, a wide range of both negative and positive reactions have been observed.

Bebko, Konstantareas, and Springer (1987) attempted to determine which symptoms of autism were found to be the most stressful for parents. These results were then compared with professional estimates regarding the degree of stress faced by each family. Cognitive impairment, communication impairments and difficulties with social relationships were the characteristics judged by parents to be the most stressful. Professionals tended to over-estimate parental stress, when compared to the stress level reported by the families themselves.

Konstantareas and Homatidis (1989) attempted to determine the relationship between child symptom severity and stress in parents of children with autism. Both mothers and fathers rated the child as more severely autistic if he or she was lower functioning, self-abusive, hyperactive, had seizures, looked unusual or did not talk. While the best predictor of stress for both parents was self-abusive behaviors, mothers also found that hyperactivity and increased age of the children produced stress. Mothers of children with autism reported more aggravations than did parents of normally-developing children, and required more spousal support.

Wolf, Noh, Fisman and Speechley (1989) suggested that parenting a child with autism would likely produce stress for the family, because of the magnitude, intensity, duration and unpredictability of the situation. When compared to parents of children with Down Syndrome, and children without disabilities, both mothers and fathers of children with autism reported significantly more stress. Greater risk of depression was found for mothers, but not for fathers, of children with autism, when compared to parents of children without disabilities. Increased parenting stress was found to be associated with dysphoria in this study. However, social support was found to moderate stress for both mothers and fathers of children with autism.

Milgram and Atzil (1988) investigated subjective indices of stress in mothers and fathers of 23 children with autism. The indices studied included overall difficulty in raising a child with autism, the share of parenting burden, the fairness of this share, and the parents' satisfaction. For fathers, the best predictor of life satisfaction was the absolute parenting burden, that is, the number of tasks they were required to do. For mothers, the best predictor of life satisfaction was the relative parenting burden, that is, the mothers' perceived fairness of their share of the responsibilities, when compared to their spouse.

In a study by Harris, Handleman and Palmer (1985), mothers, fathers, grandmothers and grandfathers of 19 children with autism filled out questionnaires to determine their attitudes toward the child with autism, and the impact on the parents' lives. In general, grandparents viewed the child with autism more positively than did the parents. Maternal grandmothers showed the most understanding of the effects of parenting a child with autism, and tended to visit most often.

Factor, Perry and Freeman (1990) investigated the relationship between stress and respite care use in parents of children with autism. Users of respite care tended to be parents of children who were lower functioning and had more behavior problems. Non-users tended to report higher levels of perceived social support, when compared to users of respite care. Further research is needed to explore families' reasons for using or not using respite care.

Prolonged stress in families of children with autism has been associated with "burn-out" (Blackstock, 1981; Sullivan, 1979). Sullivan (1979) defined "burn-out" as "the exhaustion of a person's psychological and/or physical resources, usually after long and intense caring" (p.113). She stated that "burn-out" can potentially occur in individuals who provide continual daily care to children and adults with autism. Some of the reasons for "burn-out" in parents of children with autism are lack of respite care, inadequate financial support, feelings of hopelessness, and lack of adequate coping skills. She stated that, while "burn-out" may be devastating to everyone concerned, it will ultimately have the greatest detrimental effect directly on the children with autism.

Marcus (1984) differentiated between objective symptoms of "burn-out," such as over-work, irritability, withdrawal and self-medication, and subjective symptoms of "burn-out," such as lowered self-esteem, reduced motivation, depression and isolation. He listed "burn-out" factors in families of children with autism as: (1)

unrelieved care of raising a child with severe disabilities, (2) obtaining diagnosis and appropriate services, (3) loneliness and isolation, (4) inadequate support services, and (5) neglect of parental needs. Blackstock (1981) gives a list of suggestion for avoiding "burn-out" in parents of children with autism, including learning to relax, engaging in physical activity, and making the most of the present.

Coping in Families of Children with Autism

In order to mediate stress and prevent "burn-out", parents of children with autism have been found to utilize a variety of coping strategies. Bristol (1979) found that mothers of children with autism, who reported adequate amounts of informal support tended to cope more effectively. Mothers of children with autism were divided into low and high stress groups. The mothers in the low stress group tended to have children with less difficult behavior problems. They also had better access to services and more informal support from spouses, immediate family and friends. When compared with a norm group, families of children with autism tended to have a higher religious and moral emphasis, which presumably helped them to attach meaning and purpose to their experience of having a child with autism. They also tended to have reduced participation in recreational and social activities.

Bristol (1979) identified the coping strategies that mothers of children with autism ranked most helpful in dealing with stress as: (1) helping the child, (2) controlling the meaning of the child's autism, (3) belief in God, (4) seeking spousal support, (5) focusing on the family, and (6) self-development. The least helpful coping strategies were identified as: (1) eating, (2) getting angry, (3) entertaining friends at home, and (4) explaining their situation to others. The author explains that coping with autism is a very individual process that depends on the particular family, child and situation involved.

Bristol (1987) found that, for mothers of children with autism, both the perceived level of informal support and the use of active coping patterns were associated with better adaptation. Maternal beliefs and resources influenced adaptation more than did the severity of the child's autism. Bristol concluded that studying successful family adaptation is more beneficial than studying family pathology.

Powers (1989) suggested three essential ingredients to successful coping with autism: (1) positive parental attitudes, such as love and acceptance, holding realistic expectations and fostering independence; (2) open communication; and (3) ssupportboth from the spouse and from other sources. Three common traps that parents of children with autism should try to avoid are over-involvement, over-protection and rejection.

Harris, Gill and Alessandri (1991) have discussed both adaptive and maladaptive coping responses exhibited by parents of children with autism. Both instrumental and palliative coping strategies can aide the family in dealing the stress of raising the child with autism. Instrumental coping strategies attempt to directly change people or things in the child's environment, while palliative coping strategies attempt to minimize stress internally. Support systems and individual characteristics of the parents may also affect their ability to cope. A set of parental characteristics which has recently been researched in regard to successful coping includes control, commitment and challenge, which together comprise the trait of "hardiness" (Ganellan & Blaney,1984, cited in Harris, Gill & Alessandri, 1991). Hardiness enables an individual to remain emotionally and physically healthy, even in the face of high degrees of stress, and was found to be a strong predictor of successful adaptation to the stress of parenting a child with autism (Gill,1987, cited in Harris, Gill & Alessandri, 1991).

Marcus (1984) listed some natural coping strategies for parents of children with autism, including writing about personal experiences, participating in parent advocacy groups, magnifying the child's accomplishments, and "dropping out," or not centering their lives around the child with autism. He also suggested an intervention program for working with these parents, which involves stress analysis, stress awareness and stress modification.

In order to facilitate successful coping in parents of children with autism, Morgan (1983) stated that special counseling is required, when an initial diagnosis of autism is made. The initial counselling should convey to the parents a realistic understanding of the disorder, should present information about the child's level of functioning, and should project long-range expectations. Parents should be assured that they are not responsible for having caused autism in their child, and should be provided with information about effective methods of treatment.

Autism and Family Systems Theory

Several authors have advocated a family systems approach to the treatment of children with autism and their families. Harris (1984) combined a family systems approach with behavioral management strategies. After several years of experience working with families of children with autism, the author found that behavioral management skills that parents had acquired during parent training sessions were not being maintained. Therefore, rather than focus entirely on parent training, the author broadened her viewpoint to include a family systems approach, as well as a consideration of family life cycles.

Harris (1984) suggested that there are three broad categories of families who will benefit from a combination of a behavioral training and family systems intervention: (1) families who would not be candidates for family therapy, if they had not had a child with autism, (2) families who, even without a child with autism, might have had some marginal problems, and (3) families who have some form of dysfunction not directly related to having a child with autism.

Families can also be assessed using a family systems approach. Harris (1988) suggested that the clinician must assess: (1) the functioning of the individual child and family members, (2) the interaction between the family and the child, (3) the functioning of the family system as a whole, and (4) the effectiveness of the family's social support network. This can be accomplished through interviewing the family, observing the child in various environments, and having the family complete various pencil and paper tests.

Haefele and Henggeler (1983) presented autism from a family-ecological systems perspective. They stated that the child with autism is part of several different systems, including the family system, the medical system and the educational system. There are bi-directional or reciprocal influences among the members of each of these systems, which include the child, the family, the medical profession, and the school. Professionals in the medical and educational systems can interact with families in ways that either increase or decrease the family's stress.

Morgan (1988) applied several principles of family systems theory to children with autism and their families. First, the child is part of many systems, which interact to affect behavior. Second, interaction is bi-directional, with the child's behavior affecting the parents and vice versa. Third, the family is seen as an interacting unit, with all of the members being interdependent.

Konstantareas (1991) used a variation of Hill's ABCX model of family adaptation to examine the impact of children with autism, learning disabilities and developmental delays on their families. For Factor A, three characteristics were examined as stressors: (1) disorder related characteristics, (2) severity related characteristics, and (3) epidemiological characteristics. For Factor B, material resources and psychological supports were considered. For Factor C, self-concept and locus of control were considered as cognitive and belief styles of the parents. The results showed that children with autism were the most stressful for their parents, followed by children with developmental delays and learning disabilities. The type and severity of the disability and other factors such as age, gender, and birth order interacted in a complex manner with resources, supports and parental beliefs. Regarding resources, the authors suggested some factors that have often been overlooked, such as the utilization of available resources and the possibility that resources can be simultaneously supportive and stressful. For example, relief care services may support the family, but may also produce stress because of presence of additional caregivers in the home. Regarding perception of the stressful event, low self-esteem appeared to be associated with having a child with disabilities. Also, mothers who perceived that they had little influence on their child's problems were more stressed.

Konstantareas (1991) suggested several recommendations for improving family systems research involving individuals with autism and their families. These suggestions included: (1) larger research designs to allow cross-referencing of data; (2) expansion of conceptual models to include broader coverage; (3) broadening of target populations to include extended family members; (4) systematic comparison across disabilities, employing better matching procedures; (5) consideration of successful adaptation; and (6) a longitudinal perspective across the family's life cycle. Research on family life cycles will be presented in the following section.

Autism and Family life Cycles

Several authors have discussed autism as it relates to family life cycles. Powers (1989) indicated that the needs of families of children with autism may change over time. During the child's early years, the family will have to deal with their emotional reactions to the child's diagnosis, while during the school years the family may be in danger of becoming rigid and stagnated because there is little role flexibility. During adolescence, parents may shift their focus to more long-term issues, such as independence, residential options and vocational training.

Harris, Gill and Alessandri (1991) discussed the impact of the child with autism on the family during five different stages of the life cycle: (1) infancy, (2) early childhood, (3) middle childhood, (4) adolescence, and (5) adulthood. During infancy, the parents major difficulty is adjusting to the crisis of diagnosis. Accepting a diagnosis of autism may be especially problematic for the family, because of the child's relatively normal appearance and early skill development. The diagnosis may seem even more ambiguous because of the uneven skill development of many children with autism, who may give the impression of functioning at a much higher level in some areas. During early childhood, a critical issue for parents of children with autism is behavior management. Parent training in behavioral principles is especially important at this stage. Finding an appropriate educational program is also an essential component of intervention. Middle childhood may make parents more aware of the widening gap between their child with autism and their normally developing peers. During this time, parents may have difficulty completing some of their own developmental tasks, such as career development. During adolescence, parents can no longer escape the reality that autism is a permanent disability. Increased physical size, sexual development, and reduced community acceptance may make parenting the adolescent with autism even more stressful. Adulthood in the individual with autism makes parents increasingly aware of the issues of separation, independence and parental mortality. Future concerns, such as alternate residential placement, vocational training and estate planning, become paramount.

Harris and Powers (1984) highlighted several themes, which emerge during the family's life cycle, including (1) change in role definitions as children grow older, and (2) the impact of separation on the parent and child. In the case of the adolescent or adult with autism, the parents may avoid or delay the separation process, resulting in a continuation of the caretaking role, limitations of their own activities, and increased dependence of the child on the parents.

Ackerley (1984) discussed the developmental changes in families of children with autism from a parent's perspective. Regardless, of the family's stage of development, she stated three factors must be considered: (1) the position of the child with autism in the family, (2) the nature of the family, and (3) the effect of the child with autism on the marriage. Many families of children with autism develop what the author terms an "autistic filter", which begins to color all of their experiences and prevents them from seeing that families of children without autism also experience pain and sorrow.

Autism and Parental Experiences

Several accounts of personal experience have been written by parents of children with autism (Beavers,1982; Lovell, 1978; Morphett, 1986; Park, 1982). Park (1982) described the first eight years of her daughter's life, with an epilogue fifteen years later. The book deals primarily with her daughter's progress, but also touches on family aspects and relationships with professionals.

Morphett (1986) described the gradual improvement in her son with autism, and affirmed the value of her reliance on motherly instincts and intuition.

Marmura (1980) described her experiences as the mother of a child with autism. She claimed that the strain of raising a child with autism is not so much in the day to day care of the child , but in maintaining the right priorities with respect to the child. She stated that the parents' first priority should be to love and support the child with autism, and to foster the development of meaningful relationships. The teaching of specific skills should be secondary.

Gilliam's (1981) book contained an anonymous chapter outlining some parental concerns regarding the high functioning individual with autism, whose needs have largely been ignored in the literature. Concerns, such as handling obsessions with favorite topics, and choosing whether or not to mainstream are mentioned.

Tommosone and Tommosone (1989) wrote as parents of a child with autism and another child with developmental disabilities. They stated that being the parents of a child with autism helped them to appreciate life's special moments, enabled them to give of themselves and changed their value system. They challenge parents to see beyond the autism to the child underneath.

While these parental accounts help us to understand the unique experiences of individual parents of children with autism, they cannot be generalized, because they do not explore the commonality of experience. Only one study (Dudziak, 1982), has used qualitative research methods to explore the feelings and experiences of five mothers of children with autism. The results were presented chronologically in the form of themes experienced during the time of birth, infancy and early childhood, diagnosis and initial treatment, later childhood, and adolescence.

The mother's experiences during pregnancy and birth varied. However, several of the mothers reported being concerned about their babies almost immediately after birth. The babies tended to be excessively "fussy", and were "rigid" when picked up.

Some of the issues raised during infancy and early childhood included illness of the child, cessation of vocalizations, sleep disturbances, unusual responses to sound, self-stimulatory behavior, resistance to change, destructive behavior and temper tantrums. All of the mothers reported that they felt isolated and lacked support during this time.

During diagnosis and initial treatment, four of the five mothers reported having negative experiences with their pediatricians. In particular, they felt that the pediatricians had not listened to their concerns and had not believed them. Consequently, the mothers had begun a long process of "doctor shopping". One mother underwent years of psychotherapy before actually finding out that her child was autistic. Another child was not diagnosed until school age. Reaction to the initial diagnosis varied, with some parents experiencing shock and denial, and others experiencing relief. Parents wished that doctors were not so reluctant to label a child as autistic, because only then could services be obtained.

When the child reached school age, the parents spent a great deal of time finding appropriate educational programs for their children. Some had actually moved in order to be closer to suitable schools. Enrolling the children in school reduced some of the stress on mothers and helped them to be able to pursue other interests. Mothers also received support from other parents and from the teachers at the school. However, they still had to fight for the services that their children required.

Having a child with autism also affected family relationships and social patterns. In the families interviewed, most of the child care duties were performed by the mothers. Finding skilled babysitters was a problem, making it difficult for parents to go out or to take vacations. Meeting the needs of the other children was also a problem. Siblings often had to adjust to living with a brother or sister with autism. The mothers also discussed the lack of community acceptance, especially when the children with autism displayed inappropriate behavior in public. Obtaining health care was also a problem because some doctors would not treat children with behavior problems.

Adolescence, according to Dudziak, enhances the problems faced by parents of children with autism. Programs for adolescents with autism did not exist until very recently, when parents began lobbying for better services. Services for adults with autism, such as group homes and vocational programs, are still lacking. Parents reported that adolescents with autism had difficulty handling social situations, which limited their independence. Parent worried about what would happen to their children when they were no longer available to take care of them.

Dudziak concluded her article with a discussion of implications for the nursing profession in terms of education, research, crisis intervention, parent groups, involvement in the school system and community outreach. Further qualitative research on the experiences of families of children with autism is required, in order to expand our understanding of the meaning of this experience in the lives of parents, and to supplement the information from quantitative research and parental accounts. The following section reviews the literature on autism and adolescence.

Autism and Adolescence

Mesibov (1983) indicated that there is a gap in our understanding of adolescents and adults with autism. Mesibov and Schaffer (1986) stated that when Kanner

(1943) first identified autism as a distinct disorder, little thought was give to the implications of this diagnosis for adolescents and adults. Most older individuals with autism were served in institutional settings, and were simply reclassified as either schizophrenic or mentally retarded. However, because of the improvement in services for children with autism, many older individuals are now being served in community-based settings (Mesibov, 1983), and it has been recognized that the distinct symptoms of autism persist into adolescence and adulthood. Most of our information on autism in adolescence and adulthood is based on two sources: (1) outcome studies, which provide information about the development of adolescents and adults with autism, and (2) parental and professional perspectives of needs, which provide information pertaining to current and future service provision. This review of the literature will examine both of these sources of information, and will examine the needs of adolescents with autism and their families.

Outcome Studies

According to Mesibov (1983), the outcome literature is somewhat encouraging, because it demonstrates improvements with age in activity level, behavior, self-help, communication and social skills. IQ levels tend to remain stable in adolescents with autism, while aggressive or self-abusive behavior may be more difficult to manage, because of increased physical size. However, the author cautions that the reality of life for most older individuals is not as bright, because they often do not improve enough to meet the demands of existing services.

Eisenberg (1956) was one of the first authors to describe the adolescent with autism from a clinical perspective. Sixty-three adolescents with autism were re-evaluated at a mean age of 15 years, at an average of nine years after the initial diagnosis. Approximately one third were described as having developed some degree of social adjustment. Those who had developed speech before the age of five were seen as having a better prognosis. The author also felt that those individuals who had shown the greatest improvements were those who had benefitted from extraordinary efforts on the part of their families and schools.

Brown (1969) discussed the adolescent development of children with infantile psychosis, (probably used as a term for autism at that time). In general, children who had a better presenting picture during early childhood were likely to have a better overall prognosis.

Exceptions to that statement seemed to occur with children who had been given extremely skillful therapeutic intervention during early childhood. The author reported that about one third of the children diagnosed with infantile psychosis functioned fairly well during later childhood and adolescence. Another one third showed some slow progress in sheltered environments, and the remaining third showed little or no progress at all.

Brown (1969) presented clinical case studies, illustrating three typical patterns seen in individuals with infantile psychosis, during adolescence: (1) static development, or little change in adolescence, (2) uneven development during childhood, with gradual deterioration in adolescence, and (3) continued improvement during adolescence. Some factors associated with continued development during adolescence included living at home, attending public school, having a high intelligence quotient, possessing special talents, and having a supportive family.

DeMyer (1979) stated that most people with autism have reached their level of adult functioning by early adolescence, although they may continue to make very slow progress socially and intellectually. A few, who have both favorable biological and social factors, may continue to make intellectual, social and emotional progress into late adolescence and adulthood.

DeMyer (1979) also gave case study examples of high, middle and low functioning individuals with autism. High-functioning adolescents with autism may approach near-normalcy, yet be painfully aware of their social isolation and difference from their peers. They may want to form friendships, but may lack the requisite social understanding. Individuals with autism in the middle range of severity may be much happier, because they are less aware of their own social differences. They are able to develop some functional daily living skills, and co-operate in behavioral management strategies to help them improve. Lower functioning adolescents with autism may make little or no progress. Parents may have to adjust their expectations for achievement and focus on planning for future care.

According to Gillberg (1984), several types of crisis may occur in the adolescent with autism during puberty. The majority of children with autism have an uncomplicated entrance into puberty, with some actually improving. However, other teenagers with autism may experience physical and/or psychiatric problems at this time. Approximately one quarter to one third of children with autism who have not previously had seizures will develop them during adolescence. Also, some children undergo physical changes, which make them look more handicapped (Gillberg,1983, cited in Gillberg 1984). Psychiatric problems may include deviant sexual behavior, inactivity, depression and worsening of the autistic symptoms. Deterioration is thought to occur in about one-third of all children with autism. However, some of these individuals may also improve again during their late twenties and early thirties. Because of the risk of increased problems during puberty, services for adolescents should be planned to avoid any additional stress, such as unnecessary transitions in educational placement.

In a Swedish study (Gillberg & Schaumann, 1981), five cases were presented describing children, who had progressed during childhood, but deteriorated during the onset of puberty. All of these cases showed a marked worsening of the autistic symptoms, which began about the time of puberty and had not improved significantly several years later. Three of these children were girls, which may be of importance since the incidence of autism is generally much higher in boys than girls. The authors concluded that children with autism who experience a deterioration during puberty might form a sub-group of the disorder, which could be studied in future research.

Gillberg and Steffenberg (1987) followed 46 cases of children with autism through puberty. Slightly over half of these cases showed either temporary or continuing deterioration during the onset of puberty. Temporary deterioration consisted of increased hyperactivity, aggressiveness, destructiveness and rigidity. Those with continuing deterioration also developed inertia, and lost some of their previous intellectual and communication skills. Deterioration appeared to be more common in girls than in boys. By age 16 to 23, thirty-five percent had developed seizures, most of which began around the time of puberty. Physical changes, which made the individual appear more obviously handicapped, occurred in at least one third of the cases. A particularly poor outcome was associated with the presence of chromosomal abnormalities. There was also an increase in the use of medication in the post-pubertal subjects, with approximately one-quarter taking medication before puberty, as compared to three-quarters taking medication after puberty.

Rumsey, Rapoport and Sceery (1985) extended follow-up data into adulthood by investigating psychiatric, social and behavioral outcomes in 14 men with autism. Residual social, psychiatric and behavioral symptoms were seen in all of these individuals. Some also continued to exhibit stereotypic movements and concrete thinking. None of the subjects had developed symptoms of schizophrenia, or any other form of adult psychiatric disorder.

Needs of Adolescents with Autism

Mesibov and Schaffer (1986) have stated that adolescents and adults with autism have needs in the same three basic areas as do younger individuals with autism: (1) communication, (2) behavior, and (3) social relationships. They also require specialized medical care, recreational and vocational programming, and residential facilities, and will continue to have a major impact on their families. The authors discussed each of these areas of need individually.

In terms of communication needs, Mesibov and Schaffer (1986) divided older individuals with autism into two categories: (1) those who are non-verbal and must learn to use an alternative mode of communication, and (2) those who are verbal, and must be encouraged to use their speech in more socially meaningful ways. Regarding behavior, the authors stated that generally there is an improvement in behavior as individuals with autism grow older. While aggression and self-abusive behaviors may be seen as more problematic with older individuals with autism, the actual incidence of these behaviors usually decreases in adolescence and adulthood.

However, because of the larger physical size, and greater potential for injury or harm, these behaviors are more difficult to manage in the older person. Regarding social and interpersonal skills, many individuals with autism continue to make improvements into adulthood. While no longer living in their own little worlds, they still will have difficulty with many aspects of social relationships.

Medically, individuals with autism require the same medical care as non-handicapped individuals. However, medical care may be fragmented between different attending physicians and specialists, and may be further complicated by difficulty examining the individual and by impaired communication skills. Many adolescents and adults with autism may also require treatment for epileptic seizures, and/or medication to control problem behaviors. In terms of recreation and leisure activities, adolescents and adults with autism require programs to help them make use of their extra unstructured time and increased physical strength, and to help them fulfil their needs for social interaction.

Dewey (1983) discussed the needs of adolescents with autism from a parental perspective. She stated that what parents of teenagers with autism need most is understanding from others in the community, and practical help to meet the unique needs of their sons or daughters with autism. She discussed five basic needs of the adolescent with autism, including (1) a place to live, (2) bodily nurture, (3) joy in living, (4) self-esteem and acceptance, and (5) freedom from suffering and abuse. These needs are the same as those of any other human being, except that for the adolescent with autism, they may be harder to obtain. Because of their social immaturity, individuals with autism need guidance, training and continued support into adulthood in order to meet these basic needs.

Regarding autism in adolescence, Akerley (1984) stated that often the things that parents fear their children without handicaps will do too soon, they hope that their children with autism will eventually do. Appropriate social outlets and sexual education programs for teenagers with autism must be developed. Regarding leaving home, Ackerley stressed the need for good guardianship and trustee programs, so that adults with autism will be settled before their parents die, and so that brothers and sisters are not obliged to assume responsibility for their care.

Sullivan (1977) edited an article with contributions by several parents about planning for the future of children who are severely handicapped by autism. In particular, the mother of a 21 year old son with autism described her concerns about planning for her "child", who now resides in an adult body. She discussed the emotional and developmental needs of the older individual with autism, noting that parents cannot be expected to provide for these needs forever, yet no appropriate alternate services exist.

Needs of Families of Adolescents with Autism

As the individual with autism develops physical and sexual maturity, the family will face many new stresses. Some of the problems parents face include: (1) dealing with physical and sexual development in a person who remains socially immature, (2) a lack of appropriate educational, vocational and residential facilities, and (3) parents' own physical and emotional exhaustion (DeMyer, 1979). Bristol and Schopler (1983) caution that "when discussing stress related to having an adolescent autistic child, it is important that a distinction be made between the problems of adolescence per se and the problems that are caused by lack of appropriate services" (p.260).

DeMyer and Goldberg (1983) presented results of a pilot survey of the needs of families of adolescents with autism. The results of this survey were divided into two sections: (1) the adverse effects of living with a family member who has autism, and (2) the needs of family members. Adverse effects of living with an adolescent with autism were reported in eleven major aspects of family life, including: (1) family recreation, (2) finances, (3) emotional and mental health of the parents, (4) physical health of the parents, (5) housekeeping, (6) meeting the needs of brothers and sisters, (7) relations with friends and neighbors, (8) sibling relations, (9) marital relationships, (10) personal development of each family member, and (11) relations with relatives.

Regarding family recreation, many families were not able to participate together in recreational activities because of the child's behavior. Family members were characterized as being fatigued and burned out.

Regarding finances, it was often impossible for mothers to hold regular jobs due to child-care difficulties and the excessive time-off required to meet the needs of their adolescents with autism. Consequently, family finances were reduced.

In terms of the emotional and mental heath of the parents, many of the parents of adolescents with autism experienced increased anxiety, stress and depression, related to caring for the individual with autism. Some had also experienced positive growth in their lives.

Being the parents of a child with autism had helped them to be more empathetic and had given them purpose for their lives. In terms of physical health, many parent felt excessively fatigued, and worried about the future of their adolescent with autism, in the event that they themselves became sick and could no longer provide care.

Many of the parents also reported difficulties in keeping the house clean, partly because of the additional disorder created by the individual with autism, and partly because other duties, such as behavior management, transportation and attending meetings, occupied their time.

Several families felt that siblings had been negatively affected by the presence of the child with autism, because of the reduced parental time and attention that was available for them. Siblings were also negatively affected by having to assume responsibility for some aspects of the care of their brother or sister with autism. Sometimes, having an adolescent with autism in the home was associated with increased fighting and bickering among siblings. Positive effects, such as the development of empathy and understanding, were also noted in siblings.

Having an adolescent with autism had also resulted in reduced social contact with friends and neighbors for many of the families. It was often difficult to entertain company, or to arrange respite care in order to go out socially. Some friends and neighbours also gave unsolicited advice or rejected the child with autism, especially after he or she had reached puberty. Regarding relationships with relatives, many previous conflicts had either diminished by the time the child reached adolescence, or could be dealt with by avoiding contact with certain family members.

The marriage relationship was most strained early on in the life of the child with autism. It was evident that if couples had not learn to handle the stress associated with raising a child with autism early on, separation and divorce could result. Personal development and growth of individual family members was also sometimes restricted. Mothers, especially, were limited in their ability to pursue employment, careers and other interests.

Goldberg and DeMyer (1983) divided the needs of family members into three categories, based on potential sources of help. These sources of help consisted of: (1) the professionals, (2) the community, and (3) the schools. From diagnosing and treating professionals, parents needed good residential care, respite care, counselling and legal advice. Parents appreciated professionals with specialized training in autism, and those who took the time to listen. They were most upset by professionals who blamed them for their child's autism. Needs from the general community and from relatives included respite care and relief, financial assistance, parent support and community acceptance. Ways of meeting the socialization needs of their adolescents with autism were also required. From the educational system, parents wanted good educational programs, summer programs, and sexuality training. Transition between educational programs was also a problem in many cases.

While the DeMyer and Goldberg study provided useful information about families of adolescents with autism, it was somewhat limited by the fact that it used a structured interview format, which could have influenced some of the parental responses. For example, one of the questions used was, " What aspects of family life were affected adversely by problems in rearing and seeking help for the autistic person?" (p.227). Specific probes were then given for the 11 aspects of family life previously mentioned. Phrasing the question this way is likely to skew responses toward negative experiences, and probing may lead families to discuss issues that may not be the most critical to their own situation.

A more open-ended interview format, using phenomenological methodology and thematic analysis, may be more appropriate for conducting further research on the experiences and needs of families of adolescents with autism. Although this methodology has been used with families of children with other types of disabilities, there appears to be a lack of qualitative research on the experiences of families of individuals with autism. Therefore, the purpose of this thesis is to better understand the experiences of parents of adolescents with autism, using phenomenological methods and thematic analysis.

Summary

A review of the literature has been presented in three major areas: (1) general information about families of children with disabilities, including historical perspectives, stress and coping, family systems and life cycles, and parental experiences; (2) more specific information about families of children with autism, including historical perspectives, stress and coping, family systems and life cycles, and parental experiences; and (3) information about autism in adolescence, including outcome studies and the needs of adolescents with autism and their families. A lack of qualitative research on families of children with autism, as well as a gap in our understanding of autism in adolescence, has been noted. This thesis examines the experiences of parents of adolescents with autism from a phenomenological perspective.

CHAPTER 3

Methods and Procedures

Phenomenological Research Methodology

There are basically two methods of scientific inquiry: (1) quantitative research, and (2) qualitative research. According to Berg (1989), quantitative research refers to "counts and measures of things" (p.2). In contrast, qualitative research refers to " the meanings, concepts, definitions, characteristics, metaphors, symbols and descriptions of things (p.2). Naseef (1989) further differentiated between the two types of research. He stated that, "in quantitative studies, the researcher focuses on selected predefined variables, and through prediction and control seeks the causes and effects of human behavior" (p.6). However, the qualitative researcher "seeks a holistic picture that includes peoples' interpretations and perceptions under natural conditions." (p.6).

Qualitative research methodology has been used in this thesis because it is more appropriate to the goal of understanding the experience of parenting an adolescent with autism. More specifically, phenomenological research methodology, one type of qualitative research methodology, has been selected.

Adams (1987) provided an excellent overview of phenomenological research methodology, including it's philosophical assumptions and rationale for use. A brief explanation of phenomenological research methods and a definition of the phenomenological terminology used in this thesis will be presented here.

According to Osborne (1989), "phenomenology is the science of the consciousness" (p.3). Valle and King (1978) stated that phenomenology is " a method which allows us to contact the phenomena as we actually live them out and experience them" (p.7.) It's purpose is understanding, or gaining deeper knowledge of human existence and experience in the world (Seamon, 1982). Phenomenological researchers are able to understand more about their own lives, and can empathize with the experiences of others (Seamon, 1982).

Polkinghorne (1981a) listed three essential components of phenomenological research: (1) it describes what is given in experience, (2) it strives to be pre-suppositionless, and (3) it contains structural descriptions. Describing "what is given in experience" means that the researcher focuses on a person's perceptions of an experience, rather than on causal relationships or external realities. Being "pre-suppositionless" means that the researcher attempts to consciously limit the effects of his or her own pre-existing biases on the interpretation of the data. "Structural descriptions" refer to the essential aspects of the experience that define it's nature.

Definitions of Phenomenological Terminology

Several terms adopted from phenomenological research methodology have been used in this thesis and require clarification here.

Bracketing - the identification and reduction of the researcher's own biases and presuppositions about a phenomenon, so that they do not influence the interpretation of the data. (Becker, 1986; Polkinghorne, 1981a).

Co-researchers - active participants in the research who share their lived experience with a phenomenon (Polkinghorne, 1983). In this research, the co-researchers were the parents of adolescents with autism.

Data - spoken or written descriptions of phenomenal experience (Osborne, 1989).

Data analysis - a method of extracting statements and themes from the transcribed data, in order to understand the meaning of the co-researchers' experience. The steps

suggested by Colaizzi (1978) were used for this research.
Interviews - a common method of data collection for phenomenological research (Becker, 1986; Kvale,1983) in which the co-researchers describe their experiences with the phenomenon.
Phenomenon - an experience of the human consciousness, as it perceives an object, event or person (Giorgi, 1970).
Themes - clusters of meanings derived from the analysis of data (Colaizzi, 1978). May also refer to the "structural descriptions", the essentials of an experience, described by Polkinghorne (1981a).
Validation - checking the researchers' interpretation of the data with the co-researchers to make that it truly describes the co-researchers' experiences (Osborne, 1989).

A discussion of the specific research methods used in this thesis will now be presented.

Co-researcher Selection

The co-researchers in this study were selected from the membership list of a parent association, based in a large urban setting. The association promotes public awareness about autism and provides support to local families with an autistic member. The families in this study were selected based on the following criteria:

(1) the co-researchers were members of the parent association;

(2) the co-researchers were able to describe their experiences clearly;

(3) the co-researchers were willing to participate in the study and to sign the required consent form;

(4) the co-researchers were the natural parents and the primary caregivers of adolescents with autism, between the ages of 13 and 19 years old;

(5) the adolescents with autism were currently residing in their family homes; and

(6) the adolescents had each received a definite diagnosis of autism by a qualified professional, such as a psychologist or psychiatrist.

The researcher has been a long time member of the parent association and has had previous contact with many of the co-researchers through meetings, parent support groups and other activities of the association. This proved beneficial, not only for selection of suitable co-researchers, but also for establishing credibility and rapport with the co-researchers. Further implications will be covered in the section on bracketing.

The Co-researchers

Eight co-researchers, representing six separate family units, participated in the interviews. In four of the families, only the mothers participated because each was identified by the researcher as the primary caregiver. In three of these four families, the fathers were out of town or were unavailable due to work demands and other time constraints. The fourth mother was a single parent.

The two fathers who participated in the interviews were both very involved in the daily care of their autistic adolescent. One of the fathers provided most of the daily care for the child with autism and was identified as the primary caregiver. In the other family, both the mother and father worked full time and agreed that they shared caregiving responsibilities for their child with autism.

The co-researchers ranged in age from 39 to 47 years, with a mean age of 43 years. All parents had at least a Grade 12 education, although several of the co-researchers had a post-secondary or professional education. Of the mothers, three worked full-time and three worked part-time, with careers ranging from sales and clerical work to professional positions. One of the interviewed fathers held a professional position, while the other was a tradesman.

Five of the six families resided in a large urban centre. The sixth family lived near a small town, outside of the large urban centre.

The Adolescents with Autism

The adolescents with autism in this study ranged in age from 13 years, 3 months to 15 years, with a mean age of 14 years, 2 months. Five of the teenagers were boys and one was a girl, a proportion which approximates the ratio of boys to girls with autism in the general population.

Three of the adolescents with autism were described by their parents as being "high functioning". Two of these high-functioning students were able to complete grade level academic work. None of the youths were described by their parents as being "low-functioning." Perhaps this was an artifact of the sample of adolescents selected. Alternatively, perhaps parents tend not to use the term "low-functioning", or perhaps lower functioning children are less likely to be maintained in the home environment as they enter into adolescence. It is also possible that parents of higher functioning individuals may be more likely or more available to participate in parent advocacy groups.

Two of the adolescents were integrated into regular junior high school settings, with assistance from support personnel. One attended a vocational program for students with mental disabilities, and one attended a specialized program for students with autism. The remaining two attended special education classes within the public school system, although one of these students was about to be transferred to a different placement.

Initial Contact

Osborne (1989) advocated using a three-phase interview format for phenomenological research: (1) an initial interview to establish rapport and to inform the co-researcher about the research, (2) a second open-ended interview to gather data, and (3) a final semi-structured interview to validate previous results and probe for additional information. A modified version of this format was used for this research. The researcher made the initial contact with each of the families either by telephone, or informally at an association meeting, in order to determine their willingness to participate in the study. The purpose of the study and the nature of the interview format, particularly the fact that it would be audio-taped, were discussed. Two of the families who had initially been contacted declined to participate because their children did not have a firm diagnosis of autism. For the families who were interested in participating, a mutually convenient time and place were set for the initial interview.

The Initial Interview

For five of the six families, the initial interview took place in their own homes, usually while the children were at school, in order to minimize distractions. For the family who lived out of town, it was more convenient to meet at the researcher's home, during one of their frequent visits to the city.

Before participating in the initial interview, the co-researchers were requested to sign a consent form, granting their permission for the interview to be audiotaped. (See Appendix A). They also filled out a demographic form that requested basic information about their age, education, employment, and their child with autism (See Appendix B).

All initial interviews were audio-taped, using a small portable cassette recorder. The co-researchers seemed to be quite comfortable with the tape recorder after a few minutes into the interview. The interviews varied in length from about one hour to approximately 2 and a half hours.

The interview format was very open-ended, so as not to direct the topic of discussion. Each of the co-researchers was asked to respond to the following question:

"What has been your experience as the parent of a child with autism? It is your decision as to what parts you want to disclose, in what depth, and where you want to begin." This question is similar to that used by Morgan (1987), when interviewing mothers of adolescents with hearing impairments.

Because of the researcher's personal involvement in the topic and because of methodological constraints, she refrained from commenting or questioning the co-researchers during the initial interview. Instead she maintained an attentive listening posture, nodded her head and encouraged the co-researchers to continue talking about their experiences. Most of the co-researchers talked freely and only one required even minimal prompting. At the beginning of the initial interview, all of the co-researchers were aware that the researcher was also the parent of an autistic child.

When the fathers participated in the interviews, both parents were interviewed together. The question was posed to both parents at the same time, and both were encouraged to share their experiences in the same session. Sometimes one parent tended to talk more freely than the other, but it was the researcher's opinion that a good sample of both parent's experiences was obtained.

Analysis of the Initial Interview

Before analyzing the data from the initial interviews, the audiotaped recordings for each of the co-researchers was transcribed into a typed protocol. The procedural steps for data analysis suggested by Colaizzi (1978) were then applied. These procedural steps are listed and described below.

1. Each of the co-researcher's protocols was read through several times, in order to get a "feel" for the data.

2. Significant statements (phrases, sentences or paragraphs) which described the phenomenon in question, were extracted from each protocol. This was accomplished by cutting out segments of the protocols from computer print-outs and pasting them on 5" x 8" index cards.

3. Meanings were formulated from each of the significant statements and were then sorted into themes, as they emerged from each protocol. A summary of themes was written for each protocol.

4. The themes that emerged from each co-researcher's protocol were then organized into clusters of themes, in

an attempt to discover the themes common to all of the protocols. Clusters of themes were identified by sorting and color-coding the significant statements, which had been pasted on the index cards. The clusters of themes were validated by referring back to the original protocols to determine whether any themes had been added or omitted, when compared with the original transcripts.

5. Finally, results were integrated into a summary description of the phenomenon, based upon common themes which had emerged from all of the co-researchers' protocols. This summary statement was taken back to the co-researchers for validation during the follow-up interview.

The Follow-up Interview

A follow-up interview was scheduled with each family, in most cases three to four months after the initial interview. The follow-up interview was also audio-taped in all but two cases. One parent was contacted by telephone because she was leaving on vacation. Another parent was interviewed informally following an association meeting. There were several purposes for this additional interview. First, based on the results of the analysis of the initial interview, it was determined that two specific topics were not adequately discussed by some families. Because of the open-endedness of the initial question, some families had discussed their experiences during their child's entire age span, and had not focused primarily on adolescence. It was decided that additional information regarding adolescent issues was required. Second, most families talked largely about their stresses and concerns and spoke very little about their coping strategies and support systems. Therefore, three additional questions were asked of each family: (1)"What do you think are the most important issues for adolescents with autism and their families?" (2) "How have you coped with your child's disability?" and (3) "Describe your support system." For most families the responses to the second and third questions merged into one, as they tended to describe their support system as part of how they had coped. Because of the more structured nature of this interview, the researcher had more freedom to prompt, ask questions and comment than during the initial interview.

A second purpose of the follow-up interview was to validate the results of the initial interview. For each family, the researcher went through the results and analysis of that family's initial interview. As well, general results based on the analysis of data from all of the families was discussed. In both instances, the co-researchers were asked to provide the researcher with feedback about the accuracy of the interpretation of the initial interview. They were asked to add anything that they thought might clarify the researcher's understanding of the themes and to comment on anything they thought might be incorrect or misleading.

During the follow-up interview, co-researchers were also provided with a copy of the protocol from their initial interview and a written summary of the general themes and results that had emerged from the study. They were also promised a written report, which would be sent to them when the research had been completed. A copy of the thesis document was also to be made available for them in the association library.

Bracketing

In qualitative research, the term "bracketing" refers to the process of identifying and reducing the influence of personal presuppositions and biases about the phenomenon, which the researcher brings into the inquiry. In the current study, this was accomplished through self-reflection, audio-taping of personal experiences and writing in a personal journal throughout the duration of the project. For purposes of this study, bracketing has been divided into two categories: (1) past experiences of the researcher as the parent of an autistic child, and (2) experiences through the course of this study as a result of interacting with the co-researchers and the data.

Past Experiences of the Researcher

Through working on this research, I have become more aware of some of my own personal experiences as the parent of a child with autism. Perhaps one of the most prevalent feelings has been that my time for pursuing personal interests and activities has been extremely restricted. To find the time to work on this thesis, or to find the time for social or recreational activities for myself seems to be a constant battle. It seems that as long as everything is running reasonably according to schedule, I am able to cope, but as soon as anything out of the ordinary happens, such as a child becoming sick or a problem in my son's educational program, my own plans and work suffer. While I know that this problem is common to almost all mothers, I think that it is probably even more pronounced in mothers of children with autism, because there are so many additional time demands. I have to deal with my child's often difficult behavior, carry-out his educational programs, attend to his personal care needs, advocate for services, interact with professionals and agencies, attend countless meetings, do volunteer work, co-ordinate relief care, and perform additional house-keeping duties, while simultaneously balancing the myriad of tasks that "normal" families face. The list seems endless. As I write this thesis, I feel stressed out and burned out.

I recently attended a meeting on stress management, where we were asked to complete a checklist to determine our level of stress. My scores were in the very high range for all of the subscales. One of my presuppositions is that many primary caregivers of children with autism, like myself, experience high levels of stress and excessive personal restrictions.

As the single parent of a child with autism, my own experience has been that it is primarily the mother who takes responsibility for the needs of the child with autism, and is most directly affected by the child's disability. However, this research has provided me with examples of fathers who are very committed and involved in the daily care of their child with autism.

Another bias I hold, as the parent of a child with autism, is that autism is very definitely a biogenic rather than psychogenic disorder. Like many parents, I have struggled with guilt feelings regarding some possible or imagined contribution I may have made to my son's disability. However, I have come to the conclusion that I am in no way responsible for my son's condition. Instead, I would like to think that I have had a positive influence on his life in helping him to reach his fullest potential.

I also believe that individuals with autism should be encouraged to participate as fully as possible in all aspects of community living. I am biased toward integrated rather than segregated educational options. My son's academic, social, and behavioral progress has been dramatic, since his transition from a special education program to an integrated classroom setting two year ago. He also participates in integrated swimming lessons at the local pool, attends Sunday School and church services at a nearby church and plays with the children in our neighborhood.

Emotionally, working on this thesis has been very draining for me. It has forced me to look into the past and consider some of the factors which have led to the break-down of my marriage. It has also forced me, somewhat reluctantly, to look into the future to consider what may lie ahead for my now eleven year old son. I have had the impression that many adolescents with autism regress as they grow older and become more difficult to manage behaviorally because of their increased physical size and the hormonal changes which occur during puberty. Consequently, I have found myself procrastinating in my work on this thesis, in order to avoid dealing with my own fears about the future.

On a more positive note, this thesis has made me more aware of my coping strategies and the extensive support system that I have developed, which includes family members. friends, my church, support workers, educational staff, agencies and other parents. One of the ways I have coped is by furthering my education in the area of severe disabilities. Becoming more knowledgable has helped me deal more effectively with my son's disability. It has also helped me to develop a more educated opinion about the services my son requires and therefore be able to relate to other professionals on a more equal basis. I have grown as a person and developed new goals, opportunities, and values in my own life.

Finally, I have coped through my Christian beliefs and my faith in a loving God. I believe that there are reasons why this tragedy has occurred in our family, even though I am not able to understand all of them at the present time. I hold a strong conviction that there is a higher purpose for our difficulties and that many people have been positively affected as a result of my son's disability.

Experiences During this Study

In the process of completing this study, I have had both positive and negative experiences, some that allayed my fears about the future and some that intensified them. Three of the families had adolescents who seemed to be regressing behaviorally with the onset of puberty and who were experiencing problems in terms of placement and management. These families were all very involved with their children and had coped very admirably in the past. I found this very frightening that, for some families, life had become even more difficult. In the other three families, life seemed to have stabilized or even improved, and their children had become more manageable and even complacent with age. It made me wonder what lies ahead for our own situation.

I have learned a great deal from each of the families involved in this study and I feel that I was able to contribute in some small way to each of them. I think that one of the great benefits of qualitative research is that the researcher does not have to assume a position of objectivity and distance, but that mutual interaction is permissable and even advisable.

I learned from one family the importance of advocacy, not only for one's own child, but for all persons with disabilities. From another I learned that the experience of parenting a child with autism can be very isolating, and that social support networks are essential. Another family taught me the importance of the husband and wife working together as a team and supporting one another. One family encouraged me through their persistence in seeking information and services for their child. One family showed me how they relied on faith in God to provide guidance and strength. I felt enriched by knowing how others have coped and the positive ways they have responded to their situations.

Finally, I would like to think that in some small way, I was able to contribute to these families through the research process. Several families suggested that just being able to talk about their experiences had provided them some support. One mother even said that the session had been a "catharsis" for her. In several situations, I was able to share information about available services and programs that had been beneficial to my son.

In summary, my own personal needs both to understand my past experiences as the parent of an autistic child and to explore the future possibilities for my son have been met, through completing this thesis.

Summary

A general summary of phenomenological research methodology has been provided. The phenomenological terminology used in this study was defined and a description of the specific methods used in this study was also presented. Bracketing of the researcher's biases was discussed in terms of the researcher's past experiences as the mother of a child with autism, and the researcher's experiences during the course of this study. The following chapter will discuss the results obtained through the use of the phenomenological methods just described.

CHAPTER 4

Results and Discussion - Themes

The results of this study have been summarized on Table 1. The results will be discussed in terms of six consistent themes that emerged from the interview data, including: (1) behavioral concerns, (2) social and communicative concerns, (3) family-related concerns, (4) concerns about education and related services, (5) relationships with professionals, and (6) independence and future concerns.

All six themes were discussed by all of the families. However, the emphasis on certain themes varied from family to family. In three of the families, behavioral concerns emerged as the most frequently discussed theme. These families tended to be the ones whose adolescents with autism were regressing behaviorally with the onset of puberty, and were becoming more challenging to manage, due to increased physical size. Two of the other co-researchers stressed family-related concerns, while the remaining co-researcher emphasized the importance of educational and related services. It should be noted that these themes are interrelated and influence one another. For example,

TABLE 1

Summary of Results- Themes

THEME 1: BEHAVIORAL CONCERNS

(1) Classes of behavioral difficulties
    (a) aggressive/self-abusive/destructive behavior
    (b) temper tantrums
    (c) obsessive behavior
    (d) impulsive behavior
    (e) self-stimulatory behavior
    (f) miscellaneous behavior problems

(2) Autistic behavior and puberty

(3) Dealing with autistic behavior
    (a) behavior management strategies
    (b) behavioral counselling
    (c) behavior as communication
    (d) medication

THEME 2: SOCIAL AND COMMUNICATIVE CONCERNS

(1) Inappropriate social behavior
(2) Communication problems
(3) Rejection and teasing
(4) Friendship

THEME 3: FAMILY RELATED CONCERNS

(1) Effects on parents as individuals
    (a) Personal restrictions
    (b) Emotional reactions
    (c) Stress and burn-out
    (d) Coping and support

(2) Effects on the family as a whole
    (a) Location of family residence
    (b) Family outings and recreation
    (c) Finances
    (d) Siblings
    (e) Extended family members

THEME 4: EDUCATION AND RELATED SERVICES

(1) Educational placement and decision making
(2) Parental involvement in education
(3) Educational transitions

Table 1 Con't

(4) Mainstreaming
(5) Related services
    (a) behavioral counselling
    (b) transportation
    (c) support personnel
    (d) speech pathology
    (e) summer programming
    (f) diagnostic/assessment services
    (g) relief care
    (h) financial assistance

<u>THEME 5: RELATIONSHIPS WITH PROFESSIONALS</u>

(1) Negative relationships
    (a) reluctance to diagnose
    (b) excessively negative prognosis
    (c) blaming parents
    (d) lack of knowledge and expertise
    (e) ineffective communication
    (f) battling the system
    (g) inadequate service provision

(2) Positive relationships
    (a) knowledge and expertise
    (b) responsiveness to parental concerns
    (c) support from professionals
    (d) respect for the individual with autism

<u>THEME 6: INDEPENDENCE AND FUTURE CONCERNS</u>

(1) Independence
    (a) vocational training
    (b) recreational activities
    (c) daily living skills

(2) Future concerns
    (a) hopes for the future
    (b) fears for the future

severe behavioral and social difficulties, exhibited by an adolescent with autism, may affect a family's ability to cope, thereby creating more family-related concerns. This may in turn create a greater need for specialized educational and related services, and increase a family's need to interact with various professionals. In addition, a youth, who is experiencing severe behavior problems and having difficulty relating appropriately to others, will likely be less independent, thus intensifying a family's concerns about the future.

Alternatively, a family which has emphasized education and services throughout the child's life, may find that behavioral, social and future issues have become less of a concern because the child is now functioning relatively well. This improvement is, of course, influenced by many other factors, such as the severity of a child's autism and his or her response to the hormonal changes that occur during puberty. Therefore, a relatively more successful outcome found in some children should not necessarily be construed to mean that some families have simply done a better job than others, as many other factors may be involved.

Another possibility is that families, who have focused on family-related concerns, may have developed more extensive coping strategies and support systems to deal with their child's disability. This may improve their ability to manage their child's behavioral and social difficulties, and to plan for the future. It may also affect their need to relate with professionals and agencies.

While many other scenarios could be envisioned, the three described above are examples, from the current study, of how themes may interact. Each of the individual themes will now be discussed in greater detail, bearing in mind that all of the themes are interrelated and do not exist independently of one another.

To ensure confidentiality and to protect the identities of the co-researchers and their children with autism, specific details given in examples have been changed or omitted. In addition, since there was only one girl participating in the study, all references to the adolescents with autism will use the male personal pronouns, "he" and "him". This is not sexist use of language, but an attempt to protect the identity of the one girl involved in the study. A discussion of themes now follows.

Theme 1: Behavioral Concerns

Behavioral concerns were defined as any issues discussed by the co-researchers relating to the behavioral difficulties associated with the child's autism. Three sub-themes were identified within this theme: (1) classes of behavioral difficulties exhibited by the adolescents with autism, (2) the relationship between puberty and autistic behavior, and (3) strategies for dealing with autistic behaviors, including behavior management techniques, behavioral counselling, viewing behavior as communication, and the use of medication.

(1) Classes of behavioral difficulties.

Six classes of behavioral difficulties exhibited by the adolescents with autism were mentioned by their parents. These included: (a) aggressive\self-abusive\destructive behavior, (b) temper tantrums, (c) obsessive, ritualistic behavior, (d) impulsive behavior, (e) self-stimulatory behavior, and (e) other miscellaneous behavior problems.

(a) Aggressive\self-abusive\destructive behavior: Aggressive behavior involved hitting, kicking, punching, biting, and any other behavior that could potentially harm another person. One mother described how her child had kicked her, stating, "This was something he would do from time to time. I mean it was something I've gotten used to over the years." This parent had become accustomed to living with the threat of physical aggression as a fact of her daily life. The same child sometimes hit other children when getting off of the school bus.

Another parent described how her child frequently got into fights with the other students at school. He also fought with his father and had verbally threatened to hurt family members with a knife or a gun.

One adolescent had recently become a bully in his elementary school, a role which he had not previously held. This behavior subsequently improved when he was transferred to a junior high school setting. He also did "things that are aggressive in nature, but are harmless, such as coming up to someone in an elevator and almost pointing his finger right in the guy's eye and saying,'Who are you?'"

One child with autism sometimes hit younger siblings. When upset, this individual would twist the mother's hand, while echoing, "Don't twist your Mommy's hand", a command heard previously. Two of the adolescents with autism were not currently exhibiting any aggression, although that type of behavior had been present in the past and could still potentially occur.

Self-abusive behavior involved violent or harmful behavior directed toward the individual's own body. Of the adolescents in this study, only two had been self-abusive. When extremely upset, both of these individuals had been known to bang their heads against walls or other surfaces. Besides being dangerous to the individual, these behaviors were very upsetting to the caregivers, who had to deal with them. As one parent explained, "Last year, he started banging his head really hard. If he made a mistake or did something wrong, he would hit his head really hard. And he got to the point where he was hitting it very hard against sharp edges on counters and things."

Destructive behavior involved violent behavior toward an inanimate object that could potentially damage that object. For example, one parent reported that her child threw tables and chairs when first starting at a new school program.

(b) Temper Tantrums: Another behavior, which often occurred in association with aggressive, self-abusive, or destructive behaviors, was temper tantrums. For some individuals with autism, temper tantrums had become less frequent and less intense, as they became older and more able to reason and understand. However, even the youth who was currently the most complacent, was still described by his mother as being very easily frustrated. For other individuals, temper tantrums have persisted into adolescence and are more difficult to manage, because of the child's increasing physical size and strength. Tantrums often occur in public places, such as buses or shopping malls, causing embarrassment to family members. As one parent said, "He's never really embarrassed me, except when he's had a temper tantrum in public."

Temper tantrums are usually associated with the child's inability to deal with frustration. As one parent said, "When he is frustrated, he'll have these tantrums, and that was the only explanation we could come to for them. Nobody was trying to make him have a tantrum, but he just couldn't cope with things." Temper tantrums are also attributed to the child being denied desired items. One parent said, "I don't know if I denied him a bag of chips or something, because I didn't have any money with me. But to deny him anything was to invite a big fit. So he was having this tantrum, lying on the floor." Tantrums also seem to be caused by a disruption or change in the child's daily schedule. One parent explained how taking a different route home from school would be extremely upsetting for the child, requiring them to make gradual changes until the child began to adjust. Another parent described how changes in the child's routine, such as starting in a new school or having the father work out of town temporarily, would result in a deterioration of behavior.

For most families, the most difficult thing is the erratic and unpredictable nature of the tantrumming behavior. Families do not know where or when a tantrum might occur, or what might set it off. As one parent stated," Take him out on the bus today and he'll be good. Tomorrow you could do the same thing and he'd be miserable the whole time to the point where you'd have to get off the bus." Another said," He is so erratic. You can't count on anything ever happening the way you expect it to happen." Parents feel always on guard, anticipating the possibility of difficult behavior occurring in any circumstance, not knowing how they will cope, and how others in the community will react.

(c) Obsessive\ritualistic behavior: Most of the adolescents in this study were described as having obsessive, ritualistic behaviors, or intense fascinations with particular objects, events or activities, which to other people might seem bizarre and unusual. For example, one child focused on pencils and Q-tips, while another had a fascination with socks. The same child had a fascination with spelling and numbers, asked the same questions over and over again, and liked to collect things, such as pop bottles and pieces of string. This child's mother had to clean the bedroom every few days, removing a bagful of various items that had been collected.

Sometimes, these obsessions caused only minor irritations for the family, but in other instances the consequences were more serious. One parent described her teenager's obsession with trying to take quarters from the shopping carts at their local grocery store. Unfortunately, the grocery store was very near to their home, and this youth would sometimes disappear to look for quarters. On one occasion, he was found inside the grocery store, asking for quarters from customers, before they even left the premises. The management told him he was not allowed to return to the store. The compulsion to take quarters from shopping carts remained with him for about six months, until the family moved to another location, where the grocery store was not as accessible.

Some individuals with autism have relatively high level obsessions, which take the form of obsessive thought patterns. For example, while on a hiking trip, one teenager was obsessed with the idea of scaring away a bear by squirting orange juice in it's face. "You couldn't talk him out of this. That's again the obsessive thoughts, that you have this one solution and that you don't have to think of anything else or adjust your thinking."

In most cases, these obsessions seem to be related to the resistance to change and insistence on sameness, which are hallmarks of the autistic condition. One parent said, "He had all the autistic tendencies, like getting his mind on one thing and thinking only that one thing." Another said, "He won't compromise. He won't accept other people's patterns or ways of thinking or ways of doing things."

Families appeared to deal with these obsessive behaviors in several different ways. If the behavior was not harmful, and did not interfere with family life in a major way, the obsessions were simply permitted and tolerated. When obsessions led to dangerous or socially inappropriate behavior, it was sometimes helpful to remove the item with which the individual was obsessed, or to prevent the obsessive behavior from occurring altogether. For example, one child became obsessed with the characters in his favorite video, and wanted to run away to visit them. The parents hid the video tape and the behavior eventually disappeared. Sometimes making gradual changes in routines prevented obsessions from occurring. One parent also suggested making use of obsessions and fixations in teaching the child with autism. "I'm trying to take advantage of his ability to fixate. A lot of children with autism will fixate on various things...I would take a fixation and expand on it and then I realized possibly I could get him to fixate on things I wanted him to fixate on."

(d) Impulsive behavior: Most families in this study indicated that their children with autism, even as adolescents, do not possess an awareness of common dangers, or an adequate knowledge of safety precautions. This is especially a concern because of their normal mobility, and their increasing physical size. One parent described her child's behavior on a hiking trip. "He would walk faster than the rest of us, which we didn't want him to do, because there were quite a few bears around the area, so we wanted him close to us. He'd go ahead really fast and then lie down on the trail and sleep until we caught up to him, both of which are hazardous things to do in the middle of the mountains." Another parent reported that her adolescent was not aware of inclement weather conditions and how to dress appropriately. "One time last winter, he snuck outside and got his fingers frozen, so he had to have that treated. I have to really watch him that way and make sure he doesn't go outside when it's too cold."

Two aspects of particular concern were related to traffic safety and running away from home. One child had broken his leg, when he had impulsively crossed the road without looking and was hit by a car. After that incident, the parents were hesitant to allow him to cross the road again independently. One parent said that, although the child was completely safe inside the house, he was oblivious to traffic, and had narrowly missed being hit by a car. Another parent said," He doesn't know anything about the safety of roads. He'll see a red light and he'll just go walking. Or he'll be crossing the road and he'll just go walking. That's one thing we have to teach him is to be more cautious of the road. He could get hit, if he wasn't careful."

Limited knowledge about traffic safety is a particularly serious concern, when combined with the tendency of many of these adolescents to wander or run away from their home or school. One couple described how the child had run away from a relief care worker, while the parents were out. The child was found an hour later by a couple, who had seen him wandering around his school, some distance from his home. Another adolescent with autism frequently left school at various times during the day, and would either return home or wander around the neighborhood. The school would typically phone his mother to report that he was missing. During the follow-up interview, one parent described how her child had recently run away from a residential setting, where he was temporarily staying and was missing for almost twelve hours.

Impulsive behaviors, such as those just described, are extremely stressful for caregivers and families. Constant supervision is often required, in order to protect these individuals from danger, and even then, potentially dangerous situations cannot always be prevented. The independence of individuals with autism may also be limited, because although competent in other areas, they may not be sufficiently aware of danger to care for themselves.

(e) Self-stimulatory behavior: Self-stimulatory behaviors are stereotypic behaviors that provide sensory feedback to the performer. Self-stimulatory behavior was mentioned by three of the co-researchers, but appeared to be a relatively minor behavioral concern. The most common self-stimulatory behavior mentioned was some unusual type of hand movement, such as clapping, hand flapping or finger-twirling. One parent described the behavior as follows, "He uses his hands quite a bit and looks at his fingers and twirls them around." This child would stop the behavior simply by being told to keep his hands still. Another family found that imitating their child's hand-flapping behavior to show him how strange it looked was useful in reducing the behavior. They also showed him alternative things that he could do with his hands when he was excited, such as putting them in his pocket or sitting on them. However, for one teenager, very little seemed to help stop this behavior. The parent asked, "How do you stop an autistic child from clapping his hands when he's really emotionally happy? It's almost impossible."

(f) Other miscellaneous behaviors: Several other miscellaneous behavior problems were mentioned by the co-researchers, which might also be associated with autism in the individual adolescents described in this study. One child had a problem with stealing money, especially from the mother's purse. Disturbances in sleeping and eating patterns, as well as difficulties getting up in the morning, were observed in some of the youths. Noncompliance and loud vocal behaviors were also reported. Inappropriate social behavior was such a major problem area that it will be discussed later as part of a separate theme, under the heading of social and communicative concerns.

(2) Autistic behavior and puberty.

For two of the youngsters in this study, behavior problems were less of a concern now that they have become teenagers. Both were described as being fairly independent, compliant, and complacent. Their parents attributed this improvement in behavior to all of the programming and teaching that had been done with them, when they were younger. It is also possible that these teenagers had not fully entered puberty, or were experiencing less dramatic hormonal changes.

Some of the other adolescents with autism had deteriorated behaviorally with the onset of puberty, and were now more difficult to manage. Several of the co-researchers indicated that the increased physical size, which accompanies adolescence, was sufficient to cause greater difficulty in behavior management. One parent said, "Being bigger, he's harder to handle now and it's going to be tricky to say the least." Another added, "He's very large right now too. He's bigger than his dad. I went grocery shopping with him yesterday, and I was standing behind him and my head doesn't come up to his shoulders. He's really big. And because he was so much easier when he was little, it's pretty hard to adjust to."

Some of the adolescents have also become more aggressive as they got older, and have more unpredictable mood swings. One parent said, "They equate his aggression to moving into puberty and hormonal changes. It's a new pattern of behavior. It's these hormones, and he is having these mood changes."

While hormonal changes sometimes caused behavioral difficulties, parents also recognized that they were, in fact, normal changes. As one mother said, "Well, I guess if he's going through this at this point with adolescence, with the usual problems, normal body changes, we have to celebrate that it's normal and yet we hate it. You know that he's changing and growing and he's right on track with puberty."

(3) Dealing with autistic behavior.

The co-researchers in this study mentioned several strategies for dealing with autistic behaviors. Behavior management strategies, such as reward systems, use of a time-out room or a time-out chair, or environmental manipulations were mentioned. Many of these strategies were the ones being used in the child's educational setting. One of the parents had used a behavioral counselling agency to help set up behavioral management programs in the home. However, two of the other parents felt that agencies and professionals, who understood autism, were competent in behavior management counselling, and had a knowledge of common adolescent problems, were not readily available.

Some parents felt that a valuable way to deal with their child's difficult behavior was to view it as a form of communication. When an adolescent went through a particularly difficult period behaviorally, it could often be traced to a difficulty at school, or in some other aspect of the environment. Making appropriate program changes often resulted in a subsequent improvement in behavior. For example, one parent said, "He just knew he wasn't happy there and probably didn't know why. So over the years, I've learned to read his behavior."

Administration of various medications to the teenager with autism was also used by some families to control difficult or aggressive behavior. Three of the individuals described in this study were currently taking some type of behavior-controlling medication. Several different medications were mentioned. For some of the individuals, medication did seem to improve the behavior. One parent, who had tried to stop the medication, observed, "When he's off the medication, he's a lot louder, he jabbers even more, and claps his hands a lot more. Everything intensifies. So I know that, at this point, certain amounts of these drugs are beneficial." However, some of the parents were concerned about side-effects of medication, such as liver damage and over-sedation. One parent said, "We don't like to give him too much, because some of them can cause liver problems, so we have to monitor it." Another said, "We increased his medication over the weekend. Before that he was always cracking jokes. There was always some pun or something coming out. But he's really low-key now. So I think we'll either have to take him off the medication or try another medication or reduce the dosage." One parent suggested that too much medication could also affect learning. "You hate to get them so doped up on it, because then they can't even function. They can't even learn properly." The difficulty was "finding a balance between giving just enough so that he's settled down more, but not so much that he can't learn."

Three of the families had not tried medication with their children with autism. One parent stated that it had never been a consideration. Another family was against using medication, feeling that it should be avoided at all costs. They felt that other techniques, such as controlling diet and routine, had worked better than medication with their child. One family had considered using medication to control aggression, but were hesitant and had decided to try working on the environment first.

In summary, behavior problems in adolescents with autism may be very severe, and may include aggression, destruction, self-abuse, obsessions, impulsive behavior and self-stimulation. Behavior problems may worsen with the onset of puberty in some children. Families may deal with difficult behaviors through behavior management techniques, behavioral counselling, viewing behavior as communication, and through the use of medication.

Theme 2: Social and Communicative Concerns

All of the co-researchers in this study had concerns about the abilities of the adolescent with autism to communicate appropriately and to relate socially to others. Some of the areas of concern included: (1) inappropriate social behavior,(2) communication problems, (3) teasing and rejection by peers, and (4) the inability to form meaningful friendships. Each of these areas will be discussed in further detail.

(1) Inappropriate social behavior

In addition to the numerous behavior problems discussed in the previous theme, many of the adolescents in this study exhibit unusual or inappropriate social behavior and difficulties relating to others, which cause them to be noticeably different from their peers. Contrary to the popular stereotype of children with autism, living in their own little worlds, most of these adolescents actually want to be sociable and to interact with others, but don't know how. They often lack requisite social skills and appropriate social judgements. For example, one mother described her child's attempts to initiate social interactions. "He really wants to be sociable. He really wants to talk to people.

He talks to everybody, wherever he goes, and he just has no idea whether something is appropriate or not, or to whom he should speak. That causes a lot of problems when you're out with him. If you're going shopping, he will walk up to someone who is obviously preoccupied doing something and start telling them jokes. He really needs some kind of social outlet and social training too." He would also wander into other people's houses. When the family had gone out to a smorgasbord restaurant, he wandered around and talked to all of the customers in the restaurant.

Another child exhibited similar inappropriate social behavior. If he wanted to play with someone, he would go up to the window, hoping to see the person inside. However, sometimes he got the wrong residence and was taken for a Peeping Tom.

Another child would accost strangers in the elevator, and say things that were entirely inappropriate. His parents reported that most of the time people seemed to understand that the child was handicapped, and were very accepting. However, the parents often worried that one day someone might take exception to this behavior, creating a potentially difficult situation.

One family had tried a creative solution for dealing with inappropriate social behavior. They had enrolled their child in a modelling class to develop more socially appropriate ways of relating to other people.

(2) Communication problems

One of the characteristics of autism is delayed or deviant language and communication. While most of the adolescents in this study were verbal, and possessed at least some functional language skills, a variety of communication problems still existed. One child was echolalic and liked to repeat the same questions over and over again. Another child would stumble over words, get upset and say "My mouth can't talk", but would try the sentence again more slowly. One parent felt that his child had developed an ability to analyze his environment, and was very adept at sensing on a non-verbal level how other people were feeling.

One child, although quite able to converse, still said things that did not make sense. For example, when on a bus, which was waiting at the bus stop, he got impatient and said, "Eat the bus driver." The parents explained, "You've got to understand what he's trying to tell you with body language, because the words he uses are right off the wall, out of context, maybe one word answers, could be echolalic. He may speak in words, but they'll be jumbled and they'll be run-on." The parents had found it helpful, especially when the child was younger, to focus on any attempt to communicate. They also found it helpful to speak very slowly and space the words. They were also convinced that working with a speech pathologist and a communication aide had been very beneficial.

(3)Rejection and teasing

Because of the inappropriate social behavior and communication difficulties exhibited by these adolescents with autism, they were often rejected and teased by their peers, and sometimes even by adults in the community. One child took a considerable amount of teasing and abuse from the other children at school. "They make this noise that he can't stand and it drives him nuts. He gets angry and chases them." He had been in several fights at school during the past year, which the parents felt had been provoked by the other students. The school had been very supportive in trying to reduce the teasing, by providing consequences for offending students. However, the parents still worried about senior high school, where the adolescent might be exposed to even more remarks and abuse.

One parent felt that teasing and rejection was more of a problem in junior high school than it was in elementary school, due to the "pecking order of the school", and the different attitudes students have when they go to junior high school.

Teasing and rejection also occurred in the neighborhood environment, as well as at school. One child was teased by other children in the neighborhood because, although older, the child was unable to tie a shoelace. The mother stated, "There is a lot of rejection involved in being handicapped." One individual with autism was coaxed by other children in the neighborhood to undress outside. Fortunately, an adult had observed the incident and reported it to the child's parent.

Lack of tolerance for the individual with autism was also sometimes exhibited by adults in the community. The youth obsessed with taking quarters from shopping carts, was treated very roughly by an employee at the grocery store, according to a customer, who had witnessed the incident. The mother explained that, while some people in the community had a big heart for her child, others couldn't be bothered making special allowances. One parent was hesitant to have the child work as a trades person, because the youth might not be accepted. The examples of teasing and rejection just described indicate that there is still considerable work to be done among the general public in developing tolerance and acceptance toward individuals with autism and other handicapping conditions.

(4) Friendship

The parents interviewed for this study were concerned about inability of adolescents with autism to form meaningful friendships. They wondered how they could help their teenagers to form friendships and relate more successfully to their peers. Often these teenagers seemed to relate better to younger children, or to other children with handicaps. As one parent put it, " I guess what's been coming up for me, especially in the last couple of years, is the ability of children with autism to interact with other kids their same age. The fact that they don't form friendships in the same way, and don't have the same social outlets that other kids their same age do. That seems to be a big issue for us to try and find an outlet for that, a way for him to be able to socially interact with other kids. And what we've been doing are little programs, but they haven't resulted in friendships." However, this parent also described a positive situation in her child's former school, where the teacher had implemented a pupil-assisted learning program. The students with handicaps were accepted as valuable, contributing members of the school. In that setting, "He was a very popular kid and had real friends. Real friends that were not kids in his special education class."

One parent said, " We have gone a long way out of our way to encourage relationships for him, and he has tried in his own way to make friends himself, but unfortunately, although he's more or less accepted in the classroom, most of the kids do not accept him as a friend. Now there are a couple of kids at school that he considers as more or less friends. The best friend he's got, he doesn't see much of at school, but the friend does come over periodically." The school had tried to develop a "circle of friends" for the student, but the parents felt that this approach had not been very successful. The parents themselves were trying to facilitate a friendship with another child, who was a friend of the family. The parents felt that this relationship was built upon mutual respect, and hoped that the children would participate in a variety of recreational activities together.

The development of friendships in other community settings was also problematic. One family wanted their child to attend a youth group at their church, but the child had difficulty fitting in with his peers. They finally hired a support worker to attend the group with the child, which temporarily improved the situation. However, maintaining regular, consistent workers was sometimes a problem.

In summary, parents had a variety of social concerns pertaining to their adolescent with autism. These concerns included inappropriate social behavior and communication problems exhibited by the individual, and relationships with peers and other community members. Specifically, teasing by peers and the development of friendships were important issues for parents.

Theme 3: Family-related Concerns

Family-related concerns were divided into two categories: (1) those affecting the parents as individuals, and (2) those affecting total family life. Regarding the effect on personal life, one parent stated, "So having a child like this does interfere with your life. This is definitely true. You just don't have the freedom that you should have." Effects on parents as individuals included: (a) personal restrictions,(b) emotional reactions, (c) stress and burn-out, and (d) coping and support.

Regarding the effect on total family life, another parent said," That's the reality. It's sad, I think, in many ways, when it means total family life. And that's what it is... It's not that it's just a minor kind of problem. It could determine what happens to the rest of each of our lives, and to the family as a whole." Impact on the total family life included factors such as: (a) the location of the family residence, (b) family recreation, (c) finances, and (d) effects on siblings, and (e) extended family members.

(1) Effects on parents as individuals.

(a) Personal restrictions: Most parents suggested that having a child with autism definitely restricted their own personal lives. Restrictions often seemed to be related to the constant supervision and assistance with daily living skills, required by these children. One mother mentioned, "Even if he does most of it himself, I still have to make sure his hands are washed and that he's got clean underwear on. I just have to make sure that he walks out of the door properly dressed and clean." One mother said she couldn't even take a shower, when her child was in the house, because he couldn't be left unsupervised even for ten or fifteen minutes.

Also, families sometimes had difficulty obtaining relief care for their teenagers with autism, and even when relief care was available, sometimes the workers were not able to handle these children behaviorally. Parents were left feeling that they should not, or could not, go out alone, and consequently found it difficult to attend to other personal aspects of their lives. One couple, who were out when their child ran away from a relief care worker, said, "We didn't know of anything else we could have done differently, other than stay at home."

Even when the adolescent with autism was at school, the parent's responsibility for constant supervision did not entirely end. One mother reported that, if her child was having a bad day at school, she was often expected to pick him up early and keep him at home for the remainder of the day. Another child had a habit of leaving school at various times during the day, either arriving home unexpectedly, or wandering around the neighborhood. The mother, who had just gone back to work, said, "I just can't go through ten months of waiting for a phone call and not being able to go anywhere, because he is going to skip school and come home again, and won't go back, unless I'm there to tell him to go back."

Some of the children, because of their difficult behavior, were unable to ride on the school bus. Therefore, their parents were responsible for transporting them to and from school each day, often interfering with their own schedules. As one parent said, "My life right now is that I have to find transportation for him, and so I'm driving him."

Advocating for appropriate services and programs also demanded a considerable amount of time away from parent's other activities. As one parent said, "I've gotten things for my child because I would take the time. There have been times here where I've stayed in this house for four days, waiting for somebody to call me back." Parenting the child with autism was described as being a "twenty-four-hour-a-day-adult-controlled situation."

The personal restrictions just described have a major impact on the parents' social lives and careers. One mother described her experience as being socially very isolating. Significantly, all of the parents interviewed indicated that they had made adjustments in their careers, and in their availability to work. One father had sacrificed a well-paying job to stay home with his child. He said, "Basically, I couldn't travel any more and still pay attention to my child and focus on his problem. My wife continued working and basically that's what's carried us over the years financially." This arrangement had meant a considerable decrease in financial resources, as well as a psychological adjustment for the father. Another father had continued to work out of town, but his child usually regressed behaviorally, whenever he was away. During one crisis situation, this father had to return home prematurely, because his wife had taken ill, and was temporarily unable to cope with the child's difficult behavior. One mother had somewhat reluctantly quit her job, in order to be more available for her child's needs. She said, "I realized that I was much more able to cope with my son, if I wasn't at work. The hardest decision for me to make was to quit that job, because to me it meant some independence financially and it was part of my self-image. I felt this was something I could do. I wasn't just the mother of an autistic child. This was something else I could do. It was very hard for me to leave, but I could see that, for my son and for me, it was a much better situation, if I wasn't working."

Another mother had been at home during her child's earlier years, but was now returning to work part time. While finding the work fulfilling, she found it difficult to leave in time for work in the morning, because her child was often not ready.

Those parents who had managed to continue working full time relied on the understanding and flexibility of their employers. As one mother put it, "Luckily, I have support at work and my husband has too. I can cancel my work, and it is okay with them. They're very concerned and it is absolutely essential to have that backing." Even with an understanding employer, some of the working parents had contemplated having to quit work. One career woman said, "It has serious implications in terms of our own personal selves. Our careers. Maybe I should quit my job. Maybe my husband should quit his job. All of that is implicated with this problem."

(b) Emotional reactions: For most of the parents, emotional reactions regarding the child's disability tended to be related in the past tense. Parents described the feelings they had experienced, particularly around the time of the initial diagnosis, rather than their current emotional reactions. Yet, some of these reactions were still vivid, even years later. One mother actually broke down and cried as she described an upsetting interview with the doctor, who had initially diagnosed her son. The doctor had felt that the problem was emotional in nature, and was probably due to environmental deprivation. The mother described her feelings of isolation and guilt, feeling that she was somehow to blame for her child's autism. "I was blaming myself, blaming myself constantly. There must have been something I must have done wrong. I mustn't have eaten right. I mustn't have done something that I was supposed to do. Maybe I didn't stimulate him enough."

Another mother described her reactions of denial and devastation, when she first found out that her child was

autistic. "And I guess I was hoping. You're kind of in denial, or whatever you want to call it. You're hoping this won't be true. You don't want to hear it.
So it really devastated me. I went home, and for two days I couldn't do a thing." However, most of the families in this study appeared to have moved beyond living in a state of constant grief, to a point of relative acceptance. They seemed more concerned with coping with the day to day demands of raising a child with special needs. Rarely did they refer to recent emotional reactions, except those experienced during times of crisis.

At least four of the families had recently undergone a crisis period, involving either deterioration of the child's behavior, an urgent placement decision, lack of adequate support services and\or their own temporary inability to cope. One parent described some of the emotions she had experienced during a difficult placement decision, which had involved extensive negotiations with the school board. "It's been tough. It would be nice not to have to go through the fear and the panic and the tears and the anger, and we've gone through all of that."

(c) Stress and burn-out: For many parents, stress and burn-out characterized these crisis periods, and sometimes their daily lives. One family described their experience during a recent support staff strike, which had affected their child's educational program. "We were at each other throat's. I mean there was just no married life at all. There was a lot of tension. I'm not kidding you. You could 'cut it like a knife' in this house."

Another mother described her stress and burn-out, which eventually necessitated quitting her job. "I was going from one stress situation to another. Sometimes during the summer, when he would be home, I'd be totally burned out by the time I got to work at eleven in the morning, and then having to deal with people who have complaints and customers. And then after that, I'd go home, and then I'd have him again. It was like I never really had a break to be able to settle down and for my nerves to heal."

(d) Coping and support: Coping and support were not discussed extensively by most of the parents, during the initial interview. Yet all of the parents in the study appeared to be coping relatively well, and had developed numerous supports and resources on which they depended. Therefore, a probe question was included during the follow-up interview, in order to gather more information about these two aspects. These results will be discussed more fully in a later section. The information contained in the current section is taken only from the initial interview data, and describes the coping strategies and support systems of those parents who had initiated this topic. This separation has been made in order to preserve the purity of the data, and to ensure that the researcher was not leading the co-researchers' discussions in any way.

Interestingly, the co-researchers, who discussed coping strategies and support systems the most, were a couple who lived outside of the urban centre. They seemed to have spent a considerable amount of time and effort developing a support system, perhaps because they felt somewhat isolated in their rural setting. The mother said, "The fact that we live further away, we have felt and sensed that it has been like a desert in terms of supports, the formal kinds, the agencies. We've had to do everything, initiate things. People are good and co-operative, but we've pretty well had to muster up the kind of activities and decisions ourselves. We just go after it." They came to the urban centre as frequently as they could to try and build up their support.

One of their ways of coping, during a recent crisis period, was to take some time off work, try to relax and re-evaluate priorities. The father explained, "My wife took a break, while this mess was being sorted out. Stayed home with our son, gave him a break, gave herself a break. With my work, there was a convention that gave me a bit of a break too. And we had a little time to relax and to think about what's really important here, and what can be put aside?" His wife added, "If anything, it's made us become more aware of our own limitations and our own values and what we know and what we don't know." Later, she also said, "We've been forced to look at everything, how we operate and what we think is most important. It is important to do that periodically."

Another way they had coped was by cognitively reappraising their situation, and realizing that it had helped them to grow as people. The mother said, "I suppose we have to look at it as helping us, because it certainly has widened our vision about a lot of things. Being more tolerant...All the things we've taken for granted is another story. The things I used to worry about now are irrelevant. Whatever that means for our growth, I would like to think that it would make us grow up and mature to be better people, better citizens, better human beings."

Sharing stories about difficult situations with other parents, even those with normal children had also helped them cope. The mother said, "There's the sharing of horror stories. We'll listen and then I'll hear one even worse... It felt like we weren't the only ones, and it's really true." Humor was also a helpful coping strategy. She added, "We chuckled, because these are things shared that have happened... You can laugh and take a breath."

In terms of support, probably this couple's best support was each other. The wife said, "There's this wonderful revelation that we both stood for the same, on issues that we were unsure of, and that when the crunch came down we were together on this. I needed that and my husband needed that, too. We both needed each other's support and agreement." Despite having different personalities and strengths, they realized that they worked together as partners, and actually complimented each other.

This appreciation for spousal support was also echoed by other parents in the study. Another parent said, "It's got to be both parents pulling the same way. It can't be one parent telling them one thing, and another parent telling them another. That's why I say the fathers have got to figure into this thing." One mother said that she had a "wonderful, supportive, terrific husband," but still felt at times that the responsibility rests most heavily with the mother. Of course, in some situations, such as a single parent family, or a situation where the father works out of town, spousal support is more difficult to maintain, and other forms of support must be developed.

Other forms of support used by these parents included support and flexibility at work, attending a parent support group, talking informally with other parents, involvement in parent advocacy groups, receiving newsletters, and relating to friends and family. Using a combination of these resources seemed to be beneficial. For example, one mother said, "It was wonderful to be able to pull on all the different strands. And what we've been doing is, on the phone, searching, getting support, and it's nice that the support has been there."

One parent, who had little family support and had not relied extensively on professionals and agencies, felt that the best support was found when she went out informally with other parents of children with autism. She said, "The part that really strikes me is when we get together and exchange crazy stories that nobody would understand, except one of us... Somebody does understand, somebody does know." She felt that there was more support for parents of smaller children, but that the support dwindled as the children grew older. "There was a lot more support when he was smaller. Somehow that support goes away a bit more as you get older."

As previously mentioned, coping strategies and support systems will be discussed in further detail in a later section, based on responses to the probe questions in the second interview.

(2) Effect on the family as a whole.

(a) Location of family residence: One of the ways that having a family member with autism affected total family life was in choosing the location of residence. Several families indicated that they had either relocated, or had considered relocating, in order to have services more accessible for the member with autism. "We were seriously considering moving, changing locations. That's the reality of it," said one parent. One family had actually moved for the benefit of the rest of the family, but felt that the change had been detrimental to their child, who is autistic. Another parent was hesitant to move, because the neighbors watched out for the child with autism. She said, "I wouldn't want to move away from here, because he's been here since he was very small. The neighbors know him and they look out for him as well as we do, so that's one good thing about it. He knows his way around, and where to go."

One family had actually been evicted from an apartment, as a result of their child's difficult behavior. The mother explained, "It was a traumatic thing for it to happen to us, to be evicted. We've never been kicked out or evicted from anything. And because of my child we went through this, and we felt so badly. But it's so funny, because afterwards, after we got kicked out, people were still sorry that it happened to us, even though they themselves deep down were probably glad we were moving." The family had just moved into their own home, and hoped life would be better for them in a more private setting, where there were fewer other children.

(b) Family outings and recreation: Some of the families reported that having a child with autism had a negative effect on the family's recreational outings, activities and vacations. One family enjoyed rigorous outdoor activities, but their child with autism did not share their enthusiasm for these outings. The mother said, "He only goes on these outings because we make him go on them, and then he complains constantly, that we shouldn't be doing it." She was considering leaving her child in relief care during the next outing, so that the rest of the family could enjoy the activity together.

Two of the families mentioned that it was important for them to attend church together, but that they often had to make alternate arrangements for the care of their son or daughter with autism. One parent said, "I would hesitate to take him to church. I usually have someone look after him, when we go to church, because he is unpredictable. He may get really 'hyper' in church, or he may be very quiet. I'd rather not take the chance."

(c) Finances: Although most families were eligible to receive some financial assistance to cover unusual costs incurred by their child with autism, several also indicated that the family, as a whole, had been affected financially. This appeared to be primarily related to the restrictions in the parents' ability to work, as previously described.

(d) Siblings: Several families mentioned the effect on siblings as one of the ways autism affected total family functioning. Two of the adolescents with autism did not have siblings. One family made it very clear that they had chosen not to have another child, because of their child's disability. One parent felt that the siblings were sometimes teased at school, because of their brother or sister with autism. She said, "His sister/brother has problems with friends at school, and they'll get mad, and they'll say,'Boy, you're stupid, like your brother', which hurts the feelings quite badly." Another parent felt that the siblings sensed the general uncertainty associated with having a brother or sister with autism. She said, "The other children find it really upsetting, although they seem to be doing fine at school. I think it makes them really apprehensive about what's going to happen next, and maybe scares them about what they're going to be like as teenagers." One parent felt that the non-handicapped sibling was often just expected to adapt and to cope. "It's easy to look at the one and say the other will just fit in, but that's not really fair.... He seems to be the type that can fit into the situation, but how far do you want to make him feel he has to fit in?"

(e) Extended family members: Another way that the family was affected as a whole by the child's autism was in the attitudes and behavior of extended family members. Some families did have extended family members, who were nearby, and who were able to provide support. Most had family members, who were supportive, but did not live close enough to provide day to day assistance. One couple reported that some members of their extended family had actually blamed them for the child's problem. They said, "Our experience is that we have been blamed. Outright when they're angry with us, and in subtle ways, when they're not." The child had quickly been replaced as the first grandchild, in the eyes of some family members. Other relatives had noticed this situation, and it had affected the entire family.

In summary, the effects on parents as individuals included (a) personal restrictions,(b) emotional reactions,(c) stress and burn-out, and (d) coping and support. The effects on the family as a whole included (a) the location of the family residence, (b) family outings and recreation, (c) finances, (d) effects on siblings, and (e) effects on extended family members.

Theme 4: Education and Related Services

Five major educational concerns were expressed by the parents in this study, including: (1) educational placement and decision making, (2) parental involvement in education, (c) educational transitions, (4) mainstreaming, and (5) related services. Each of these concerns will now be discussed in more detail.

(1) Educational Placement and Decision Making

One of the main concerns for all of the parents in this study was finding appropriate educational programs that met the needs of their adolescents with autism. The adolescents in this study were being served by a variety of different programs, depending on the individual needs of the student with autism, the educational philosophy of the parents and the availability of suitable programs. Two of the students attended regular junior high school programs and were able to complete grade level academic work. Two of the students attended special education programs, one of which specialized in students with autism. One teenager attended a vocational program for students with disabilities and the remaining youth was about to change programs at the time of the initial interview.

One parent stressed the importance of intensive early intervention in the later development of the child. "The main thing was there was lots of one on one at as early an age as possible. One-on-one in Grade one. Plus the speech therapy. Now I feel if he hadn't received that he would be absolutely nowhere near the level he's functioning at now."

Other parents stressed the importance of having programs that were familiar with the needs of students with autism and other types of behavior disorders. One parent said, "He was in a special education class and there was extra help from the aides, but not as much as in the more specialized classes. They didn't know what to do with him any more." The child did much better when transferred to a class for students with behavior problems. Another mother said, "He had a lot of help with the mentally handicapped students in various programs. He was automatically put into a mentally handicapped group, and did not do well there. The children were not performing at the same level he was. He finally got kicked out of school, because they couldn't handle him."

This student was now making better progress in a program familiar with the needs of students with autism.

Securing an appropriate educational program sometimes resulted in a confrontation with educational personnel and school board officials. One parent described the emotional reaction experienced when the school board would not pay for a program required for her child. "He was there until the school board started to make a big fuss about paying out all this money, and again I felt, 'Oh my gosh! My feet are out from under me again. I'm scared. I'm worried.' And it was like being alone again. I get to be like a bear when it comes to my child, because I know he can't fight for himself. I went so far as to threaten the school board."

(2) Parental Involvement in Education

Many educational programs required a considerable amount of parental involvement and monitoring. One mother described a pre-school program which required her to attend daily along with her child. She found this very stressful, and coped by "becoming a therapist 'in my head'." However, her involvement with the program seemed worthwhile when her child started to make progress.

One family spends hours each night helping their child with homework. Their work was also paying off because the child was making excellent academic progress.

Several programs required parents to pick up their children on days when behavior problems were excessive. One parent was trying to decrease involvement in her child's program. "I think I've probably been less supportive of the school, but I was pretty straight with them. I told them that I couldn't take a lot of harassing him about him homework or coming and getting him, that they were going to have to solve those problems."

(3) Educational Transitions

Transitions in educational programming and situations where educational programs were not operating smoothly were very stressful for parents and for their children with autism. This was probably due to the difficulty many individuals with autism have adjusting to change. At the time of the initial interview, one child was undergoing a transition in educational placement, which had affected the entire family. The parent said, "My concern is now that the situation will be resolved and that he'll be eager to go back to school and take part. And of course, the fact that it's a change in itself could be trying to him, being that it's an entirely new school." Another parent described her child's first day in a new program. "All that change was very traumatic for him. For the first day, he was only there for an hour and a half and I had to take him home, because he was throwing tables and chairs and just 'freaking right out.' The first few days were very traumatic."

Situations where the child's programming was not running smoothly were often difficult for the parent and children. Several parents reported difficulty during a recent school support staff strike. "The only real regression we've had so far this year was when those support workers went on strike. There was a lot of tension," said one parent.

(4) Mainstreaming

The issue of mainstreaming, or integrated versus segregated programming, was a concern for most of the parents. Only two of the individuals with autism in this study were currently attending regular classes in a junior high school. Both of these students were high functioning and able to complete the same work as their classmates. The parent of one these students felt that adequate preparation in a special education classroom was crucial to placement in an integrated setting. This parent likened placing an unprepared student with autism into a regular classroom to placing an untrained boy into a boxing ring with the heavyweight champion.

However, another parent felt that placement in a specialized setting had made it more difficult for her child to relate to non-handicapped children. She said, "Once I got him into a more specialized education program, and a more specialized way of dealing with him, all of a sudden, I just could not put him back in with regular kids any more. I tried to put him in the same daycare that he had gone to the year before. You'd think that because it was a familiar place, he would be okay with it, but he just could not cope any more."

One parent was impressed with a pupil-assisted learning program that was implemented in her child's school. She said, " The worst kids in the school fought to be those kids pals." For the first time, her child had real friends in the regular school program. One family had tried setting up a Circle of Friends for their child, but found that it had not been successful.

(5) Related services

The families in this study also mentioned several related services, which were required by their adolescents with autism. While some of these services were readily available, others seemed to be lacking.

(a) Behavioral counselling: Three of the parents mentioned the need for behavioral counselling, in order to deal with their child's difficult behaviors. One of the parents had used a social service agency, which helped families to develop in-home programs for individuals with developmental disabilities and behavior problems. They had found this service to be quite helpful. However, some of the higher functioning individuals with autism did not qualify for this service. Two of the families had started looking for psychologists, or other professionals, who would do behavioral counselling. Both felt that there was a lack of qualified professionals with this expertise. Few professionals had experience both in adolescent issues and in managing autistic behaviors. As one parent said, "We wanted to find somebody who is sensitive to the changes that occur during puberty, and there's a void." When parents did find a qualified professional, financial assistance to help with the cost of counselling fees was not available.

(b) Transportation: Transportation was another related service, which could not always be utilized by individuals with autism. Although generic transportation services were available for people with disabilities, sometimes they could not be used by individuals with autism, due to severe behavior problems. As one mother said, "I suppose I could get transportation for him, but sometimes when his behaviors escalate just when it's time for him to leave, how can you put him on a bus?" Parents had typically solved this problem by providing transportation themselves. One parent reported that the school board had offered to pay the same amount for transportation, as they would pay the bus company. Another parent reported receiving an allotment of money to pay for cab fares, when her child's behavior did not permit taking public transit.

(c) Support personnel: Another related services required by most of the adolescents with autism was the provision of support personnel, to assist them in their educational programs and in accessing facilities in the community. Some parents mentioned that staff training was an issue. One parent felt that his child's best aides were university students, in either psychology or speech pathology, and felt practicuum experience with individuals with autism might be incorporated into some of these programs. According to this parent, selection of the support worker was more successful when the family had input in choosing the worker. Several families reported having a particularly difficult time during a recent support staff strike in the public school system. They realized how essential these workers were for their children's education, and how much their children were affected by staff changes.

(d) Speech pathology: One family was convinced that speech pathology services had been the key to their child's success. The parent said, "Speech therapy to me is the key to getting a child with autism, a high-functioning one at any rate, to function properly." This parent also felt that the speech therapist should work very closely with the individual's communication aide. Apparently few, if any, of the other adolescents with autism in this study were currently receiving speech pathology services.

(e) Summer programming: Summer programming was another related service that was required by many of these adolescents with autism. Many regressed during periods of change, and had particular difficulty in unstructured settings. One parent described some of the arrangements she had tried for summer programming. For one summer,the child had attended a daycare setting, but the following summer, the staff refused to take him back. The next summer, he attended a day program for children with mental and physical handicaps. As a teenager, he had attended a summer day camp for youths with disabilities. However, he could only attend this program for a few weeks out of the summer, and required his own program aide.

(f)Diagnosis/Assessment: Diagnostic and assessment services were another resource, which many of the parents felt was lacking. Some thought that inappropriate assessment devices had been used with their children. One parent felt that if an appropriate diagnosis had been made earlier, her child might be doing much better than he was. Services for assessing adolescents and adults with autism appeared to be especially difficult to find.

(g) Relief care: Relief care was also an additional service, required by many families. Some mentioned using group homes, which offered occasional respite care. Others preferred to use in-home assistance. One family had written an individualized service plan for their child and had regular workers to help with community outings. This appeared to be an ideal situation. Most families agreed that relief care was harder to obtain for an adolescent than it was for a younger child.

(h) Financial assistance: Related to relief care was the family's access to financial assistance for their child's needs. Most families were eligible for some government funding, although in some cases the assistance offered did not appear to be what the individual needed. The family who had developed an individual service plan seemed to have found a suitable arrangement for funding and service provision to meet their needs.

In summary, the students with autism in this study were being served in a variety of different programs. Most parents seemed satisfied with their children's current educational placement. The importance of early intervention and expertise in dealing with students with autism were discussed. Parents needed to monitor their children's educational programs, which involved considerable time demands. Transitions in educational programs and situations where programs were not running smoothly were stressful for families. Mainstreaming was also a concern. In addition, related services, such as transportation, behavioral counselling, personal assistance, speech pathology, summer programming, assessment services, relief care and financial assistance, were required.

Theme 5: Relationships with Professionals

All of the parents interviewed for this study described both negative and positive experiences with the various professionals who were involved with their children. Generally, a variety of different professionals had been involved, including doctors, psychiatrists, psychologists, speech pathologists, administrators, teachers, aides and other support workers. Some of the experiences had occurred when the children were much younger, such as during the initial diagnosis. Other experiences were more current. Some of the parents indicated that relating to professionals created a considerable amount of stress in their lives. In particular, one parent felt that half of the stress was caused by dealing with the autism itself, while the other half of the stress was caused by dealing with professionals. However, almost every parent also gave a glowing account of at least one outstanding professional, who had gone beyond the call of duty to help the child with autism. Examples of both positive and negative relationships with professionals will be now discussed. The reader should remember that these experiences are related entirely from the parent's perspective, and therefore contain only one side of the story. However, the examples given will hopefully serve to make professional working in the field aware of attitudes and behaviors, which are either appreciated or disliked by parents of children with autism.

(1) Negative relationships with professionals.

(a) Reluctance to diagnose: Some parents felt that professionals had been reluctant to make an initial diagnosis of autism, and that services had not been made available until the label had been applied. One child had spent an entire month in a hospital setting undergoing extensive testing and behavioral observation, but a firm diagnosis was still not made. The parents felt that the diagnostic sessions had been particularly harsh. The mother said, "They didn't really diagnose him as autistic. They rode the fence. They didn't really want to label him." It was not until a later diagnosis that adequate services were received.

Another parent felt that her child might have made more progress if an earlier diagnosis had been made. She said, "I felt that had a little more research been done, when he finished the preschool program, he might be at a higher level than he is right now."

(b) Excessively negative prognosis: Several parents were bothered by the fact that some professionals had given an unnecessarily negative prognosis, regarding their child's future. One couple was told that there was nothing that could be done with their child. They were advised to simply take the child home or find an institutional placement. With proper education, this child had, in fact, done exceptionally well. The parents were still angry that the professionals did not offer them any hope. Another parent was told not to expect her child to progress beyond a twelve year old level. Whether or not this prediction proved to be true, the parent felt that specific limitations on the child's ability to progress should not be given.

Negative prognosis for the future did not just occur at the time of the initial diagnosis. For example, one parent was recently told by a professional that her child would end up in jail if his difficult behavior was not controlled.

(c) Blaming parents: Despite the fact that autism is now believed to be a physical, rather than psychological disorder, some parents had still been in contact with professionals who blamed them for their child's disability. One mother was told by her son's doctor that he thought the problem was primarily emotional, and was due to environmental deprivation. The doctor questioned her parenting abilities. The mother recalls, "He was wondering how well I was doing as a mother, and it was very concentrated on me. My husband was there at the time, but it was very pointed. Very, very pointed."

Even when they were not seen as the initial cause of the problem, parent still sometimes felt that professionals were blaming them for their response to the child's disability. One couple was made to feel unusual because they wanted to be involved in making a placement decision for their son. The mother explained, "We have a vested interest in his education, as parents, and the administration said,'There are not many parents that come in and want to be involved with the decisions.' And I was accused at this particular meeting of being overbearing." She later added, "It's difficult when you're accused of being the 'oddballs.' I mean it's enough to have a child with a disability and be different."

(d) Lack of knowledge and expertise: One thing that particularly upset parents was when professionals claimed to have knowledge and expertise in dealing with individuals with autism, when in fact they did not. As one parent said, "You don't learn about autism out of a book. You learn about it in hands-on experience. I've talked to a lot of people that seem to feel that they know quite a bit about autism, but they learned it out of a book." Lack of knowledge sometimes resulted in professionals doing inappropriate assessments, or making inappropriate recommendations for treatment.

(e) Ineffective communication: One of the major problems between parents and professionals seemed to be ineffective communication. Parents frequently felt that professionals did not listen to them. One mother said, "I do push a bit at the school level, and say he needs more of this, or more of that. They do seem to listen to me, at least part of the time." Another parent echoed this concern. "They half listened, but yet really didn't." Another mother said, "I approached my doctor, and my doctor said that I was being foolish. He didn't pay much attention at all to my concerns."

The following examples demonstrate how parent's concerns were not taken seriously. One parent noticed that her child was not progressing in a particular program. She kept on insisting that her child might be autistic, but it took a long time before she finally got her way, and had someone assess the child. Her child finally was diagnosed as being autistic, and a more effective program was implemented. Another parent had requested that her child be integrated into the regular high school program, but was told by a teacher that it had been tried once and hadn't worked. An integrated program was not provided for her child, and he had regressed somewhat during that school year.

(f) Battling the system: Related to the difficulties with parent/professional communication, parents unfortunately often felt that they were "battling the system", in order to get what they felt to be appropriate services and education for their adolescents with autism. A number of phrases were used by parents to describe the adversarial nature of many contacts with professionals. Parents described "being challenged by the school system", "being tested", "facing the administration", "going through summit conferences" and "fighting the system." They described these encounters as being frightening and confusing. One parent mentioned feeling overwhelmed at one meeting, because she attended without her husband and was outnumbered by the professionals. Parents wondered why, on top of everything else, they had to go through these kinds of experiences. As one parent put it,"We're angry at the fact that it has to be done to parents and kids. I mean there's this big, beautiful system, with lots of professionals, but it's still dumped right back in our laps."

One parent lamented the fact that parents were not very effective in advocating for services and in communicating with professionals, because they had never received any training in these skills. "It's sad,isn't it, when you plunge in there, and you bring in what you've got from your own experience, and yet it's not very efficient, because you make mistakes." She added, "Parents aren't really given any formal education or strategies. It's like going into politics. We haven't ever been properly prepared. We've learned through trial and error."

(g) Inadequate service provision: Sometimes even when parents have advocated appropriately for services, those services are lacking, or are not properly administered. One parent described the battle to obtain speech therapy services. Long hours had been spent discussing this need with anyone who would listen, including several government officials. Other parents described teachers, who were not willing to put any extra time or effort into having a child with special needs in the class. Another parent mentioned that principals did not always spend the money allotted for the child's education on that child, but put the money into the school's general budget. Aides, designated to work with a certain child, sometimes spent their time photocopying materials for the teacher, instead of actually working with the child. One parent recommended that parents become involved in the budgeting process of the school. Parents also needed to monitor the child's program throughout the school year, to ensure that adequate provision of service was being carried out.

(2) Positive relationships with professionals.

Often the professionals most respected by parents were those who were in direct daily contact with the child, such as teachers and aides, rather than those who had a more distant relationship, such as administrators and doctors. The positive characteristics, which parents most appreciated in professionals were often the exact opposites of the negative characteristics previously described. Some examples of these characteristics will now be discussed.

(a) Knowledge and experience: Parents appreciated those professionals who exhibited knowledge and expertise in the field of autism. One mother said, "Getting it from people that are expert is important. It helped greatly having that reassurance that there was a resource right here." Parents particularly appreciated when professionals with experience could offer them hope for the future. One parent was encouraged to hear, from a knowledgable professional, about a teenager with autism who had gone through a very difficult time during adolescence, but had emerged, at age twenty-five, as a happy, independent adult. The parent said, "We hang on to words like that, because it's hope. It was hope from someone, who had worked and had the years of experience, the knowledge and the facts. Not just to be hopeful, but actually hope based on experience. So I wish there were more people like that available for us, because we hang on to those words."

One father expressed appreciation for several excellent aides, who had worked with his child. They were university students, with a background in either speech pathology or psychology. The parent felt that individuals with this type of training made the most suitable aides for students with autism.

Parents also liked professionals who applied their expertise to provide quality programming for their children. One parent praised a teacher, "who had really worked hard to get his behavior manageable." Another mother was very pleased with a teacher who had implemented a successful pupil-assisted learning program, which had resulted in the inclusion of students with disabilities into the total school program. Parents not only appreciated professionals with knowledge, but those who translated their knowledge into effective treatment of the adolescent with autism.

(b) Responsiveness to parental concerns: Parents respected those professionals who listened to their concerns, and took them seriously. One parent had spent a considerable amount of time with a teacher, providing information about autism and effective teaching strategies. The teacher used this information to provide a successful program for the child. "She listened. She listened quite well. She accomplished a lot with him and he just blossomed in her class." In another example, a principal had allowed the parents to have input into interviewing and hiring an aide to work with their child. The parents appreciated having their views considered.

(c) Support: Parents also appreciated those professionals who offered support and assistance, particularly during a crisis period. One teacher had been especially supportive in helping the family understand the hormonal changes their adolescent was going through during puberty. The mother said, " The teacher has been wonderful. He keeps reminding us that it's okay and that maybe we should allow him to go through these normal changes and painful things." The same family mentioned that during a difficult placement decision, the school had "rallied 100% behind us with letters, immediately, promptly." The mother said, "They gave us confidence. They helped us along."

(d) Respect for the individual with autism: Another characteristic that parents really appreciated in professionals was a genuine respect for the individual with autism, as a valuable human being. One teacher exhibited that attitude by assuring the parents, "He's an okay guy. He's a neat guy." Another parent described a babysitter, who although not specifically trained to work with individuals with autism, genuinely liked her child. "She seems to just love him. She seems to like coming and looking after him very much. She gets a kick out of him. She laughs at him, but she's laughing, in a joking manner, with him." Parents feel much more comfortable with professionals who can see the positive qualities in their children with autism.

In summary, both negative and positive examples of relationships with professionals have been described from the perspective of the parents of a child with autism.

Parents did not like professionals who were reluctant to make a diagnosis, gave an excessively negative prognosis, blamed the parents, lacked knowledge about autism, or failed to listen to the parents. They were concerned about inadequate service provision, and did not like to feel that they were "battling the system", in order to obtain services for their child. On the other hand, parents did appreciate knowledgable professionals who offered them hope based on experience, who listened and responded to their concerns, and who offered support during periods of crisis. Most importantly, parents appreciated professionals who genuinely liked and respected their adolescents with autism.

Theme 6: Independence and Future Concerns

All of the interviewed families mentioned specific concerns about the independence of their adolescents with autism. They also related their hopes and fears for the future. While independence and future concerns will be considered as separate issues, they are definitely interrelated, as an adolescent's current ability to function independently will affect future placements and outcomes.

(1) Independence.

Three specific aspects of independence were discussed by most of the families in this study. These areas were (a) vocational training, (b) recreational activities, and (c) daily living skills. Each of these topics will now be addressed.

(a) Vocational training: Many of the individuals with autism in this study were involved in some type of vocational training and work experience, although none of the parents mentioned having a definite long-term plan in effect that would facilitate the transition from school to employment. One adolescent with autism was attending a vocational high school for students with mental disabilities. The parents had chosen this program because of the variety of options it offered for vocational training and work experience.

As part of a work experience program, one student helped to deliver flyers in the neighborhood near the school. Another adolescent, whose school program consisted primarily of academic subjects, had a paper route. The mother said, "I wanted him to get some job experience. I think it's important to give him the idea of what work is, and that he can be part of the working world."

One parent hoped the child would gain enough education to be accepted into some type of valuable employment, perhaps in the field of computers. This parent said, "I've tried to ingrain in my son that education is first and foremost, when he's young, and that he should get as much education as he possibly can to fit into the type of employment he wants later on."

(b) Recreation and leisure activities: The range of leisure and recreational activities appeared to be limited for many youths with autism. One mother reported that her child had very few interests other than watching television and playing video games.

One child had a traumatic experience with athletic activities at a younger age. Since then, this child did not like to participate in sporting activities, but got exercise by walking to school and riding a bike. Another teenager with autism liked to participate in some of the activities at a local boy's and girl's club. Another family hired support workers [illegible] take their child on recreational outings, such as bowling and swimming. However, in general the range of recreational and leisure activities for these teenagers with autism was quite restricted.

(c) Daily living skills: Most of the individuals in this study were fairly independent in terms of self-help skills, such as grooming and dressing. During the follow-up interview, two of the parents indicated that they were now able to leave their adolescents with autism alone without supervision, for a few hours at a time. Both individuals were dealing quite well with this new responsibility.

Another area of daily living skills mentioned by some of the parents was spending money. One youth had saved up a substantial amount of money, but did not want to spend it on anything. Another was given small amounts of money, as a reward, and liked to spend it on treats. One teenager with autism was able to shop independently at the corner store.

While these examples indicate the beginnings of independent functioning, they are very limited, when compared with the independence enjoyed by most normal teenagers. There is also a great discrepancy between the current skills of these adolescents with autism, and the skills they would need to be able to function independently as adults. Consequently, parents had both hopes and fears regarding their children's ability to function independently in the future.

(2) Future concerns.

(a) Hopes for the future: Most parents hoped that their adolescents with autism would be able to achieve their fullest potential, whatever that might be, and live happy, productive lives. One parent said, "We've had one goal and that's for him to function as normally and as 'mainstreamed' as possible, and basically to try and get him as independent as we possibly can." Another said, "My desire would be that he enjoys his life during each day, and looks forward to it...As long as he's a happy person. That's my main worry for him, that he will look upon life as something to be enjoyed, and not something to be endured."

(b) Fears for the future: Families expressed a considerable amount of uncertainty about the futures of their adolescents with autism. Some of the concern expressed was fairly short-term, such as whether the child would be able to manage eating lunch in the school cafeteria in the coming school year. Other concerns were more long-term in nature, such as where the individual with autism would live as an adult, who would provide care, and whether the family would be able to continue to cope. As one family stated, "We still have a lot of fears about what is happening now, and long term, too." They had similar concerns about their non-handicapped son, but had tended to focus on their concerns about their child with autism.

A major concern for parents involved their own ability to continue coping over time. This was often expressed by their observations about other families of older individuals with autism. One mother said of other parents, with whom she had come in contact, "I've seen some individuals who are washed out. After years and years of this, they just get washed out. And that's my biggest fear, that I'll become one of these dependent, washed-out, burned-out individuals, and it could happen." Another mother referred to the experience of William Christopher, an actor on the television show "MASH", and his wife, who have a son with autism. She observed, " The two of them had put a lot of effort into this kid. And when he hit puberty, that was it. He attacked his mother...They tried different kinds of drug treatments. They tried different sorts of behavior modification. They couldn't control his behavior at all. And after all those years and years and years of having him a part of their family, they had to put him in an institution. It's really scary, when you hear stories like that. It's quite awful." Another family said, "It's like there's no guarantee. We'd like to have a guarantee that everything will work out."

Parents were also concerned about future placement for their child. One parent asked, "What if things go wrong? Well, then where will he be? How will he be looked after? " Another mother was concerned, based upon comments made by a professional, that her child could end up in a jail, or correctional institute.

One mother, although she felt that her teenager would become steadily more independent, could not foresee an independent living situation. She envisioned a group home setting as a possibility. She said, "He may be able to be in a place, such as a group home, where he could go to work, come home, but there would be one person, to look after four adults, and make sure that different things are done." However, she acknowledged other possibilities. "I may have him all my life. I don't know. If anything should happen to me, my other children would take over."

Two of the other parents also mentioned their own mortality, and their concerns about what would happen to their children when they were no longer there to look after them. One parent said, "We could die in the meantime and he could go sailing on ahead. It's just that there's no guarantee." Another said, "We want him to be as independent as we can, because we don't know of anybody who's really going to look after him after we're gone."

In summary, parents had both hopes and fears for the future for their adolescents with autism. The hopes involved maximizing their potential for independence, in the areas of vocational training, recreational skills and daily living skills. Their fears involved the uncertain outcomes in terms of their child's future placement, their own ability to continue coping and care of their child, after they were gone.

Probe Questions and Validation

As indicated in the Methods section, a second interview was conducted with each family to validate the interpretation of the initial interview data and to probe for more detail on certain issues. Three probe questions were asked of each family: (1) What do you think are the most important issues for adolescents with autism and their families? (2) How have you coped with your child's disability? and (3) Describe your support system. The responses to each of these questions will now be described. Validation of the results will also be discussed.

(1) Adolescent Issues

Question 1 was asked because the families had discussed their experience parenting a child with autism over the child's entire life. The researcher wanted to ensure that adolescent issues had been adequately covered. In fact, only one new issue was brought up in response to Question 1 that had not been discussed during the first interview. This validation would indicate that parents had discussed adolescent issues during the first interview and that perhaps Question 1 need not have been asked.

The new adolescent issue that was raised in response to Question 1 was the issue of sexuality. This issue was apparently a concern to many parents who were perhaps hesitant to discuss it in response to the more general question asked in the first interview. Parents were concerned with emerging sexuality in their adolescents who were so lacking in social skills. One of the boys had started showing an interest in girls, and always tried to sit next to a girl when he went on rides at the amusement park. This sometimes was not appreciated by the girls he had chosen to sit beside. He had also picked up some "one-liners" or inappropriate remarks, which he would say to girls, even though he didn't appear to understand what they meant.

One adolescent with autism was physically developed, and as his mother phrased it, "is a six year old mentally and an adult physically." Other children had sometimes asked him to show them his private parts, and he didn't know that he shouldn't comply with their requests. The mother worried that he wouldn't know how to take [illegible] of himself if someone ever tried to molest him.

One mother lamented the lack of information available regarding sexuality in people with autism and other types of severe disabilities. She stated, "I don't know if there hasn't been enough attention paid to it. There isn't enough information on what to expect or how to handle it. There really isn't a lot of information to do with sexual questions and concerns."

(2) Coping and Support Systems

The responses to Question 2 and Question 3 tended to merge into one answer, because many parents discussed their support system as one of the ways in which they had coped. Most parents initially stated that they did not think that they had coped very well.

One parent had coped by going to meetings, particularly those related to issues for people with disabilities. She said, "At meetings, you're always working with a group of people who have the same concerns that you have. You get a lot of support. People listen to what you say, which your child doesn't necessarily do. And you're usually successful in some of the things you try to do. You feel you've got a whole community of people working on the same kind of issues. They understand the same kinds of things that you understand. They're wonderful."

Another parent had coped by accepting her child as he is. This parent had found that the more accepting she was, the more accepting other people became.

One parent had coped by reading a lot about autism in order to get as much information about the child's disability as possible.

Several parents reported that becoming involved in personal interests and activities had helped them cope. Several mothers indicated that taking a job outside the home had helped them cope, but sometimes also increased their stress. One mother reported that going back to school had been an important step for her. "My son had been my whole life up to that point. His whole behavior, everything, occupied all my thinking, almost to the point where I couldn't think of anything else. That's when I decided that I should really do something else, so that I'd have another outlet in life. And I just poured myself into those studies." Other interests, such as exercising and playing the guitar were also mentioned.

One parent had coped by becoming more involved in church activities, prayer and spiritual support. "I guess what God did in my life was help me become stronger spiritually, so that I would be better able to deal with things in the natural."

When asked about support systems, one parent replied, "I don't think I have one." Other families referred to a variety of supports, both formal and informal, on which they depended. One parent differentiated between emergency and day to day support. In a recent emergency situation, numerous friends and neighbors rallied around to help. However, fewer people were available to help on a daily basis.

Spousal support was an important coping mechanism for many families. As one mother said, " A lot of times what I did was unload on my husband, whether he liked it or not, because I needed somebody to talk to." One parent mentioned that the other children were a valuable source of support.

Few families had immediate family members near by who could help. They relied on friends to talk to and to provide basic services, such as transportation. However, friends rarely provided respite care. Most families relied on social service agencies to provide relief care. Several families mentioned the support they received from other parents of children with autism, especially through the local association. Several families also indicated that support, especially as the child grew older, was lacking, and that they wished that they had more help with their adolescents with autism.

(3) Validation

Parents were asked to give feedback regarding the themes derived from the initial interview. In general, most parents indicated that the interpretation fit their experiences and went on to give other examples which further illustrated a particular theme or issue. This would indicate that the issues derived from the initial interviews were truly representative of the concerns of these parents.

Summary

The results of this study have been discussed in terms of six consistent themes that emerged from the interview data. These themes included: (1) behavioral concerns, (2) social and communicative concerns,(3) family related concerns, (4) educational and related concerns, (5) relationships with professionals, and (6) independence and future concerns. Results of specific probe questions on adolescent issues, coping strategies, and support systems were also discussed. The researcher's interpretation of these results were validated by discussing it with the co-researchers to obtain feedback. Generally, the co-researchers indicated that the results accurately described their experiences as parents of adolescents with autism. The following chapter will discuss the implications of these results in terms of the objectives of this study. Limitations of the study and personal implications will also be addressed.

CHAPTER 5

Conclusions and Implications

The results of this study were summarized at the end of the previous chapter. These results will now be considered as they apply to the stated objectives of the study, namely: (1) to understand the phenomenon in the lives of the parents interviewed, and (2) to identify needs of adolescents with autism and their families, making recommendations for service provision. In addition, results will be compared to the existing literature on the families of individuals with autism, and families of children who have other types of disabilities. Each of these objectives will be considered separately. Finally, the limitations of the study and the personal implications of the study will also be discussed.

Understanding the phenomenon

Understanding the phenomenon of parenting an adolescent with autism was accomplished in this study through the thematic analysis of interview data. Parents of six adolescents with autism were interviewed regarding their experiences, using phenomenological methodology.

The following six themes emerged from the interviews: (1) behavioral concerns, including specific behavior problems, the effect of puberty on behavior, and behavior management strategies; (2) social and communication concerns, including inappropriate social behavior, communication problems, teasing and rejection, and the inability to form friendships; (3) family-related concerns, including the effects on parents as individuals and the effects on the family as a whole; (4) educational and related concerns, including securing an appropriate educational program, educational transitions, mainstreaming, and lack of related services; (5) relationships with professionals, including both positive and negative relationships, and (6) independence and future concerns, including vocational training, recreation, residential placement, and hopes and fears for the future.

During a second interview, three probe questions were asked and the parents validated the results of the initial interview. The probe questions asked for more detail on adolescent issues, coping strategies and support systems. Most of the adolescent issues had already been raised during the initial interview, with the exception of sexuality. Parents were concerned about the emerging sexuality and physical maturation in their adolescents with autism who were still so socially immature.

A variety of coping strategies, including attending meetings, spousal support, developing personal interests, accepting the child with autism, and spiritual support were used by these parents. Support systems involved both informal supports, such as friends, family, and parent support groups; and more formal supports, such as relief care agencies and various professionals.

Interpretation of the initial interview data was validated by parents, who generally reported that the themes accurately described their personal experiences.

Implications for Service Provision

The results of this study indicate several possible directions for service provision to adolescents with autism and their families, particularly in the local context of the study. Services that parents reported to be lacking include: (1) behavioral counselling that is sensitive to the hormonal changes that might be occurring in adolescents with autism, (2) transportation that is flexible enough to meet the behavioral needs of adolescents with autism, (3) support personnel who are trained to provide educational programming and community access to older individuals with autism, (4) speech therapy services, which are currently difficult to access, to facilitate communication in adolescents with autism, (5) summer programming for adolescents with autism, so that gains made during the school year are not lost, (6) diagnostic and assessment services, which appear to be particularly lacking in the region at the present time, (7) relief care services, which seem to dwindle as the individual with autism grows older, and (8) financial assistance, which is available but not always appropriate to the families' needs. The need for effective behavioral counselling from a family systems perspective seems to be particularly note-worthy, given the families' emphasis on behavioral concerns. Programs to provide social training and sexual education training for older individuals with autism are also desperately lacking.

Regarding future concerns, there also seemed to be a lack of options available for vocational training, recreational programming and residential placement. None of the parents in this study had seriously begun any long range planning for their adolescents with autism. Perhaps it was because of their reluctance to look into the future, but more likely it was because the required services currently do not exist.

Comparison with the Literature

The results of this study are in agreement with the literature on stress and coping in families of children with autism (Bristol, 1979; Bristol, 1984; Bristol & Schopler, 1983; DeMyer, 1979; Wolf, Noh, Fisman, & Speechley, 1981). The fact that families of adolescents with autism do experience significant levels of stress is substantiated by this study. The results of this study are also consistent with the view that stressors faced by families are mediated by other factors, such as coping strategies and social support (Bristol, 1979). Coping strategies identified by parents in this study, such as spousal support, accepting the child, and relying on a social support network, are similar to those identified in previous research (Bristol, 1979; Harris, Gill & Alessandri, 1991; Marcus, 1984; Reddon, 1989).

Although the purpose of a phenomenological study is to understand a phenomenon rather than to provide support for a theoretical framework, the results of this study can be viewed according to family systems theory (Harris, 1984; Konstantareas, 1991; Morgan,1988). The child with autism was seen to affect the parents as individuals and the family as a whole. The families in this study were also imbedded in a variety of other systems, such as the educational system, their social support system and the community at large (Haefele & Henggeler, 1983; Harris, 1988).

Regarding adolescent issues, many of the themes that emerged from this study relate to issues that have already been discussed in the literature (DeMyer & Goldberg, 1983). However, the results of this study seem to indicate a greater emphasis on the behavioral and social concerns of families of adolescents with autism. Perhaps this difference is due to the fact that the co-researchers were not led by structured interview questions, but were free to talk about the issues that concerned them the most.

The results of this study also seem to be consistent with the information available on autism and puberty. Some of the individuals in this study seemed to be continuing to improve, while others seemed to be regressing behaviorally with the onset of puberty. This trend of differing outcomes for different individuals is also noted in the literature (Gillberg, 1984; Gillberg & Schaumann, 1981; Gillberg & Steffenburg, 1987).

The results of this study have both similarities and differences to the one previous phenomenological study on families of children with autism (Dudziak, 1986). In terms of differences, Dudziak's results are presented chronologically, as issues that emerge during different stages of the family's life cycle. Apparently, parents of children of varying ages were interviewed in that study. The present study focused more on the adolescent age group, although some of the families discussed issues that were relevant to when the child was younger.

Another difference between the Dudziak study and the current study was the emphasis in the current study on behavioral and social concerns of parents. Dudziak did mention several behavior problems exhibited by children with autism, particularly during early childhood, such as sleep disturbances, self-stimulatory behavior, resistance to change, destructive behavior and temper tantrums. While these were some of the same behaviors mentioned in the current study, they were not given as much importance in the Dudziak study. Perhaps these issues are more of a concern with parents of adolescents with autism, than with parents of children at varying ages. Alternatively, there could be a difference in interpretation between the two studies. Based on personal experience and the validation by the co-researchers in this study, it is the researcher's contention that behavioral and social concerns do play a major role in the experiences of families of children, particularly adolescents, with autism.

In other respects, the results of the Dudziak study were very similar to those of the current study. Themes that were discussed in both studies included negative and positive relationships with professionals, especially diagnostic issues and professional responsiveness to parental concerns; educational concerns, including selection of appropriate educational programs; and family-related issues, such as personal restrictions, relief care, and the effect on siblings.

The adolescent issues, cited by Dudziak, were also similar to some of the issues discussed in the current study. Lack of services, social difficulties, independence and future concerns were mentioned in both studies.

In general, the results of these two studies seemed to be quite consistent, with the exception of the stronger emphasis on behavioral and social concerns of parents noted in the current study.

Comparison to Families of Children with Other Disabilities

When compared to the results of previous phenomenological studies of families of children with other types of disabilities (Adams,1987; Hancock, 1988; Morgan, 1987; Waggoner, 1988), the results of this study indicate that parents of children with autism share many of the same concerns expressed by parents of children with other types of disabilities. Concerns about education, relationships with professionals, the impact on the family and future planning appear to be common to families of children with all types of disabilities. However, in this study, parental concerns about behavior and social relationships may be more specific to the disorder of autism.

The researcher suggests the possibility that some children with autism may have an even more profound effect on their families than children with other disorders, although this cannot be resolved from the current study, and requires further investigation. Adams (1987) referred to the predominant influence of the child with multi-handicaps on the mother's life-world. Autism, because of it's pervasive nature, may have a predominant influence on the life-world of the entire family. Results of quantitative studies that compare families of children with autism to families of children with other types of disabilities, have tended to support the notion that families of children with autism experience greater stress and difficulties than do other families (Donovan, 1988; Holroyd & McArthur, 1976; Konstantareas,1991). Perhaps this difference is related to the behavioral and social difficulties exhibited by individuals with autism, as previously discussed.

Limitations of the Study

This study had several limitations. First, a small sample of parents was interviewed. This is not a major problem for phenomenological research, as the meaning of a phenomenon in a person's life can be determined with only one individual. However, generalizability may be limited. All of the parents interviewed for this study were members of one association. Perhaps their experiences might differ significantly from families who are not involved in a parent association. Also, the parents interviewed for this study had adolescents with autism who were all currently living at home. The experiences of families who had placed their adolescents in alternative residential facilities were not sampled. Children who were not living at home may have had more severe behavior problems, and may have been more stressful for their families to manage. Alternatively, families of adolescents with autism who are not living at home might be less stressed, since they are no longer required to provide daily care. The results of this study are not readily generalizable to families of adolescents with autism who do not live at home. Validation of the results of this study with families of adolescents with autism who live elsewhere would need to be conducted to increase generalizability.

Another limitation of this study relates to the age of the adolescents with autism sampled. The oldest individual with autism was only 15 years old, because older teenagers with autism were not readily available in the group sampled. Perhaps older individuals with autism tend not to live at home, or perhaps their families are no longer involved in parent advocacy groups. However,the results of this study may not be generalizable to families of individuals with autism who are 16 years or older. The extent of generalizability could be determined by validating the results with families of older adolescents with autism.

Another possible limitation of this study could have been the researcher's identity as the parent of a child with autism. While every attempt was made to bracket presuppositions and biases, it was very difficult to totally empty oneself of the effect of experiences that are so much a part of one's own life. It is possible, perhaps even likely, that personal experiences in dealing with my own son may still have colored my interpretation of some of the data. However, the themes that emerged from this study were validated by the families who participated. In some ways, the researcher's personal involvement in the phenomenon may have resulted in greater sensitivity and awareness of issues that might otherwise have been overlooked. Being the parent of a child with autism was definitely an asset in establishing rapport with the co-researchers. Only one of the co-researchers required even minimal prompting in response to the open-ended interview question. Possibly, co-researchers may have been more open and candid in their responses because they knew they were talking to someone who understood their situation. Hannam (1988) and Naseef (1989), who both conducted qualitative studies as parents of children with disabilities, noted similar benefits.

Personal Implications of this Study

The completion of this study has fulfilled a psychological need for me to understand, in a deeper sense, my own experience as the parent of a child with autism. I have come to the realization that I must no longer be afraid of looking into the future because it is essential to begin planning for my son now. A great deal of work must be done to ensure that the required programs are in place when he needs them.

I have also become more aware of my own physical and psychological exhaustion, that as my son gets older I can no longer care for him entirely on my own. As much as I love my son, I need to stop centering my life around his needs. He needs to develop his independence apart from me, and I need to expand and grow in my own personal life. I agree with Pivato (1990) that normalization for individuals with severe disabilities has often resulted in de-normalization of the family. I sense a need to restore balance in our family, while still somehow providing normalizing experiences for my son.

Finally, throughout the writing of this thesis, I have come to realize that having an adequate support system is essential for effective coping in families of individuals with autism. I am so grateful for the special group of family, friends and professionals, who have stood by my family and have so willingly offered their practical help and support. What has seemed insurmountable alone, has been made bearable, at times even enjoyable, because others have walked alongside. I encourage other families of children and adolescents with autism to actively seek out the supports that they need. Hopefully, the results of this study will provide professionals and other people in the community with a better understanding of the experiences of families of individuals with autism, enabling them to provide the empathy and practical assistance that these families require.

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APPENDIX A

Interview Consent Form

I agree to participate in this parent-interview project conducted by Layne Fong for her M.Ed. thesis, under supervision of Dr. L. Wilgosh and Dr. R. Sobsey. I also agree to having the interviews tape-recorded with the understanding that complete confidentiality of my name, identifying characteristics and personal opinions will be guaranteed. I understand that results will be reported as issues and concerns commonly raised by parents and will not be associated, in any way, with individual parent identities.

Signature (parent)

Signature (researcher)

Date

APPENDIX B

Demographic Information

Child's age:

Child's Date of Birth:

Child's Sex:

Diagnosis:

Severity:

Current Educational Setting:

Parent's Age:

Parent's Education:

Parent's Employment:

Parent's Marital Status: