

This is to certify that the

thesis entitled  
QUALITY OF LIFE IN FAMILIES WITH AUTISTIC  
CHILDREN: A COMPARISON WITH FAMILIES  
OF NON-HANDICAPPED CHILDREN

presented by

Mary McPhail Gray

has been accepted towards fulfillment  
of the requirements for

Ph.D degree in Family Ecology

Date Aug. 1, 1980

Herman Hildebrand  
Major professor  
Margaret Bullock



MAY 03 '87

000 A 128

OCT 25 1993

JAN 09 2005

AUG 12 2009

070609

OVERDUE FINES:  
25¢ per day per item

RETURNING LIBRARY MATERIALS:  
Place in book return to remove  
charge from circulation records

MAY 28 '88  
200 D334

MAY 88

© 1980

MARY McPHAIL GRAY

All Rights Reserved



QUALITY OF LIFE IN FAMILIES WITH AUTISTIC  
CHILDREN: A COMPARISON WITH FAMILIES  
OF NON-HANDICAPPED CHILDREN

By

Mary McPhail Gray

A DISSERTATION

Submitted to  
Michigan State University  
in partial fulfillment of the requirements  
for the degree of

DOCTOR OF PHILOSOPHY

Department of Family Ecology

1980

## ABSTRACT

### QUALITY OF LIFE IN FAMILIES WITH AUTISTIC CHILDREN: A COMPARISON WITH FAMILIES OF NON-HANDICAPPED CHILDREN

By

Mary McPhail Gray

Purposes of the study were to: (1) explore the effects of autistic child on quality of life in families, (2) compare self-reported affective evaluations of life by autism parents with evaluations of life by parents of non-handicapped children, (3) identify the resources which are the most powerful predictors of family life evaluation for parents of autistic children in comparison to parents of non-handicapped children, (4) identify the evaluations of people and shared time resources which are the most powerful predictors of parent evaluations of family life in autism families in comparison to families with non-handicapped children, (5) investigate the differences in patterns of affective evaluations of life and family life in mothers of autistic children as compared with fathers, (6) describe the differences in affective evaluations of life, family life and selected resources by autism mothers who work for pay out of the home compared with autism mothers who do not.

Data for the 22 autism families were collected in January and February of 1980 on individual self-administered written questionnaires

completed by men and women in their homes in the presence of the researcher. Data for the 237 families of non-handicapped children were collected in the winter of 1978 on the same self-administered written questionnaires as part of the Quality of Life Research Project of the Departments of Family and Child Sciences and Human Environment and Design at Michigan State University. All families lived in the same household with at least one school-aged child. The autism sample was a volunteer group from a larger survey and represented autism families who were enough similar to those previously described in the literature to allow meaningful comparisons of results. The autism families and the families of non-handicapped children showed strong demographic similarities except for a somewhat smaller mean family size in the autism sample.

Respondents evaluated their overall quality of life and family life by resources selected from Rettig, and by identified people and shared time resources, utilizing a terrible-delighted interval scale.

Results of Pearson product moment correlations and forward stepwise regression analysis indicated that when evaluating family life, autism women consistently substituted variables evaluating children and shared time with children for variables evaluating spouse and marriage. Autism men consistently responded in patterns which were more similar to the parents of non-handicapped children.

For autism women, people and shared time resources accounted for 52 percent of the variance in evaluation of family life; the

Rettig resources accounted for only 42 percent of the variance in evaluation of family life. For autism men, the Rettig resources accounted for 82 percent of the variance in evaluation of family life as compared to only 63 percent accounted for by the people and shared time resources. The Rettig resources were more powerful predictors of affective evaluations of family life for both men and women in families with non-handicapped children than the people and shared time resources.

In cross tabulations of husbands' and wives' evaluations of life, family life, spouse, marriage and children, the autism couples showed the highest agreement for evaluation of children, and the least agreement on evaluation of marriage and life-as-a-whole. While the autism parents' evaluations of their spouse were generally high, women do not use this variables to evaluate their satisfaction with family life. Family, for autism women, was more directly linked to life with children than was true for autism men or men and women in families with non-handicapped children.

When autism women were separated into employed and unemployed samples, the employed women showed significantly higher evaluations of overall life and satisfaction with sexual relationship than the unemployed women.

## DEDICATION

To  
Ernest and Luella Gray  
for providing me a  
quality of life  
which has enabled me  
to Love and to Learn

## ACKNOWLEDGEMENTS

The quality of this research has been enhanced by a unique group of individuals who supported me in a variety of professional and personal ways. I have been enriched and moved by them all.

I acknowledge -

Dale for his love and his intense and brilliant challenges of mind and spirit.

Elizabeth for her capacity to understand and know the complete range of my brilliance and stupidity.

Sean for his watchful and honest reflection of who I am.

Morgan for his life woven into the life of this work.

My fellow students, especially Shirley Gogoleski and Kathryn Rettig for their love, intense sharing and challenge to excellence.

My major professor Dr. Verna Hilderbrand who has through the years of my Master's and Ph.D. work proven a true friend, a loyal and compassionate guide, and a professional mentor.

My committee, Dr. Beatrice Paolucci, Dr. Margaret Bubolz and Dr. Ronald Wolthius for their uniqueness, their inspiration, their respect and support of me through an elongated student experience. I aspire to their qualities of ethics, scholarship and humanness.

The college of Human Ecology at Michigan State University for financial support through assistantships and Fellowships.

The first mothers--Donna, Evelyn and Florence who taught me so much that I was blinded by the need to know more.

Cindy Jennings for support and skill "above and beyond" in typing the manuscript.

Frank Jenkins for his skillful, caring and supportive consultation around the statistical analysis.

## TABLE OF CONTENTS

	Page
List of Tables . . . . .	.
 Chapter	
I. INTRODUCTION. . . . .	1
Statement of the Problem . . . . .	1
Need for the Study . . . . .	6
Conceptual Framework . . . . .	9
Objectives. . . . .	11
Assumptions . . . . .	13
Definitions . . . . .	13
Hypotheses and Questions . . . . .	15
Limitations . . . . .	19
II. REVIEW OF RELEVANT LITERATURE . . . . .	21
Early Diagnostic History of Autism. . . . .	21
Literature on Epidemiology and Parents . . . . .	24
Parents and Socioeconomic Class. . . . .	31
Family Reactions to Child . . . . .	38
III. METHODOLOGY . . . . .	62
Autism Sample Selection . . . . .	62
Autism Sample Description. . . . .	65
Oakland Sample Selection . . . . .	69
Oakland Sample Description . . . . .	69
Data Collection . . . . .	71
Instrumentation . . . . .	72
Description of the Variables. . . . .	73
Data Analysis. . . . .	79
Statistical Methods and Assumptions . . . . .	79
IV. FINDINGS . . . . .	90
Objective A. . . . .	90
Objective B. . . . .	92
Objective C. . . . .	97
Objective D. . . . .	113
Objective E. . . . .	131
Summary of the Findings . . . . .	135



Chapter	Page
V. LIMITATIONS, CONCLUSIONS, DUSCUSSION AND IMPLICATIONS. . . . .	141
Limitations . . . . .	141
Conclusions . . . . .	144
Discussion . . . . .	147
Implications. . . . .	152
Beyond Hypotheses Testing . . . . .	155
APPENDICES . . . . .	160
A. NSAC Definition of Autism. . . . .	161
B. Questionnaires . . . . .	167
C. Demographic Tables . . . . .	214
D. Cross Tabulation Tables . . . . .	236
BIBLIOGRAPHY . . . . .	246

## LIST OF TABLES

Table		Page
1	Questionnaire Items Used to Measure Variables Under Study. . . . .	76
2	Descriptive Statistics for Means of Autism and Oakland Parents on Affective Evaluations of Satisfaction with Family Life and People Resources . . . .	93
3	T-Tests of Means of Affective Evaluations of Selected Domains and Resources for Women in Autism and Oakland Group. . . . .	
4	T-Tests of Means of Affective Evaluations of Selected Domains and Resources for Men in Autism and Oakland Groups . . . . .	96
5	Summary of Spousal Agreement for Life-As-A-Whole, Family Life, Marriage, Spouse and Children in Oakland and Autism Groups. . . . .	98
6	Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Marriage and Resources Received, order not specified for Women in Autism Group . . . . .	101
7	Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Marriage and Resources Received, order not specified for Men in Autism Group . . . . .	104
8	Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Satisfaction with People and Shared Time, order not specified for Women in the Oakland Group. . . . .	106
9	Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Satisfaction with People and Shared Time, order not specified for Men in the Oakland Group. . . . .	108

Table		Page
10	Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Satisfaction with People and Shared Time, order not specified for Women in the Autism Group. . . . .	109
11	Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Satisfaction with People and Shared Time, order not specified for Men in the Autism Group. . . . .	110
12	Summary of Paired T-Tests for Affective Evaluations of Selected People Resources by Mothers and Fathers of Autistic Children. . . . .	114
13	Pearson Correlation Coefficients (r) for Evaluations of Family Life by Satisfaction with Resources Received for Men and Women in Autism and Oakland Groups . . . . .	116
14	Pearson Correlation Coefficients (r) for Evaluations of Family Life by Satisfaction with Resources Received for Women in Autism and Oakland Groups. . . . .	119
15	Pearson Correlation Coefficients (r) for Evaluations of Family Life by Satisfaction with Resources Received for Men in Autism and Oakland Groups . . . . .	121
16	Summary of Highest Pearson Correlation Coefficients for Evaluations of Family Life by Satisfaction with Resources Received for Women in Autism and Oakland Groups . . . . .	123
17	Summary of Highest Pearson Correlation Coefficients for Evaluations of Family Life by Satisfaction with Resources for Men in Autism and Oakland Groups . . . . .	124
18	Summary of Highest Pearson Correlation Coefficients for Evaluations of Family Life by Satisfaction with Resources Received for Men and Women in Autism Group . . . . .	125
19	Means of Evaluations of Selected Resources Received by Men and Women in Autism and Oakland Groups . . . . .	127
20	Pearson Correlation Coefficients of Evaluations of Family Life with Evaluations of Selected Resources Received for Men and Women by Autism and Oakland Groups . . . . .	128

Table		Page
21	Paired T-Tests of Means of People and Shared Time Resources for Men and Women in the Oakland Group. . . .	129
22	Paired T-Tests for Means of People and Shared Time Resources for Men and Women in the Autism Group . . . .	130
23	Summary of T-Tests of Means of Affective Evaluations of Life-As-A-Whole, Family Life, Satisfaction With People, Shared Time, and Resources Received; Means for Employed Women in Autism Group Higher than Unemployed Women in Autism Group . . . . .	132
24	Summary of T-Tests of Means of Affective Evaluations of Life-As-A-Whole, Family Life, Satisfaction With People, Shared Time, and Resources Received; Means for Unemployed Women in Autism Group Higher than Employed Women in Autism Group. . . . .	133
25	Summary Statistics for Men and Women in Autism Group on Affective Evaluation of Independent Variables. . . .	136
C-1	Age of Autistic Child in Two Autism Groups. . . . .	214
C-2	Presence of "Other Handicapping Conditions" in Two Autism Groups . . . . .	214
C-3	Presence of Verbal Ability in Two Autism Groups . . . .	215
C-4	Number of Children in Families of Two Autism Groups. . . .	215
C-5	Age of Mothers in Two Autism Groups . . . . .	216
C-6	Ages of Fathers in Two Autism Groups. . . . .	216
C-7	Distance from Nearest Relative in Miles for Two Autism Groups. . . . .	217
C-8	Selected Indices for Gray Autism Sample and DeMyer Sample. . . . .	218
C-9	Education and Socioeconomic Status of Gray Sample and DeMyer Sample . . . . .	219
C-10	Age of Respondents - Oakland . . . . .	220
C-11	Age of Respondents - Autism. . . . .	221
C-12	Race of Respondents . . . . .	222

Table		Page
C-13	Household Composition for Autism and Oakland Groups .	223
C-14	Number of Own or Adopted Children Living in House- Hold for Autism and Oakland Groups. . . . .	224
C-15	Number of People Living in Household for Autism and Oakland Groups . . . . .	225
C-16	Age Range of Children Living in Household - Oakland .	226
C-17	Age Range of Children Living in Household - Autism .	227
C-18	Ages of Children Listed as Not Living in the House- Hold for Autism and Oakland Groups. . . . .	228
C-19	Highest Level of Formal Education for Women in Autism and Oakland Group . . . . .	229
C-20	Highest Level of Formal Education for Men in Autism and Oakland Group . . . . .	230
C-21	Employment Status of Women in Autism and Oakland Groups . . . . .	231
C-22	Employment Status for Men in Autism and Oakland Groups . . . . .	232
C-23	Types of Occupations Held by Women in Autism and Oakland Groups . . . . .	233
C-24	Types of Occupations Held by Men in Autism and Oakland Groups . . . . .	234
C-25	Total Family Income before Taxes for Autism and Oakland Group. . . . .	235
D-1	Cross Tabulations of Women's and Men's Affective Evaluations of Life-As-A-Whole in the Oakland Group .	236
D-2	Cross Tabulations of Women's and Men's Affective Evaluations of Life-As-A-Whole in the Autism Group .	237
D-3	Cross Tabulations of Women's and Men's Evaluations of Family Life in the Oakland Group . . . . .	238
D-4	Cross Tabulations of Women's and Men's Evaluations of Family Life for Autism Group. . . . .	239

Table		Page
D-5	Cross Tabulations of Women's and Men's Evaluations of Marriage in the Oakland Group. . . . .	240
D-6	Cross Tabulations of Women's and Men's Evaluations of Marriage in the Autism Group . . . . .	241
D-7	Cross Tabulations of Women's and Men's Evaluations of Spouse in Oakland Group. . . . .	242
D-8	Cross Tabulations of Women's and Men's Evaluations of Spouse in Autism Group . . . . .	243
D-9	Cross Tabulations by Women and Men of Evaluations of Children in the Oakland Group. . . . .	244
D-10	Cross Tabulations by Women and Men of Evaluations of Children in the Autism Group . . . . .	245

## INTRODUCTION

This study is a preliminary attempt to identify variables which affect life quality as perceived by the parents of severely handicapped children compared with parents of non-handicapped children. The group of families with severely handicapped children all have children who have been diagnosed "autistic."

### Statement of the Problem

Currently, a proposal is before the Michigan State Department of Education which would establish a separate diagnostic category for autistic students in this State, define rules for programs for autistic students, and establish teacher endorsement requirements for teachers of the autistic. This marks the third time in the last 8 years that a concerted effort has been made by a coalition comprised of parents and key service personnel to bring a proposal to the State Board Level. On Wednesday, April 2, 1980, largely in response to testimony heard from parents or their representatives attending the meeting, the State Board moved to table the proposal so that members could review the "volumes" of documents presented on this "very technical issue." The vote to table passed in spite of articulate protests from several board members who felt that the established legal process for the promulgation of new public rules had been strictly adhered to over the previous eighteen months and that this process (which

includes open public hearings) allowed ample opportunities for extensive study and discussion among all relevant parties.

The decision to table the autism proposal was in marked contrast to the ameliorative, positive decision "theme" which appeared to surround all previous special education requests on this day. The response appeared to be reflective of the Board Members' concerns regarding the parent testimony. In spite of extensive advocacy experiences which have wrestled with realities of the political/economic state power structures, the parents were unable to present a supportive united statement to encourage board passage. Instead, they raised questions regarding specific details of school schedules and urged diagnostic "reductionism" which tended to illustrate a reactionary, disorganized, and self-seeking lobbyist group.

This very prospect of more intensive service to autism has once more brought public attention to a group of people who reflect the intensive strains of parenting children who have been repeatedly described as the "most puzzling" (Funneaux and Roberts, 1977) and the most severely psychotic (Cohen, 1973; Graziano, 1974) of all handicapped students. Life with autistic children has presented unique family strains. Assaulted by twenty-five years of "blame etiology;" professional ignorance, ambiguity, and controversy about diagnosis; premature and ill-informed hopes for "cures;" and the virtual lack of public school services, parents of autistic children have little historical precedence for positive, reciprocal relationships with public and private service systems. In addition, the specific



behavioral traits of autism present extreme stress on families by the nature of the caretaking activities demanded and the constancy of this role. DeMyer (1979), a clinical psychiatrist who has specialized in the treatment of autism for approximately twenty years, and is herself the parent of an autistic child, comments that...."All parents experience severe stress in caring for an autistic child" (p. xii). Koegel and Rincover (1977) comment that "some of the most pressing problems reported by the parents of autistic children seem to stem from having to watch their child continuously all of his waking hours" (p. 125). DeMyer (1979) further states that this intensive care of the autistic child does not "pay off" in a "normal" reciprocal exchange sense, because "most, but not all cases, end tragically in an adult life of partial or total dependence" (DeMyer, 1979 p. xii). In other words, with an autistic child in the family the present is a severe strain and the future may be no better. Parents who are knowledgeable and assertive enough to be public advocates for their children probably realize the angering tragedy of prognosis for their children. They are confronting a macro-system which works largely on an economic exchange model. When the discussion centers around the costs of programs to autism and asks for a justification in terms of "economic investment in human capital," parents are realistically frightened that their child may not be a "sound investment" in that utility value system.

Services to autism in Michigan are currently at a level higher than in most states in the Union, but probably approximately half to three-quarters of Michigan's autism population has not been clearly

identified and evaluated by professionals knowledgeable in this specialty. Given the low incidence of the disability<sup>1</sup> and the splintered nature of diagnostic services for children, more appropriate programs will most likely be obtained only through a continued parent advocacy movement. However, parents who live with the stress of an autistic child can only sporadically apply their energies to public awareness/advocacy efforts. While mandatory legislation has dictated that school programming must be provided for this population, autism as a severe psychosis has more traditionally been viewed as the responsibility of the mental health/psychiatric community. It will be some time before enough educators are trained to respond with an appropriate service model to this group. In addition, the mandate is for service to the child; previously if service were provided from mental health there was a treatment bias toward including the parents and/or entire family in treatment efforts. While the theories of etiology which predominate in the mental health community (Kysar, 1968; Roth, 1970) are antithetic to parents and current professional researchers in the field, there was an attempt to treat "whole systems" around a child. Public schools are truly in the business of service to students, and special educators have no mandate to parents except to involve them in decisions concerning their child's federally mandated "Individual Education Plan." Since school districts are not hiring new personnel to implement this considerably increased communication process, it would appear that parents will obtain little opportunity for

---

<sup>1</sup>Incidence figures have varied from .02% to .078% with a general acceptance of 4-5/10,000 (Lotter, 1966).

involvement with the schools about particularistic strains arising in their family because of the autistic child. How will parents indicate their concerns and desires? Who will be making decisions which facilitate or limit the possibilities of family maintenance, and responsive re-creating? Parents have often found themselves needing to educate and advocate when they need some appropriate support to maintain life quality for themselves and their children.

Love (1970) reports that the incidence of divorce in special education families is twice the national average. In a family with an autistic child, the strains would appear to be dramatically heightened, yet very little is actually available in the research literature about how families of the autistic cope with this stress in their lives. There are autobiographical accounts which provide awesome and dramatic stories of some autistic children and their families, yet the writers of such books tend to represent unusual energy-rich family systems which may be the exception and thus inadequate as information sources for designing family services.<sup>2</sup> DeMyer (1979) comments that some parents of autistic children "falter as individuals and marital partners and others appear to develop increased strength" (p. xii). As special education services are gradually increased to all severe handicaps, we have very little

---

<sup>2</sup>See for example: Copeland, James. For the Love of Ann, Arrow Books, Ltd., 1973; Greenfield, Jose, A Child Called Noah. New York: Warner Books, Inc., 1973; Park, Clara Claiborne, The Siege. Boston: Little, Brown and Co., 1967; Wexler, Susan Stanhope. The Story of Sandy, New York: Bobs-Merrill Co., Inc. 1970.

research data to assist in designing supportive services to a majority of this population of families.

### Need for the Study

Services to autistic children and families have been offered through the public schools in Michigan only since 1973, when Wayne County Intermediate School District and Kent County each began to serve this population. While these programs have grown steadily, without a mandated separate service category in the State and a specific program rule, it is likely that only the most disruptive children or the children of the most angry parents are being served. Most of the current program directors feel they are serving from one-fourth to one-third of the autism population. It is to be expected, therefore, that programs will be in the development/identification stages for some time to come. Without adequate teacher training processes and the high stress presented by these students, much administrative time is devoted to staff training and supervision. In addition, the very difficult process of developing an accurate diagnostic model, and all of the system-system interactions required by low incidence cross-district school programs, fall on the administrators. Programs with social workers<sup>3</sup> have often seen this profession used almost entirely for agency referrals, funding coordination and state/private institution relationships. Resources for a careful assessment of family needs and interests are not available. As Eyman et al. (1966) reports,

---

<sup>3</sup>To my knowledge, only four in the State: Grand Rapids, Detroit, Muskegon, and Flint.

it is often the most assertive special education families who receive service; in other words, in a self-selection process, those who feel (for whatever complex of reasons) that they need a particular service, seek it if they are skilled and confident enough to do so. School personnel therefore are often responding to crisis calls from grief-stricken, angry parents who have exhausted their own physical and socio/emotional resources and need relief. In a current depressed economic situation, family advocates are requesting expensive respite care, vocational rehabilitation services, group homes, or institutional care for individuals who appear severely handicapped. With a national and state advocacy movement toward independent living and de-institutionalization of the handicapped population, it is extremely difficult to find public support for twenty-four hour care systems for autistic children. The literature contains very few studies which attempt to assess family system responses to these children. As Paluszny (1979) says, "we do not yet know how this stress is affected by the severity of the child's handicap, the age of the child, or the socioeconomic background of the parents. We do not know as yet all the adaptive strategies and the formal and informal support systems that make the difference between the parents who can cope and the parents who are overwhelmed with the problems of caring for their autistic child. We can, however, be sure that there is no single strategy, no single pattern tht will fit all families well" (p. 147).

The increase in efforts to serve autistic children which has occurred in the last five years represents a newly available centralized population for study of these families. In the Garden City

(Wayne County) Autism program, there are 36 teachers, 36 aides, 2 separate buildings housing only autistic classrooms, and 180 students. Leo Kanner saw only 150 autistic children over a clinical practice of 20 years (Lotter, 1966) or approximately 7-8 per year. Much of what is written about families of autistic children before 1975 consists of clinical descriptions of parents and children already labeled "severely disturbed," (Kanner, 1943; Eizenberg, 1957; Bettelheim, 1976; Polan, 1959; Roth, 1972). More recent writing by such parent/professionals as John and Lorna Wing (1968) Bernard Rimland (1964) Clara Park (1967) and Marian DeMyer (1979) have presented a more descriptive less psychoanalytic interpretation of realistic family activities. There are increasing accounts of attitudinal changes even in "intervention trainers" who comment like Marcus, Lansing, Andrews, and Schopler (1978) that "inappropriate childrearing practices are best considered as a normal response to a peculiar and difficult child" (p. 626). Kanner (1943) originally postulated that autism was an "inborn defect of affective content" and felt there was support for a biogenetic theory of etiology. But his position at an East Coast University in the first United States Child Clinical Psychiatry practice, probably skewed the population he was able to study. In spite of his attempts to locate a broader selection of socioeconomic classes, he claimed to observe a continued bias toward upper socioeconomic classes among families of autistic children. In the 1970s, this controversy still continues (see Lotter, 1967; Roth, 1972; and Schopler et al. 1979) but it has only been in the past five years that Michigan

programs (and those reported elsewhere) have begun to represent greater ethnic and socioeconomic class integration. Thus it is perhaps only in the coming decade that we can begin to conduct family research that more accurately reflects the rich variety of individual system responses to the severe and chronic stress of an autistic child. This research is conceived of as a preliminary step in the process.

### Conceptual Framework

Various researchers have conceptualized people's subjective evaluations of life as providing critical information for the assessment of a society's performance in meeting mankind's needs (Andrews, 1974; Campbell et al., 1976; Foa and Foa, 1974; Rettig, 1980). As social creatures, humans live significant portions of their lives in the environments of families and other interactive systems of work, friends, community, school etc. Family appears to be a highly significant system for the explication of developmental processes in each of its members. The identification of family membership and the practices which become "normal" for that particular group are powerful influences for the development of individuals. Campbell et al. (1976) and Andrews and Withey (1976) identified the importance of family life to people's evaluations of their life as a whole. Andrews and Withey (1976) suggest that people separate their lives into "domains" or "places, things, activities and roles" which they evaluate by "criteria" or values and personal judgments. Such "things" as family and work, can be conceptualized as domains which

contribute to a person's evaluation of their satisfaction with life totally. The theoretical contributions of Foa and Foa (1974) suggest that people interact in these various domains to meet essential needs through an exchange of resources which are identified as money, goods, services, love, status and information. Rettig (1980) built upon this exchange model and suggested that shared time among members is a necessary condition for the exchange of resources in the intimate environment of the family. The Foa and Foa model suggests that these resources can be ordered hierarchically according to particularistic-generalistic continuum. Those resources which are more particularistic (love, services, status) tend to be highly dependent for their value upon the individuals involved in the exchange; hence family members frequently are involved in particularistic exchanges with each other. The more generalistic resources of money, goods and services are more "universally valuable" and are not as dependent upon the specific individuals involved in the exchange. Family is a domain within which specific people are involved in exchanging highly valued particularistic resources, i.e. love, status and services. The degree of satisfaction with these exchanges impacts on overall quality of life.

In families with autistic children, the severely handicapped person presents resource needs which impact significantly on specific family members and/or their exchanges. The autistic person is rarely a resource to the family system; she usually presents demands for resources which must be provided by the family's store



of human and material resources. Families of autistic persons may require an unusual abundance of resources to support the demands of their handicapped child. Given the reciprocal nature of exchanges within the family such resource demands from the autistic person impact in complex ways throughout the system. As an identifiable source of stress, autistic persons may be responsible for lowered satisfaction with family life, or specific exchanges in family life. This lowered satisfaction with family life has obvious implications for parents' perceptions of their overall quality of life. If family members are involved in exchanges with other systems external to the family which provide them vital human and material resources, they may be better able to cope with the needs of their handicapped child. The specific choices made in response to those needs are felt to be highly particularistic and dependent on each individual's perception of their own well being as reflected in their satisfaction with people, shared time, and resources exchanged.

### Objectives

The objectives of this preliminary study encompass issues and interests in the fields of family ecology, special education, psychology/psychiatry and political advocacy. It was the intention of this work to provide directions for further important areas of research which then might offer information useful in structuring services to families with handicapped children.

Specifically, objectives of the study are as follows:

- A. Obtain demographic information on a volunteer population of parents of autistic children for comparison to published information in the literature.
- B. Compare the relationships between parent reporting of overall evaluations of life, family life, marriage, children, and spouse in families of autistic children with families of non-handicapped children.
- C. Explore the relationships between parent evaluations of selected dimensions of family life in families with autistic children and families of non-handicapped children.
  - C.1. Identify the resources which are the most powerful predictors of family life evaluation for parents of autistic children in comparison to parents of non-handicapped children.
  - C.2. Identify the evaluations of shared time and people resources in families of autistic children which are the strongest predictors of parent evaluations of family life in comparison to families of non-handicapped children.
- D. Explore the relationships between evaluations of selected dimensions of family life by fathers of autistic children in comparison to mothers of autistic children.
- E. Explore the evaluations of specific dimensions of family life by mothers of autistic children who work for pay out of the home and those who do not.

### Assumptions

In the process of this study the following assumptions have been made:

1. A family system attempts to allocate resources in a manner which may support or limit the optimal development of each family member.
2. Parents are able to reflect their evaluations of their family and their lives by answering a questionnaire which asks for quantification of evaluation with specific resources.
3. When husbands and wives answer separate questionnaires simultaneously these can be construed as two independent cases.

### Definitions

For purposes of this study, the following definitions are used:

Family.--A system of interacting and interdependent persons who share common resources, exhibit a theme, and have a commitment over time. In this study specifically, all families consisted of a male/father, female/mother and his/her and their children living in one household.

Autistic Child.--A child enrolled in a segregated special education program for autistic children in one of three separate urban areas of Michigan selected for the study. In general, the programs utilized a definition of autism made by the National Society for Autistic Children (NSAC) (see Appendix).

Resources.--Objects, events, activities or human beings that are available in the family environment and might function to influence optimal development of its members.

Quality of Resources.--Subjective judgments (evaluations) made by parents of the quality of their resources.

Particularistic Resources.--Those resources whose value is influenced by the particular persons involved in exchanging them and by their relationship.

Generalistic Resources.--Those resources which are valued by their inherent qualities and not dependent for value on the persons involved in the resource exchange.

Love Resources.--These particularistic resources which contribute to a person's belief that she is loved/respected and involved in a committed intimate relationship.

Service Resources.--Those resources which a developing person receives as activities done with her needs for activity goal achievements in mind.

Information Resources.--Those resources which offer the developing person facts, concepts, or ideas which affect her growth and development.

Material Resources.--Goods or money which have a generalistic exchange value but are provided to a particular family member for need satisfaction.

### Hypotheses and Questions

The hypotheses and questions developed from the research objectives are as follows:

#### Hypotheses for Objective A:

H1. The sample of autistic families used in this study is representative enough of the universe of autistic families reported in the literature to permit meaningful inferential statements about autistic families known to other researchers.

H2. The sample of autistic families used in this study is similar enough to families in the Oakland Quality of Life Study to permit meaningful comparisons of data.

#### Hypotheses for Objective B:

H3. Parents of autistic children will report lower mean scores of evaluations of family life, marriage, children, and spouse than will parents of non-handicapped children.

H3a. Mothers of autistic children will report lower mean scores of overall evaluation of life, family life, marriage, children, and spouse than mothers of non-handicapped children.

H3b. Fathers of autistic children will report lower mean scores of overall evaluations of life, family life, marriage, children, and spouse than will fathers of non-handicapped children.

H3c. Mothers and fathers of autistic children will show no differences in the pattern of spouse agreement of evaluations of life-as-a-whole, family life, marriage, spouse and children when compared to mothers and fathers of non-handicapped children.

#### Hypotheses and Questions for Objective C:

Q. Do parents of autistic children show the same pattern of resources as predictors of their evaluation of family life as do parents of non-handicapped children?

Q2. Do parents of autistic children show the same pattern of shared time and people resources as predictors of their evaluation of family life as do parents of non-handicapped children?

H4. In families with autistic children, the mothers' evaluations of marriage do not contribute significantly to the prediction of evaluation of family life.

H5. In families with autistic children, the mothers' evaluations of love and affection experienced do not contribute significantly to the prediction of evaluation of family life.

H6. In families with autistic children, the mothers' evaluations of how comfortable it feels to be at home do not contribute significantly to the predictions of evaluation of family life.

H7. In families with autistic children, the mothers' evaluations of how openly and honestly feelings can be expressed do not contribute significantly to the prediction of evaluations of family life.

H8. In families with autistic children, the mothers' evaluations of the amount of respect received do not contribute significantly to the prediction of evaluations of family life.

H9. In families with autistic children, the fathers' evaluations of marriage do not contribute significantly to the prediction of evaluations of family life.

H10. In families with autistic children, the fathers' evaluations of things done together do not contribute significantly to the prediction of evaluations of family life.

H11. In families with autistic children, the fathers' evaluations of how comfortable it feels to be at home do not contribute significantly to the prediction of their evaluation of family life.

H12. In families with autistic children, the fathers' evaluations of the sexual relationship do not contribute significantly to the prediction of evaluation of family life.

H13. In families with autistic children, the fathers' evaluations of love and affection received do not contribute significantly to the prediction of evaluations of family life.

H14. In families with autistic children mothers' and fathers' evaluations of marriage, contribute at the same level to their evaluations of family life as those of mothers and fathers of non-handicapped children.

H15. In families with autistic children, mothers' and fathers' evaluations of children contribute to the prediction of evaluation of family life at the same level as mothers and fathers of non-handicapped children.

H16. In families with autistic children, mothers' and fathers' evaluations of spouse contribute to the prediction of evaluations of family life at a level equal to that of mothers and fathers of non-handicapped children.

H17. In families with autistic children, the mothers' and fathers' evaluations of time spent with children contribute to the prediction of evaluations of family life at the same levels as those of mothers and fathers of non-handicapped children.

H18. In families with autistic children, the mothers' and fathers' evaluations of time spent with spouse contribute to the prediction of their evaluations of family life at a level equal to that of mothers and fathers of non-handicapped children.

H19. In families with autistic children, the people and shared time resources are stronger predictors of affective evaluations of family life than are the identified Rettig resources.

#### Hypotheses for Objective D:

H20. In families with autistic children, mothers' evaluations of overall life, family life, children, marriage, and spouse are significantly lower than fathers' evaluations of these same dimensions.

H21. In families with autistic children, mothers' evaluations of selected resources will form the same predictive pattern for their evaluations of family life as do fathers'.

#### Hypothesis for Objective E:

H22. Mothers of autistic children who work for pay out of the home show the same mean evaluations of selected resources



received in the family as mothers of autistic children who do not work for pay out of the home.

### Limitations

The families in this project were selected from an available pool of one-hundred ten voluntary respondents to an initial College of Education Survey in 1979. Their commonality with a universe of families of the autistic population can only be inferred by a careful review of available demographic information in the research literature (see Chapter Three).

Writers such as Seligman (1979) Graziano (1974) and Love (1970) have described the stages of parent response/acceptance of the realities of a handicapped child in the family. Although some authors have suggested that this process is developmental (Love, 1970) others (Thurston, 1960; Roth, 1972) have described the intensity and rapidity with which grief-stricken responses to the condition of having a severely handicapped child in the family can be retrieved in interaction with professionals. Since Love (1970) describes denial as a second stage of this process, it might be expected that a parent in this stage of response would tend to "mask" or "blunt" the effects of this autistic child on their family. Thus the responses to the research questionnaire may contain very superficial unrealistic evaluations of life in all areas. Because there was no attempt made to assess the family's "stage of response" to their autistic child, it must be assumed that the bias might be distributed across the age groupings of the families.

A methodological limitation is inherent in the data collection design. The researcher made appointments to meet with the families of autistic children in their own homes and remain there while each mother and father completed a questionnaire. The original intention of this model, as opposed to the Oakland Quality of Life Study wherein the questionnaires were left at the respondents' homes for independent completion and then picked up by a research staff member later, was to provide a check against collusion for a "research wary" group and to offer a resource to the parents. The researcher felt that observing and caring for the couple's autistic child would provide more rapport and relaxation in the interview process so that the parents would be able to respond more truthfully and thoughtfully. In actuality, in only one home was the researcher encouraged to interact with the child; he happened to be a high functioning, unusually social child who had been "expecting you." In the other homes, therefore, after an initial explanation and socializing process, the researcher "busied" herself in note taking and reading except for necessary item explanations.

REVIEW OF RELEVANT LITERATURE  
Early Diagnostic History of Autism

In 1943, the first American child psychiatrist, Dr. Leo Kanner, published a paper in which he described eleven children whose behavior was so bizarre and so similar to one another's that he suggested a new diagnostic category of "an autistic defect of affective content." Utilization of the term "autistic" was unfortunate because of its previous connotation advanced by Blueler in 1919 as one of the two fundamental symptoms of schizophrenia. The term has for forty years inaccurately suggested that autistic persons are essentially normal organisms who have chosen to retreat from reality.

Between 1943 and 1964, much professional dialogue was devoted to an appropriate choice of the "necessary and sufficient" criteria for diagnosis (Bender, 1947; Eisenberg and Kanner, 1956; Creak, 1966; Rutter et al. 1967). In addition, beginning with Kanner's descriptions of his original eleven families, a tendency was adopted to view the syndrome as caused by the social/psychological environments of its victims. In particular, parents of autistic children were described as possessing certain personality traits which "caused" or at least "contributed to" autism (Kanner, 1943, 1949; Eisenberg, 1957; Bettelheim, 1967; Tustin, 1973; Parks, 1967).

As a result of this theory of etiology, the major treatment of choice by leading professionals into the 1960s was that of

non-directive play therapy for autistic children and analysis for parents. A whole body of literature has emerged in the last fifteen years which chronicles parent social/psychological wounds as a result of this theoretical position.<sup>4</sup> In fact the founding of the National Society of Autistic Children (NSAC) in 1967 occurred as a consciousness-raising advocacy group which had heard its angry limit of "blame etiology" and began to challenge the system with accusations and alternative views.

When Rimland, a bio-chemist and father of an autistic girl, gave in 1964 a cogent argument for investigating biological factors in etiology, a landmark in research themes was made. The subsequent effects on treatment of the consideration of a biogenetic cause were clearly seen in the rising criticisms of Bettelheim's work advocating "familyectomy" (1967) and the serious attention paid to Lovaas (1965) and his utilization of behavior modification techniques to "re-train" autistic children. Lovaas was influential in documenting the prevalence of severe mental impairment among much of the autism population (Lovaas et al., (1973) and reinforcing the "co-trainer" responsibility of parents.

In the 1970s, autistic children have finally arrived in the public schools. Public Law 94-142, passed in 1975, mandated that

---

<sup>4</sup>In particular see: Parks, Clara Claiborne "View from the Couch". American Journal of Orthopsychiatry 1969, 43, 321-326; Greenfield, Josh A Child Called Noah. New York: Warner Books Inc., 1973; Kysar, J. E. "The Two Camps in Child Psychiatry: A Report from a Psychiatrist Father of an Autistic and Retarded Child." American Journal of Psychiatry. 1968, 125, 103; and Russell, Robert. An Act of Loving. New York: Vanguard Press, 1967.

all children, regardless of handicapping condition, must be provided with a free and appropriate public education beginning in the Fall of 1977. In addition, all handicapped children are entitled to non-discriminatory testing and to due process which involves parents in decision-making systems.

In addition, in 1975, amendments to the Federal 1970 Developmentally Disabled Services and Construction Act were passed which included autism as a developmental disability. This legislation assures parent participation in the State Developmental Disabilities Council which reviews plans for service, and it includes the autistic in the search for alternative community placements for the handicapped (Paluszny, 1979).

DeMyer (1979) summarized research on the unequivocal neonatal findings, evidence of greater speech and learning problems in autistic siblings and extended family members, and the higher percentage of autism in pairs of monozygotic twins compared with fraternal twins. Of striking evidence in twin studies, when the non-autistic twins were compared across identical and fraternal twin pairs, 85% of the non-autistic identical twins had some cognitive abnormality such as speech delay while none of the non-autistic fraternal twins exhibited such handicaps. Spence's (1976) review of twin research data caused him to hypothesize that in some cases genetic factors alone are necessary and sufficient to cause autism, in some, the sole cause appears to be injury at birth, and the remainder seem to suggest a genetic vulnerability combined with brain damage. Furthermore, the specific mechanism causing autism would appear to be multifactoral

and involve an insult to the central nervous system. It has been documented to occur three times as frequently in boys as in girls; thirty percent of the lowest-functioning autistic children show seizure disorders by adolescence (Schopler and Rutter, 1978).

One of the most difficult findings that has emerged through experiences with treatment is that, as DeMyer (1980) comments, "autism is notorious for its resistance to clinical intervention, especially over the long run" (p. xii). DeMyer's longitudinal research on one-hundred twenty autistic children concluded that the best prognosticator for an autistic child is still her performance on intelligence tests in the early years. Rutter (1978) reported a similar finding with longitudinal studies in England though he added the components of communicative speech and symbolic play skills as yielding a three-pronged predictive unity.

As we enter the 1980s, we have learned that autism is a life-long disability which is probably the result of some as yet unidentified insult to the central nervous system, and that it remains minimally impacted by past treatment efforts. Public schools must now serve autistic students; but someone must first be taught to identify them and ideally, train teachers to meet their needs. The role of parents has thus far been largely one of mutual support and program advocacy; new directions for parent research and service are needed.

#### Literature on Epidemiology and Parents

The literature dealing with parents of the autistic, tends to divide itself into the following areas; attempts to link parent/

personality characteristics and functioning to etiology, search for the bias of socioeconomic class, descriptions of personality-patterns among parents, parent/child interaction patterns, and parent performance as co-trainers of their children. Attempts at unbiased survey and research designs have been few, many published reports involve small numbers of families, and there are other significant methodological problems.

### Epidemiology Studies

In the 1960s, for the first time, some controlled studies began to identify incidence rates and useful diagnostic criteria for autism. The Middlesex Survey (Lotter, 1966) investigated all 78,000 children aged 8, 9 or ten who lived in the county of Middlesex, England and found a possible one-hundred thirty five cases of autism. Extensive testing, interviews with teachers and mothers, behavioral observations, and examination of medical records resulted in the selection of fifteen cases of "Kanner's syndrome", seventeen with "many autistic features," and twenty-two who were judged "not autistic" but showed some behavior similar to autism. This study therefore yielded incidence figures of 2/10,000 of "pure" autistic, 2.5/10,000 of "autistic-like" and 3.3/10,000 as "autistic-appearing."

Of interest to this work are the parent assessments made on this very large sample. The parents of the "pure" autistic group tended to be in the Registrar General's social class I or II, to have professional training, and be superior in intelligence to the other groups. The Lotter Study did not show any raised prevalence of schizophrenia or other psychotic illness, though other form of mental

illnesses (neurotic patterns, crisis reactions, etc.) were more prevalent in the more "pure" autistic groups than in the less pure.

Treffert (1970) examined all case records for children 12 years and under seen in Wisconsin at thirty centers for mental health treatment during the years 1962 and 1967. His incidence rate for autism was 3.1/10,000--but he accepted only those children already diagnosed as autistic. One-half of Lotter's Middlesex group had not been previously diagnosed prior to the survey (Lotter, 1967) so Treffert's case finding methods may have depressed his incidence level. Treffert's autistic group showed an excess of college graduates among fathers, and no abnormal prevalence of pregnancy or birth complications. Both Treffert and Lotter found boys to out-number girls in autism by a ratio of 2.4-3 to 1.

Brask (1970) conducted a survey of children aged 2 to fourteen in the county of Aarhus in Denmark. She found an incidence level almost the same as Lotter's, but did not explore the socioeconomic class bias.

Extrapolating these incidence figures to the United States, there should be approximately 100,000 autistic persons of all ages in this country. In Michigan, there should be 4,000 of which approximately 2,000 are of school age. This represents an incidence rate which is one-half that of deafness and equal to that of total blindness. But in cities of 10,000 inhabitants when 4-5 autistic persons might be spread across the age span and appear at a variety of levels of handicapping severity, it is very difficult for them to be accurately identified.



### Parents and Psychogenesis

The implications of Kanner's (1943) reports of the parents of his first eleven cases have been mentioned above. While he later (Kanner, 1968) stated that "at no time have I pointed to the parents as the primary, post natal sources of pathogenicity" (p. 20) yet the lucid clinical descriptions of parent behavior he wrote and the unusual prevalence of higher socioeconomic class in his sample (90% of his parents were in the highest professional class( Kanner and Lesser, 1958) have made a deep impression on new students. From a child and family development point of view, it is important to recognize that in the 1930s when Kanner was first meeting and collecting clinical histories on autistic children, there was prevalent a popular belief that competent parents (certainly represented by Kanner's group) should apply rather rigid externally structured parenting practices to their children (Winch, 1970). Some workers subsequent to Kanner (Bettleheim, 1967; Despert, 1951; Goldfarb, 1961; Rank, 1959; Ward, 1970 and Roth, 1972) have also implicated parents for providing an environment where normal bonding did not occur.

This seductive theory received some initial refutation when professionals, who were also parents (Rimland, 1964; Wing, 1960; DeMyer, 1975), began publishing scholarly works. The number of articulate balanced presentations in autobiographical form by parents of autistic children (Copeland, 1973; Parks, 1967; Kaufman, 1976) could previously be discounted as "biased non-professional" pleas. It is difficult to read these "parent" books however and not feel that they represent a group of extremely strong, articulate and balanced personalities

whose descriptions of family efforts to help their autistic children are challenging indictments of professional knowledge and practice. The suggestions of the epidemiology studies mentioned above did not support a psychogenetic theory of etiology, but some human problems of causality, as Bronfenbrenner (1979) suggests can truly not be "proven" by research. Therefore much responsibility for critical reading and thoughtful data collection has rested on individual diagnostic and service personnel.

In a study of 33 couples with autistic children matched by age of child, ordinal position in the family, number and sex of siblings, race, sex, socioeconomic status and religion with 33 other couples with non-handicapped children, a series of 9 semi-structured interviews were conducted by DeMyer and her associates (DeMyer, 1979). Attempts were made to elicit information on aspects of child development (eating, sleeping, socialization, communication, play and toiletting) as well as information about their personalities as individual and marriage partners. In order to more fully explore the nature/nurture argument of etiology, an additional group of parents of learning disabled children was observed and interviewed regarding parenting activities. Results showed that the autistic parents were much like the normal parents in their infant acceptance, nurturing warmth, and appropriate stimulation of the infant. In contrast, parents of the learning disabled population put more performance pressure on their infants, were less responsive to her crying, spent less time talking and singing to her and were judged to be "less warm" (DeMyer, 1979). Furthermore, retrospective interviews with the parents showed no

differences between the autistic group and the normal group on attitudes toward the pregnancy and feelings toward their neonates, findings which DeMyer felt disproved a psychogenetic theory of autism, a la Bettelheim (DeMyer, 1979).

Creak and Ini (1960) investigated the families of 100 autistic children and making clinical judgments, did not think that the personalities or attitudes of those parents were particularly abnormal. Rutter et al. (1971) compared the parents of high functioning autistic children with parents whose children were equal in intelligence but were diagnosed as having receptive "aphasia." They utilized structured interviews and questionnaires, finding no differences on measures of psychiatric illness, obsessiveness, emotional warmth toward child, enthusiasm and empathy. Rutter did note, however that half of the members in each group had shown neurotic or depressive disorders, a finding he attributed as reactive to caring for a handicapped child.

Rutter, Greenfield and Lockyer (1967) found that only 9 percent of autistic children came from single parent families as compared with 22 percent of children with other forms of psychiatric disorders. Bender and Grugett (1956) found that "broken homes" and "poor emotional climate" were less frequent in the backgrounds of young schizophrenics and autistic patients than in the histories of children with other psychiatric problems. Furthermore, in a study of children exposed to severe trauma from neglect, hospitalization, or institutionalization, Rutter (1968) found no cases of autism.

Pittfield and Oppenheim (1964) compared mothers of 100 autistic, 100 normal and 100 Down's Syndrome children by means of a questionnaire

to measure attitudes toward child rearing. The mother's of the autistic group were felt to be "more indulgent" and "more uncertain in their attitude," differences which the authors felt represented child differences rather than characteristics of mothers. Ferster (1961) wrote a theoretical paper postulating parent reactions which he predicted would cause autistic behaviors, with no effort at observation or controlled research. His comments that autistic children do not develop useful speech because of parent inattentiveness have been disproven by mounting evidence of abnormal pre-linguistic behavior in autistic children (Rutter, et al. 1971; Wing, 1971).

Tinbergen and Tinbergen (1972) on the basis of their ethological work, suggest that over-arousal resulting from chronic confusion and fear not normally abated by parent interpretation and support, is the cause of autism. By its emphasis on interactive microsystems, the theory is intriguingly descriptive, but does not appear to help explain why some children normally are easily reassured and comforted, while autistic children appear not to be.

Schopler (1978) reviewed approximately 100 studies linking autism and schizophrenia to parent pathology and declared them heavily time bound--mostly published prior to 1965 and containing research questions couched in the prevailing psychoanalytic theory of the times.

In summary, it appears impossible to "prove" that parents do not cause autism, but writers in the field now echo DeMyer's (1979) comment that "parents do not 'cause' autism any more than they cause well-marked neurological conditions such as Down's Syndrome," or Paluszny's (1979) remark that "there is so much evidence against the

view that autism is a primarily psychogenic disorder that it would not seem worthwhile to investigate it further" (48).

A note should be made however, that while researchers of the seventies have largely refuted this view on etiology, many families have met professionals for whom "these findings may be ignored in clinical practice", to quote DeMyer (1979). Kysar (1968), a psychiatrist who is the father of an autistic boy, was moved to write eloquently of the severe depression which occurred in his wife and the great strain which marked their marital relationship while he, even though professionally "knowing better" attempted to cooperate with a group of psychogenesists who held out hopes for cures to his wife and boy. Parks writes in "View From the Couch" (1968) that it took great self determination and anger to discount all the accusatory messages of professionals in "helping" roles. Warren (1978) writes of "A Society That is Going to Kill Your Children" and Robert Russell (1967) killed his son and went to jail for homicide rather than see him live with inadequate treatment and no hope of improvement. These stories have been very eloquently expressed and certainly strike a fiercely defensive and protective memory link in almost any parent of an autistic child. Such knowledge should form part of the "information resources" available to professionals who attempt interventions with parents of older autistic children, in particular.

#### Parents and Socioeconomic Class

The intensive reactions surrounding the suggestion that autism is a disability found most often in the upper socioeconomic classes,

probably reflects the concern about this correlational evidence being used to make causative arguments for the psychogenesis of autism. The research in this area suffers because of a recurrent combining of the diagnostic categories of autism and schizophrenia and a confusion about how to diagnose autism alone (Schopler, 1978).

Subsequent work in epidemiology and in clinical evaluations of parents have reiterated this socioeconomic bias when parents of the autistic are compared with parents of the normal population and parents of other child psychiatric patients (Bender and Grugett, 1956; Lotter, 1967; Rutter and Lockyer, 1967; Treffert, 1970). These same studies did show however that these differences are only relative, that is there are autistic children from all socioeconomic classes and from parents of all levels of intelligence, even though proportionately more parents come from intellectually and socially advantaged sections of the population (Cantwell et al., 1978).

A major study which did not support this bias was one by Ritvo et al. (1971), which compared seventy-four hospitalized autistic children with 74 non-autistic hospitalized psychotic children. It is suggested by Cantwell et al. (1978) that this study included a broader definition of autism which would predictably include a greater severely retarded group and hypothetically, a more varied family population. DeMyer's (1979) data on one-hundred twenty autistic children included a large sample of middle socioeconomic class families and very few in the low-income group. DeMyer (1979) suggested that referral services are not as readily available to low-income rural families

and remarked that their service area (the State of Indiana) included several low-income sub-culture groups who reject professional services of all kinds.

Schopler et al. (1979) compared approximately 12 studies which supported the higher socioeconomic bias with eight studies that did not and presented an exploratory model for testing. Seven criterion which were thought to operate in a selection bias toward higher socioeconomic class (age at onset, age of treatment admission, normal cognitive potential, complexity of rituals, distance traveled for treatment, availability of services and detailed child history) were selected for discriminate function analysis of 264 cases in North Carolina. Results showed that four of these criterion were biased toward higher socioeconomic classes. The authors suggest that these biases have been operating since Kanner's early work at Johns Hopkins and probably have compounded our diagnostic skills toward a social class bias. More realistic programming for autistic students in compliance with the federal mandates will need more sensitive screening and identification. In all likelihood, this bias has impacted upon chosen school/home interaction systems for a number of years.

#### Research on Parent Personality and Family Interaction Factors

From Kanner's (1943) earliest descriptions of parents of autistic children, other authors have contributed lists of specific personality characteristics of this group. Thus they have been described as formal introverted and obsessive (Rank, 1955; Eisenberg, 1957) overprotective, symbiotic, and indecisive (Goldfarb, 1961; Meyers and

Goldfarb, 1961; Rank, 1955). However, Creak and Ini (1960) represent another group of researchers who have not found these differences.

Bene (1958) used the Rorschach to compare mothers of children with "primary" (early onset Kanner's Syndrome) versus "secondary" autism. Results indicated that mothers of the primary group showed more removal in social/emotional relationships than mothers of children with secondary autism. It is noteworthy that these results which were interpreted to reveal maternal personality deviance--might more adequately be interpreted from an interactional viewpoint to illustrate the result of caring for an extremely withdrawn handicapped child whose disability was evident within her first year of life.

Three separate studies of parents of autistic children utilizing the Eysenck Personality Inventory (Kolrin et al., 1971; Netley et al., 1975; and Cantwell et al., 1977) showed no differences on extroversion/neuroticism scales when compared to parents of normal children. The MMPI has been utilized by Kolrin et al. (1971) and McAdoo (1978) with parents of autistic children and revealed no abnormal pattern of neurotic tendencies. Gonzales et al. (1977) compared parents of autistic, deaf, and retarded children and found parents of the autistic to be somewhat more empathetic and more sociable. McAdoo (1978) found mothers of autistic children to have more positive self images than either mothers of non-autistic psychiatric clients, or adult female psychiatric clients.

Netley et al. (1975) used a thought disorder test to compare parents of autistic to parents of psychotic, non-autistic children.



While all seven fathers showed no differences, five of the seven mothers of the autistic showed abnormal scores compared with only five of the nineteen mothers of non-autistic psychotic children. A replication attempt by Lennox et al. (1977) did not find these results; autistic parents most closely resembled parents of normal children. In their discussion of such findings, Cantwell et al. (1978) make repeated references to the necessity of separating autism from schizophrenia in the diagnostic categories of the children, and the variance in diagnostic criteria seen between Europe and the United States.

Byassee and Murrell (1975) attempted to assess elements of family functioning with normal families, autistic families, and families of an emotionally disturbed child, utilizing the Ferreira and Winter Unrevealed Differences Task. No differences were found between families of the normal and the autistic children; families with the emotionally disturbed child showed less spontaneous spouse agreement.

In an ingenious study by Gardner (1977) a systematic detailed study was made of mothers interacting with both their autistic child and then with someone else's normal child and autistic child. What Gardner found was that mothers spoke more to autistic children, but used shorter utterances, more questions, more commands, and more verbal rewards and punishments. Furthermore, the mothers of the autistic children tended to be less "active" with either normal or autistic children. Mothers of normal children elicited more cooperative behavior, spoke more, asked more questions, made more commands and created a

different parent role. Gardner concluded that the characteristics of the autistic children elicited different parent behavior.

In other interactive research, this time based in the child's own home, Cantwell et al. (1977) made detailed descriptions of a child's "standard day" by classifying interactions as concentrated, continuous, available, or available--not used, in families of autistic and dysphasic children. The two groups did not differ significantly on any of the degrees of intensity of interaction, or on the relative patterns with fathers versus mothers. However, there was a sizable difference for peer/sibling interactions; dysphasic children having much greater interaction with other children.

Furthermore, Cantwell et al. (1978) elicited parent interview data on the frequency of specific activities the children might consider pleasurable. Findings showed that fathers of the autistic children spent twice as much time playing with their children as did fathers of the dysphasic group. It might appear that with autistic children's severe social relatedness problems, it is intrusive (largely boisterous and rough housing) play which attempts to pick up a "normative activity" slack. Then in a series of observations of family interactions within each group, the only significant difference between the dysphasic and autistic group was that the fathers of the autistic children were more consistent in emotional relatedness than fathers of the dysphasic children (Cantwell et al. 1977). Child/mother interaction patterns in the homes were observed, taped and analyzed for character and affective qualities. In a complex series of linguistic and affective analyses, the only differences seen were

that mothers of autistic children made more affectionate remarks to their children and used significantly more positive and less neutral tones. One might believe that these are "compensatory patterns" due to the greater severity of the autistic handicap, or the historical suspicions of professionals concerning autistic parents; but this finding is remarkable as a statement of strength in the face of a stressful parenting task. Of importance to further work in this area is Howlin's (1973) finding that parent/child interactions in clinic settings are different from those in the homes of the autistic population. This is in keeping with results found in other population groups (Nerlove, et al, 1978) and supports the importance of assessing behavior from an ecological perspective.

Overall, it would appear that repeated efforts to attach a static-clinical model of psychiatric abnormalities to parents of autistic children have proven futile and inappropriate. In addition, preliminary available information would suggest a lower divorce rate and a more positive child/parent interaction pattern in the families of the autistic.

In the repeated efforts at "diagnostic" research, one is struck by the amount of literature which has been generated by professionals viewing the autistic parent as client/object in a service relationship. It would appear that a significant number of professional/parent interaction hours have been spent attempting to categorize and describe these parents in some manner which is useful to the psychiatrically-oriented professional community. It would seem that parents of the autistic have "done their time" under the

microscope of "psychiatric" research. Furthermore, there is a clear absence of sensitivity and/or interest in family theory--including the seemingly obvious areas of family functioning, family development, family resources, family satisfaction, family stability etc. It would seem that when autistic children are first seen as deviant, families struggle to obtain services, or at least supportive responses, from professionals who are trained to suspect, identify and treat "deviance." When research has been generated from this "pathological" world view, it has been difficult to understand how the parents of autistic children truly evaluate and design their lives on a daily basis. The direction toward dynamic ecological research with an appreciation for diversity seems imperative.

#### Family Reaction to Child

In the past fifteen years; information in the research literature has begun to turn from attempts to document certain personality characteristics of parents of autistic children to limited assessments of family reaction to the handicapped child, or to a specific decision event (for example, the considerations surrounding the institutionalization of the child). While these are still admittedly static research designs, they do nevertheless appear more useful in identifying actual functioning of families, particularly with regards to certain characteristics being important for effective family functioning. To date, however, very few of these attempts have specifically dealt with autistic children and their families.

### Reactions in Families with Autistic Children

Holroyd et al. (1975) reviewed the literature in the field and declared that there has been no systematic study of the effects of an autistic child on the family. Subsequently these investigators studied twenty-nine husband-wife pairs who had an autistic child and completed parent interviews and a 285 item true/false "Family Problems Questionnaire" comprised of fifteen separate scales which clustered as "parent problems", "family problems" and child problems." The sample included families across socioeconomic classes, and was divided into two groups; those who had institutionalized their autistic child and those whose child remained at home. Two social workers did the parent interviews and made clinical judgments about the relative amount of stress a family exhibited. The social workers felt that fifty percent of the families fell into a "moderate stress" range, while one quarter were "high stress" and one quarter "low stress." Criteria for these judgments were made by noting the presence of financial problems, parent use of tranquilizers, sibling school problems and "deviant social/emotional behaviors" in the present family functioning. Results of the analysis showed that the severity of the autistic child's impairment did not differentiate between high and low stress families. In addition, fathers answers on the questionnaire did not differentiate between the two groups. However, mothers' questionnaires showed that the following "areas" (a combination of individual items which formed one scale) differentiated between the two groups:

1. Lack of social support
2. Pessimism
3. Lack of family integration
4. Limits on family opportunities
5. Financial problems

In the low stress families (5) all fathers completed the questionnaire; in the high stress families, only one out of four returned it. The mothers of the institutionalized children differed from the mothers of the home-care autistic children in the higher reporting of the following problems (by priority):

1. Parent pessimism
2. Child's physical incapacities
3. Child's difficult personality characteristics (screaming, hyperactivity, running away, etc.).

Fathers' of the institutionalized children reported a higher number of the following (by priority) than did fathers of the home-care children:

1. Child's physical incapacity
2. Child's occupational limitations
3. Child's difficult personality characteristics.

While not statistically significant the authors reported a trend toward older families experiencing more stress, evident only on the "Financial Problems" Scale. There was a trend for the social workers to believe that young autistic children interfered more in family functioning, but this trend was not substantiated by the

family reports. This interpretation may have been an artifact of clinical judgments because young families are more child centered.

To test some of these relationships further, Holroyd et al. (1976) gave the same questionnaire to three groups of mothers: twenty-two mothers of autistic children, twenty-two mothers of Down's Syndrome children, and thirty-two mothers of psychiatric out-patient clients. Again there was an attempt to obtain data from fathers, but so few completed the questionnaires that they were not analyzed. The mothers' responses showed that the autism group reported more problems in all areas except financial problems. One particularly problematic area was the difference between parents' expectations of their autistic child for self-help skills and independence and the child's actual achievement. This could be either measuring inappropriate parent expectations or the autistic child's great unevenness in skill development. Since most scale items enmeshed child variables with parent attitude variables, the authors urged that further work is needed to ponder the effects of socioeconomic class, age of child, and severity of the disability. They felt that the mothers of autistic children exhibited elevated scores on "negative attitudes toward the child" but interpreted this finding as a typical parent response to a class of very difficult children. The mothers of autistic children were statistically significantly higher on a measure of the "occupational limitations of the child" as compared with the other two groups.

In an effort to look at effects on parents of having an autistic child, Wolf and Morris (1971) compared parents of autistic

children with parents of schizophrenic children. The authors found both groups of marital pairs were in general agreement on the behavioral traits of their child, that fathers of autistic children had MMPI profiles which were not statistically significantly correlated with the profiles of the fathers of schizophrenic children, but the mothers' scores for both groups showed a positive correlation of .67-.76. Again the authors felt that these results showed "maternal relations entail more involved exposure to the stressful child" (p. 160).

This differential effect on mothers was also found by DeMyer (1979) in her study of thirty-three families of autistic children matched with families of normal children by age and sex of the probands in each family. DeMyer's work was not a dynamic research study, but was an interview design in which a series of open-ended questions were posed to the husbands and wives separately, whose answers were taped and later analyzed by other coders. Repeated mention is made of the guilt that is felt by the mothers (66% of the autism group) and the self-doubts about their mothering ability. Increased psychological and physical tension was mentioned or alluded to by one or both of each member of the autism couples. DeMyer states that it was extremely rare to hear any overt expression of anger toward the autistic child, though a few mothers reported being able to express anger at a particular behavior of the child's and then felt better afterwards. One-third of the autistic mothers had troublesome depressive symptoms (by clinical judgments) but



did not become dysfunctional in a "major way." One nine percent of the normal mothers were judged to have symptoms of depression.

In open-ended questions to both autistic and normal parents about the worst/best points in "your own behavior as a parent," both groups (seventy percent) admired open expressions of affection and love for the children. Fathers admired mother's traits which facilitated smooth mother-child interaction and mothers admired fathers' traits which led to good modeling, teaching, discipline, and participation in the children's activities.

The most admired traits for the marital role tended to be expressions of affection, listening and talking to the spouse, and being a "good parent." DeMyer's associates in the study felt that parents in both groups were better prepared and less defensive in talking about each other's parenting role, as opposed to spouse role. The suggestion was that "many did not understand with any depth the nature of their relationship with their spouse" (p. 159). The professional orientation of the research group and the interview model may have made this an artificial finding, based on client/professional differences in perception about the appropriate activities for this study was on parents' relationships with their children, parents might object to disclosure in an area they did not feel had direct legitimate relevance to their parenting roles.

Raters did not feel there were significant differences between the autistic and the normal parents in an evaluation of marital happiness, though they felt there tended to be more "extremely happy"

or "happy" marriages among the normal families. The researchers rated the autism marriages as follows: 36% extremely happy or happy, 39% bored (unhappy-happy), and 29% unhappy or very unhappy. Among the normal families, it was felt that 42% were extremely happy or happy, 39% were bored, and 18% were unhappy or very unhappy.

In discussions with parents who were reflecting enough distress to consider divorce, 27% of the autism families cited "child's problems" as the reason for their consideration, while none of the families of normal children gave this as a reason for divorce consideration. Obviously, raters judged the problems of the autistic child to create stress in the marriages.

In attempts to elicit information about the degree of support the spouses offered each other in the care of the autistic children, the authors stated that almost all of the mothers were full time housewives and experienced the major responsibility for child care. "Moral support" was extremely important to these mothers and their most frequent complaint about their husbands was a lack of adequate support. While 33% of the mothers of autistic children felt their husbands shared their burden, 27% of the mothers felt an acute lack of support from their spouse. The remaining one third were reflective of felt needs for more support, though not yet at the acute stage.

While the differences were not significant, parents of normal children tended to have better sexual adjustment than parents of the autistic. The DeMyer groups felt that they observed a clear difference in the arousal systems and integrative function of sex

for men and women, particularly in the autism group. Husbands tended to desire the same level of sexual activity as they enjoyed prior to their problems with the autistic child. They saw sexual activity as a regenerative expression of intimacy. Mothers tended to feel stressed by the care of the autistic child in a manner that reduced their interest in sexual activity; they saw sexuality as a dependent variable, whereas the husbands seemed to assign it an independent variable status. These findings have been reported elsewhere in the literature of sexual adjustment and satisfaction (Reiss and Miller, 1979).

The DeMyer group reported that problems with housekeeping, finances and family outings were significantly more serious in the marriages with autistic children than in the marriages with normal children. In addition, mothers of autistic children spent more time "cleaning up" and one-third of their husbands (as contrasted with 15% of the normal fathers) reported dissatisfaction with their spouse's housekeeping standards. DeMyer provides two eloquent quotes which interpret requests that the autistic marital partners seemed to be making of each other.

"When all the verbiage was cleared away, mothers seemed to be asking of fathers:

'Please support me in trying to do the best I can with this trying child. Tell me I'm doing a good job. Let me cry on your shoulder, listen to my observations about our child, go with me to see the doctors, don't retreat from us. Take us out for some fun even though you are embarrassed by our child in public. Don't criticize me, but help me.'

In turn, fathers seemed to be asking of mothers:

'I'm trying to do the best I can to earn a living and to understand what's going on, but I understand our autistic child even less than you do and I'm uncomfortable because of all your painful emotions. Society has taught me that it is not brave to cry and you do a lot of it. One of the reasons I married you was because you were laughing and joking and affectionate. You're not that way anymore and you are immersed with the problems of one child. Let me have some fun alone even if you yourself can't get away from home or your thoughts enough to have your own fun'" (p. 169).

From this quote it is apparent that research is needed to ascertain how accurate this description of marital impasse in families of the autistic is, and how to facilitate the buildings of resources in these families so that their roles with their children and each other can be more growth producing.

#### Family Reactions to Other Handicapped Children

In 1965, Farber and Ryckman introduced an extensive review of the literature on the effects a severely mentally retarded child had on a family by stating that "research on family relationships with the families of the severely mentally impaired has been undertaken in most instances not so much to document the presence of problems, but to indicate more precisely the kinds of problems which arise" (p. 1). This apriori reasoning has often yielded descriptive research which is of a static nature and which often assumes content by its theoretical bias, but does not offer understanding of actual family functioning: much writing is of a clinical nature with very little empirical data. Farber and Ryckman reviewed studies which involved families whose children functioned at the measured IQ level of 50 or below; in special education terminology these

are the trainable, severely mentally impaired, and multiply impaired populations. Since sixty percent of autistic children have been found to function at these levels, this review seems appropriate for purposes of this study. Farber and Ryckman gleaned from the literature support for the following being important independent variables for predicting the "family effect" of a severely handicapped child:

1. Family member's role.--Mothers are affected differently than fathers or siblings. Love (1970) reviewed research that suggested that fathers' acceptance or rejection of the handicapped child showed a .83 positive correlation with the child's acceptance or rejection from the entire family. The mother's acceptance/rejection was correlated at only .09. The authors' interpretation of these effects were that fathers set an affective tone for the family and mothers were better able to conceal their evaluations.
2. Sex of the handicapped child.--It appears that fathers are more negatively impacted if the handicapped child is a boy and mothers are most impacted when the child is female. However, this effect appears age-linked or developmental. Love (1970) found that families are more willing to institutionalize a male child than a female child.
3. Age of the handicapped child.--Families appear to be more negatively affected by a handicapped male child

as the child becomes older. The authors felt that males created more social problems for families. It may, however be that these are actually problems in "role failure" described by Goode (1971). Families may have higher performance expectations for males; the nurturing of a female handicapped child may be a more acceptable social role assignment. In addition, there appeared to be a tendency for families to over-rate the performance of a younger child more than an older child. The authors suggested that the age/performance disparities are much clearer for older children, and that there has been a longer time for "adjustment" and recognition of the extent of the handicap by parents of older children.

4. Socioeconomic class of the family.--The reviewers found different patterns of family reactions linked with socioeconomic class. In higher educated families, there appeared to be higher expectations for children and thus greater distress and despair over inadequate performance. Fathers appeared to be dominant in decisions to institutionalize a handicapped child in higher socioeconomic families for reasons relating to job mobility, community status, and exosystem relationships. In lower socioeconomic classes, mothers appeared to be dominant in decisions to institutionalize a child with a rationale based much more on the immediate problems of nuclear

family functioning. Research also suggested that a predominant effect on the family of having a handicapped child was a reduction for all members in exosystems-- informal social contacts, group memberships, and frequency of shopping. These effects may be felt most negatively in a higher socioeconomic family. Fleming (1973) felt that a handicapped child is less of a threat to a family with few resources already. Reviewing literature on values and socioeconomic class, Fleming suggested that family problems arise when the child deviates so greatly that the values held by the parents are felt to be threatened.

5. Family form.--Research with handicapped children appears to suggest that homes with both mothers and fathers in the family were most supportive of progress in the handicapped child
6. Severity of child's handicap.--The more severely handicapped children are more likely to have mothers who do not work out of the home for pay. In addition, Farber and Ryckman speak of the "role crisis" created by the excessive care demands placed on the mother. The more she is involved with the handicapped child, the less she is available for roles with other family members. Tavorimina et al. (1977) found that mothers of physically handicapped children showed clearer signs of good mental health if they worked for pay out of the home. Skelton

(1972) felt that children who were institutionalized generally showed a greater severity of problems than those who were kept at home, but outstanding exceptions to these findings suggest that the specific strengths of individual families were also a powerful predictor.

In an effort to understand the family effect of a severely handicapped child, Fotheringham et al. (1972) interviewed families just before and one year following the placement of their handicapped child in a residential institution and then compared these findings to a control group of families who maintained their handicapped children at home. On a scale of family functioning, the researchers found that the families who had institutionalized their children showed a decrease in effective family functioning at the end of the year, which was comparable to the loss shown by families with their children still at home. However, in the initial evaluation before institutionalization, the experimental families appeared less adequate in all areas of family functioning than the community control group of families. In spite, of the year of "relief" these families continued to deteriorate in functioning. The researchers theorized that maladaptive family patterns had been developed to cope with the stress of the handicapped child, and time alone did not alter these habits. In particular, it appeared that the siblings of the institutionalized child experienced a decrease in quality of physical health. Farber and Ryckman (1965) found that when the severely mentally retarded child is institutionalized, the normal female sibling is most positively affected by the change. It is



obvious that significant research is needed in the area of sibling effect. This piecemeal listing of family problems is reflective of inadequate theoretical development in the area of the handicapped child's effect on the family. It is likely that the female sibling effect is a correlational effect with complex links to total family functioning.

Kohut's (1966) review of the effects of a brain damaged child on a family suggested that the degree of "social disorganization in the home has a significant correlation with the quality of care the child receives" (p. 163). There are not however many examples of research based on theoretical models for family functioning. Singular concepts which are more often related to individual family members' personalities or activities still seem to predominate in this literature.

In summary, the presence of an autistic child in the family has been conceptualized as an example of family stress when the specific qualities of autism and the more general qualities of a handicapping condition are considered. It would appear to impact most heavily on mothers, but also show unique effects on siblings and fathers. In writing of parent "Burn Out Syndrome," Sullivan (1979) speaks of the complete and total exhaustion of physical, psychological and emotional resources which some parents of autistic children experience after long and intense caring. Sullivan suggests that this is not rare and should be the impetus for important sensitive, dynamic research. In summarizing a study of a twenty-four hour respite care institution that was a "burn out extravaganza"

after eighteen months, Sullivan notes that a "few employees did not burn out. They were the ones who had come to the unit with several years experience with autistic children, who knew what to expect from the beginning, who did not require emotional feedback from the children, who were fascinated by the tiny behavioral gains and who were skilled in consistent management. In addition, they had strong outside attachments to their own families that enabled them to utilize time off for emotional respite" (p. 126). If such a high level of professional and personal knowledge and maturing was necessary to prevent "service bankruptcy" in professionals serving the autistic, it is likely that parents are experiencing severe discouragements in the parenting role. This is conceptualized as impacting on family functioning in comprehensive ways--both in action and reflection/evaluation.

### Quality of Life

Schopler and Rutter (1978) summarized available research on longitudinal treatment effects with autistic persons and concluded that there have been shown almost no difference in the child's intellectual level, only a modest impact on long-term language development, but real differences in socialization, communication, normalized behavior, and scholastic achievement. These areas of success might impact on the family by lessening the intensity or quantity of deviant behaviors; but might also suggest the vital importance of the home/living environment as the appropriate area for such teaching. If our best efforts with autistic children only

yield "behavioral socialization," families remain primarily responsible for the care of very dependent children. Since the impetus for program advocacy was partly to give the parents a more normalized family development experience, it is suggestive of failure when mature independent behavior is not the result of the resource investment in autism. For families, this may mean renewed efforts at advocacy for life-long care programs or concerted attempts to become "co-trainers" in the home environment. Farber and Ryckman (1965) reported that after a initial period of "euphoria" during the handicapped child's first year in a public school program, the family appears to be impacted very little by the child's schooling. Bricker and Casuso's (1979) experience with parent training in families of the handicapped have taught them that parent education must be approached from a comprehensive base and other family needs must often precede the teaching of intervention skills. In addition, Bricker and Casuso felt that new parenting behaviors could not be maintained without child response and professional support. Since autistic children often change only slowly, the response rate may severely discourage a parent's, "teaching/training" efforts.

In the DeMyer (1979), Schopler et al. (1979) and Marcus et al. (1978) descriptions of work with autistic parents, one is struck by the references to mothers as observers, counselees, and co-trainers. It is likely that most of these women do not work for pay outside the home and they are creating for the family system a supportive information resource. Their membership in the systems

of school/clinic is assured by the actuality of having a deviant family member. Professionals have often been impressed by the fact that many of these mothers feel unsupported by their spouses (DeMyer, 1979) and may have very few other social contacts. How then do such parents evaluate their lives? Does satisfaction/happiness become relative, for example, like Greenfield's (1973) gratefulness for one night of uninterrupted sleep? It would appear that the divorce rate among autistic parents is lower than that for other handicaps (Love, 1970; DeMyer, 1979), but what does that suggest about the quality of such marriages? Fotheringham and Morris (1976) believe husbands and wives with handicapped children may blame each other for their tragedy, sacrifice for the child and the family, but basically withdraw and remain aloof from intimacy. It is possible that the "despair and frustrations will out number the delights of having a new child in the family and will adversely affect the family's total functioning" (p. 11). Such families may remain intact legally, but represent the condition described by family theorists as "emotional divorce" (Olson et al., 1979).

Clancy (1970) described an ongoing series of summer camps for families of autistic children in Australia. Developed by two professionals who were also parents of autistic children, the camps were held in a resort area where there were abundant opportunities for recreation and leisure activities by different combinations of family members. University students were assigned to care of the autistic children for certain periods and activities were planned for whole families, parents only, normal siblings, and all children.

As a reflection of the parent/professional value position, there were opportunities for families to work on specific goals with their autistic children, if they so chose. The model involved twelve families for vacations from eight to twelve days in length and stressed an atmosphere of informality and mutual support. Clancy (1970) commented that "The family of any handicapped child finds that their lives become inevitably woven around the needs and limitations of the affected child. This is emphasized dramatically if the handicap is that of the autistic process, for this disorder manifests itself primarily as a social one. In such a family, the mental health of all members is at risk and it is not uncommon for marriage to be jeopardized" (p. 150). This model is the only reference found in the literature which possibly utilized a total environmental "laboratory" for research. Unfortunately, since the experience was described as primarily family-supportive, research data on specific family functioning and family satisfactions were not reported.

Another interesting example of total planning for an autistic child is reported by Gabriel (1973) who supported an autistic child through the entire process surrounding necessary open heart surgery. While the planning described was certainly similar to that accomplished by experienced teachers, two aspects of the report were extremely interesting as examples of the ecological constraints or supports for a handicapped child. First, the author makes it very clear that a great deal of public relations information processing had to be carried on with very complex service systems in

order to carry out the recommended plan. The routine laboratory and supervisory details of the hospital were practically homeostatic with reference to any consideration of a small handicapped boy's need for stability, consistency and sensitive handling. Second, Gabriel considered that the medical process went well, largely due to meticulous staff planning and commitment. Only in a fairly casual way, was it revealed that the mother of the autistic child remained at the hospital during the entire 10 day period and that the autistic child's sister was simultaneously hospitalized for this same procedure. It is likely that the re-creation of a "family system" with the hospital system contributed greatly to a successful "medical" experience.

The above work represents the intriguing nature of autism to many professionals and the constancy of stand-by care demanded by parents of autistic children when there is child interaction with any system exogenous to the family. Graziano (1974) comments that many parents of the autistic overlook physical problems in their children because the symptoms are often marked by the child's aberrant behavior and inability to communicate pain, as well as the relationship problems inherent in seeking medical service for a bizarre, disruptive child. This tendency has very real economic impacts on the quality of life for both children and families. Such family practices which reflect the severe difficulties presented by autistic children in even the providing of fundamental life needs have not been investigated by researchers. The DeMyer (1979) study is the first reported effort of longitudinal research which attempted

to include family functioning as one of the arenas of concern. However, the family measures are generally not longitudinal in nature, only basic demographic information is reported in time comparative terms. Families which contain severely handicapped children and can no longer be described as causative agents in their offsprings' disabilities, have not yet been studied with any intent to accurately describe or comprehend their unique functioning. It is often assumed that their overall quality of life is diminished (Byassee, 1975; Cantwell et al, 1978; and Culbertson, 1972) but there is no documentation to that effect.

Rettig (1980) reviewed literature in the area of quality of family life and felt that "studies of family well-being are in agreement that the marital relationship is of central importance in determining health of the family system. The marriages in healthy family systems were characterized by strong affectional bonds and emotional support, shared responsibilities and leisure time, high levels of interest and satisfaction with the sexual relationship, open communication, and competence in problem solving" (p. 74). In view of DeMyer's judgments on the quality of marriages in parents of the autistic, and the special stress of the autistic child described above, one might predict an overall depression of marital and family satisfaction in this population.

However, it is also probable that the presence of an autistic child in a family, however great the specific stress he or she generates, is not a significant variable in predicting the quality

of family life. As Lewis et al. (1976) suggest, there may be no "single thread" which can justifiably be used to predict family well-being or family quality of life, given the impressive complexity of family interrelationships. Yet autism appears to stand as such a severe disability that its impact on quality of family life would appear to be pervasive and complex.

Social science research literature in the past ten years has increasingly attempted to document measures of the quality of life in "subjective" ways as described by Andrews and Withey (1974). These authors suggest that there are significant social and public policy rationales for exploring people's internal sense of well-being; all societies appear to universally agree that while means of achievement may differ, the goals of individual life quality are worthy and of crucial significance to societal leaders.

Andrews and Withey (1974) suggest that one of the key objectives of quality of life research is to document developmental trends in specific population subgroups to understand whether people are becoming more or less satisfied with their lives. Because service to special education students is a relatively recent universal phenomena in the United States, educators are impressed by progress in the establishment of specific services and tend to infer a resultant increase in life quality for both these students and their families. Yet Andrews and Withey (1974) suggest that the external "generalized" indicators of well-being may improve while the parallel measures of people's internal sense of well-being show decreased satisfaction.



Therefore, increased public education service to autistic and other severely handicapped children may not impact on the quality of their families lives.

Rettig (1980) reviewed research on quality of life which included evaluations of marriage and family life as dependent variables. "Studies of perceived quality of life consistently found feelings about family life to be highly correlated with feelings about life-as-a-whole" (Rettig, p. 75). It appeared that the predictive power of family life for overall quality of life was particularly high for women and satisfaction with family life was most important during the biologically productive years of life. While in general, variations in perceived quality of life were not explained by certain demographic variables (age, race, sex, income, education or family life cycle stage) married persons were more satisfied than single persons and family life consistently appeared to be the most powerful or second most powerful predictor of life satisfaction for both men and women. In a review of studies which included family life as a dependent variable, Rettig (1980) documented studies in which men appeared to evaluate their family life by slightly different criteria than women. Men appeared to use individual meaningful experiences such as satisfactions with leisure, friendships, beauty and attractiveness to a greater extent than did women in evaluating satisfaction with family life. Both men and women appeared to use marriage or spousal relationships as a significant contributor to their evaluation of family life, but both men and women expressed

greater satisfaction with their children than either family life or overall life. In her study designed to test the power of the Foa and Foa resource exchange theory in the prediction of evaluation of marriage, family life, and overall life, Rettig (1980) found that: marriage is the dimension of family life which yields the most satisfaction and is the best predictor of quality of family life for both men and women; men evaluate marriage and family more positively than women; more husbands and wives agree on evaluation of family life than marriage; and husbands and wives evaluate marriage higher than family life or overall life. In addition, subjective evaluations of satisfaction with resources received was more predictive of overall satisfaction with family life than were frequency counts of resources received. These resources appeared ordered in their power to predict satisfaction with family life, in the following manner; love and affection, recognition and respect, comfort and assistance, sharing and companionship and shared meaning (Rettig, p. 222). Rettig discovered that it was possible to identify key individual resources, which were slightly different for men and women, and which formed a credible and manageable set to use for predicting evaluation of family life. In descending order of power, for women these were: marriage, love and affection (love), comfortableness at home (service) open and honest expression of feelings (information) and respect (respect). For men, these identified variables were: marriage, things done together (shared time), comfortableness at home (services), sexual relationship, (love/services) and love and affection (love). It is noteworthy that

Rettig (1980) found that while satisfaction with family life is reported as being highest during child rearing years, satisfaction with children does not enter the most powerful predictive set of variables for either men or women in predicting satisfaction with family life.

## METHODOLOGY

This research study involved an analysis of quality of life measures comparing a group of twenty-two couples who are parents of autistic children with the two-hundred thirty-seven couples surveyed in the Oakland County Quality of Life Study.

### Autism Sample Selection

In the Spring of 1979, a "Needs Assessment Survey for Parents of Autistic Children" (See Appendix) was circulated to all eight of Michigan's existing self-contained programs for autistic students. These questionnaires were either sent home with each child or were given personally to parents attending parent organization meetings at the school. The total population of families originally receiving questionnaires was approximately 350. The parents were all given stamped envelopes for return to the Department of Special Education, Michigan State University. One-hundred ten questionnaires, or approximately one-third of the total were returned with the fifty-two items completed. Parents were asked to indicate their name and phone number if they were willing to be contacted for further interviews. Of the one-hundred ten returned questionnaires, approximately three-fourths provided information for follow-up contacts.

To select the autism group for this study, considerations of time and other costs eliminated respondents who were located in

low-incidence areas of population in the State. In addition, it was felt important to have several separate school programs represented and to obtain parents whose children represented a variety of ages. The researcher's knowledge of autism programming in the State reinforced the concept of selecting the oldest school programming areas for several reasons. Most importantly, the oldest programs are in the State's larger urban areas and have developed stable diagnostic processes for student eligibility. The confusion over accurate diagnosis is an extremely serious problem in new programs, particularly in low population areas where diagnostic personnel may not be adequately experienced with this handicapping condition. In addition, the severe behavior disturbances of the autism populations must somehow be implicated in the recurrent stress surrounding home/school relationships. It has been observed that programs experiencing the greatest stress between school and family representatives appear to be in the program philosophy developmental stages of the first three years. Since the researcher, as a former director of an autism program in the central Michigan area might be perceived by families as a "school representative," it was felt important to draw the sample from the most stable programs whose parent/school relationships were at least "comfortable." In addition, the administrators of the three programs from which the sample was eventually drawn are well known to the researcher, have been in their present positions an average of four years, and possess great skill in public relations. While no direct effort was made to

contact any families through the schools, each of the directors was informed of the research project and had general knowledge of its area of concern. In actuality these relationships did prove helpful to the successful completion of the sample. After the researcher had made phone contacts and obtained cooperation from a parent group in one city, the parents were meeting in a routine public relations, "clear the rumors" session with the autism program administrator. One mother raised the issue of appropriateness and ethics of this research study. The administrator was able to offer very positive support and encouragement toward their participation.

Once the three urban areas were selected for sample sites, all single parent and foster parent homes were eliminated for purposes of this study. From a pool of thirty-one families in the three cities, phone calls were made directly to each family by the researcher. The intent of the research project was explained and it was made clear that both husbands and wives were needed for participation.

Of the twenty-seven families eventually called (four were unable to be located because of incomplete or inaccurate information) one family was eliminated who had institutionalized their child between April and December of 1979. In addition, two families could not find a meeting date during January and February of 1980 which would allow for the researcher's travel schedule and their family work schedules. The fourth family was eliminated because of extremely high stress and inability to participate at that time; the mother

had recently entered graduate school and they were seeking an institutional placement for their low-functioning aggressive adolescent son. The fifth family was eliminated due to the mother's unexpected surgery after the appointment had been made.

The response of parents to the request for participation was overwhelmingly positive. In the original phone contacts, only two persons indicated they wished to ask their spouse's agreement; most call backs were simply to coordinate the appointment schedule. While some parents indicated concern for the exact intention of the study, their overwhelming response was positive toward the ideas of "helping improve programs for my autistic child" or "telling how it really is" in life with their son or daughter. Several parents suggested the names of other families they thought would enjoy participating (these were not used unless they were already on the sample list).

#### Autism Sample Description

Because of the deliberate selection of families whose children were in the older, more stable school programs, it was suggested that these twenty-two families might represent an unusual sample as compared with the entire one-hundred ten respondents. Therefore, simple frequency counts were obtained for key demographic variables comparing the chosen sample with the eighty-eight non-selected. Within the Gray sample, there is a relatively higher percentage of children in the preschool ages and a lower percentage in the adolescent years. The mean age of the Gray sample is therefore

one year younger than the non-selected. The Gray respondent group reported more evidence of "other handicapping conditions;" it is difficult to know whether this represents greater diagnostic sophistication, greater honesty and acceptance of their child's severity of disability, or an artifact of the questionnaire item. Since one-sixth of autistic adolescents show seizure disorders and approximately two-thirds of the autism population function at trainable level or below, it is felt that this parent report does not truly represent a difference in actual child functioning between the two groups. Lotter (1967) reported that none of the autistic children in the Middlesex Survey with IQ's above 50 exhibited other handicapping conditions. However, 77% of those with IQ's less than 50 showed other handicapping conditions.

Fifty-nine percent of the Gray sample reported their children to be non-verbal as compared with fifty-one percent of the remaining eighty-eight. However, since there were fifteen percent missing data on this question for the group of eighty-eight, it is difficult to believe that there are any absolute differences on this measure for the two populations. The Gray sample is weighted toward somewhat smaller families, over fifty percent having two to three children. When the two groups are compared by ages of mothers and ages of fathers, the mother's ages are almost identically patterned, while the fathers in the non-selected group show a much greater range of ages.

Families were asked how far they lived from their nearest relative; the results indicate that approximately two-thirds of



both groups have a relative within five miles. The patterning is slightly different with the Gray sample showing families somewhat closer.

On the original questionnaire, parents were asked questions pertaining to information sources regarding their autistic child's diagnosis and program needs, school/home communication, family relationships, and contacts or knowledge of other social service agencies. The Gray sample group answered in substantially the same manner as the remaining autism families except for six of the fifty two items. An analysis of these responses indicates that the Gray sample group is reporting more problems with the autistic child's interference with the home "running smoothly," more satisfaction with the amount of time spent away from the autistic child, more emotional support from relatives, and slightly more confidence in the ability of community agencies to provide service to their autistic children. The Gray group reports more sibling upset with the autistic child and slightly more contact with a professional advocacy organization. Since the Gray sample was pulled from the longest established programs, it may be that a more highly developed communication/support system would be accessible to these families. Since the Gray sample was somewhat closer to relatives, this distance may explain their reporting of significantly more relative support. It would appear, however, that the Gray sample represents families who may feel somewhat more satisfied with their family life and more satisfied with support from a variety of exosystems.

When comparing this autism sample to published descriptions of other autism groups, there are substantial similarities to the DeMyer (1979) and Lotter (1967) demographic reports. The mean of age of the Gray sample is twice that of the DeMyer group, but other comparisons of sex, race, number of siblings, age of parents and verbal behavior are substantially the same. There are fewer Gray autism parents who have less than a high school diploma; there are more Gray autism mothers who have at least a college degree. The comparison between socioeconomic status and occupational status is uneven; it would appear that the Gray autism families represent a slightly higher professional/managerial population bias. Lotter (1967) found 43 percent of fathers of autistic children to be university graduates or above, which is comparable to the DeMyer and Gray figures.

In summary, of the original one-hundred ten respondents to the College of Education survey, it appears that the selected research sample represents families which tend to be smaller, feel somewhat more satisfied with their families and have fathers who are somewhat older. There is a trend for the Gray families to feel slightly more positive about support received from outside the family. In comparison to reports in the literature, the Gray sample would appear very similar to the group studied by DeMyer except for the age of the autistic child and the mother's education level. Tables for these comparisons can be found in the appendix.

### Oakland Sample Selection

The two-hundred thirty-seven husband-wife pairs were drawn from the Oakland Quality of Life Research Project which is an on-going effort of the Departments of Human Environment and Design and Family and Child Sciences in the College of Human Ecology at Michigan State University. The project has received funding from the Michigan and Minnesota Agricultural Experiment Stations<sup>1</sup> data on four-hundred eighty-one subjects was originally collected in November and December of 1977 and January and February of 1978. A nationally known research firm was hired to draw the sample from Oakland County in Michigan and to complete the process of delivery and collection of the research instrument. Rettig (1980) has described the selection process in detail.

### Oakland Sample Description

Preliminary analyses completed on the data and reported Sontag, Bubolz, and Slocum (1979) reveal a sample in which all families were in the child-rearing stages of the family life cycle. While the Oakland data were taken two years ago and hence the respondent's would presently show a mean age of 39.5 for women and 42.2 for men, the age at time of survey completion for the two groups of women is extremely close, with a 1.5 year higher mean age for men in the autism sample. The distribution of ages for the two

---

<sup>1</sup>The research was funded by the Michigan Agricultural Experiment Station under Project Numbers 3151 and 1249 with additional support from the Minnesota Agricultural Experimental Station.

groups of women is very similar; the pattern between the two men's group is different with a smaller percentage of autistic fathers falling in the middle age ranges.

In the two groups, there are relatively equal numbers of households containing additional relatives who were not members of the nuclear family. For the autism group, these actually represented only two families in which adolescent male nephews were living with the families for purposes of education/employment support. A somewhat higher percentage of autism families have only two children.

There are more families among the autism who still report older children living at home. In absolute numbers for the study, this represents two families. In one family the child over twenty-three is autistic, in the second family an older daughter who is still attending college resides at home.

While approximately two-thirds of the Oakland women have a high school diploma or less, sixty percent of the autism sample have education beyond high school. For the men, forty-seven percent of the Oakland group and fifty percent of the autism group have a high school diploma or less, but the pattern of higher education is quite different. For the autism group thirty-six percent of the autism fathers have education beyond bachelor's degrees. The employment status comparisons of women in the two groups reveals that a higher percentage of autism women are actually working; this figure is consistent with the higher levels of education found in this group of mothers. An equivalent pattern of employment status

is seen between the two groups of men. There is a slight tendency for women in the autism group to hold more professional, managerial and sales positions in comparison with the Oakland group. This direction is quite pronounced in the comparison between the two men's groups. When comparing total family income levels, this disparity between groups is not seen. Particularly since the Oakland data are two years old, it would appear that the average income may be slightly higher among the Oakland sample. With the evidence of somewhat smaller families within the autism group, however, the per capita income should be quite comparable.

In summary, frequency comparisons for demographic data on the autism group and the Oakland reveal that autism families have somewhat fewer children, a higher percentage of women working for pay outside the home, and higher education levels for both husbands and wives with resultant greater percentages of professional and managerial employment positions. Tables of comparisons of this demographic information are contained in the appendix.

#### Data Collection

The data collection for the Oakland sample is described by Rettig (1980) and involved nominal payment to each family for the completion of a questionnaire by both husband and wife. The research team then called at each home to pick up the completed questionnaires. Separate sealed envelopes were provided for both husband and wife with instructions to discourage collusion of answers.

For the autism study, the researcher made initial phone contacts and set weekend or evening appointments for a time both husband and wife could be at home. After a brief description of the study's intent, the researcher gave separate questionnaires to husbands and wives and they were completed in her presence. Questions regarding the utilization of the scaled responses were answered and occasional examples of a item's meaning were provided. In one home where the husband could not read well, the researcher read the questions while he recorded his answers on a separate questionnaire. The wife was not in the same room during this process. In one other home, both husband and wife were poor readers and asked frequent questions about vocabulary, but filled out the questionnaires independently from opposite ends of the table.

#### Instrumentation

The major portion of the questionnaire for administration to the families of autistic children was obtained from the Oakland County Quality of Life Questionnaire (see Appendix). For purposes of this research effort portions of the original questionnaire which dealt with items about clothing, national government, children, and energy conservation were deleted. The final research questionnaire therefore contained thirteen scales, only one of which is used for analysis in this effort. All questions were originally developed by the research staff at the Michigan State University Quality of Life Research Project. The original questionnaire had been approved by the Michigan State University Committee for Research

on Human Subjects. Informed consent forms were signed by each subject (see Appendix).

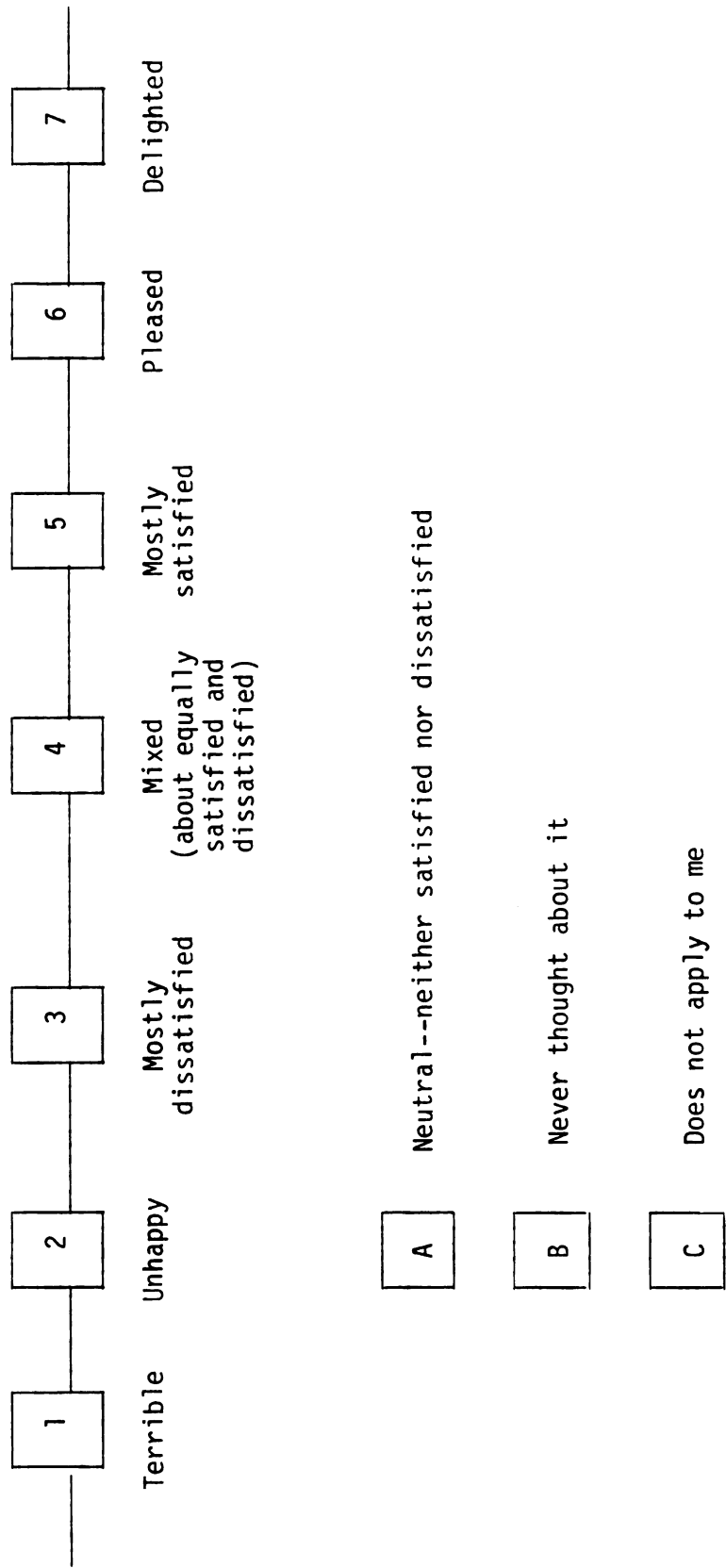
The statistics for all items on the portion of the questionnaire utilized in this analysis were taken from the Terrible-Delighted Scale (see Figure 3.1) which was developed by Andrews and Withey (1974) and was found by them to adequately function as an interval scale with the property of linear additivity for their large research sample. Attempts by Andrews and Withey (1974) to substitute other, more mathematically complex scales, did not prove elucidating.

### Description of the Variables

#### Affective Evaluation of Family Life

Numerous writers (Culbertson, 1977; Sullivan, 1970; Kysar, 1968; Paluszny, 1979) have commented on the serious effects which an autistic child has on family functioning and satisfaction. Others such as DeMyer (1979) and Warren (1978) feel that the presence of an autistic child may either strengthen the family or lead to debilitation of individual members and then the entire group. The literature suggests that the numbers of single parents among the autistic families is lower than the present national average and lower than the special education rate suggested by Love (1970). In Holroyd's (1976) research, the mothers of autistic children reported more parent problems, more child problems and more family problems than either the mothers of Down's Syndrome or psychiatric outpatient clients. However, the autism mothers of the "high stress" groups

Figure 3.1.--The Andrews-Withey Terrible/Delighted Scale.



Source: Frank M. Andrews and Stephen B. Withey, Principal Investigators, Development and Measurement of Social Indicators (Ann Arbor, MI: Institute for Social Research, Social Science Archive, 1975), Codebook, July Data, p. 28.



were differentiated from the low stress group by the reporting of five specific problem areas; four of these areas were classed as "family problems."

To date, no research has attempted to evaluate autism effects on normal siblings and Sullivan's (1979) writings have begun to highlight the enormous effect that autistic children have on the quality of family life. As a beginning research effort, it would seem appropriate to utilize parents' subjective evaluations of family life as a dependent variable to explore some of the relationships among quality of life and people and resources judged important to this evaluation. Therefore, affective evaluation of family life is utilized as a dependent variable for the major analyses in this research effort. In keeping with the model proposed by Andrews and Withey (1974) for evaluation of overall life and utilized by Rettig (1980) and Sontag et al. (1979), the statistical definition of this variable is the mean of Family Life 1 and Family Life 2--two identical questions asked approximately thirty minutes apart in the questionnaire. See Table 1 for a complete listing of the variables as questionnaire items.

#### Affective Evaluation of Life-As-A-Whole

Because previous research (Andrews and Withey, 1974; Jackson, 1979; Rettig, 1980; Sontag et al., 1970) had utilized the concept of an individual's subjective evaluation of satisfaction with total life as a significant dependent variable, this variable was utilized in a like manner in this research for several of the preliminary

TABLE 1.--Questionnaire Items Used to Measure Variables Under Study

Variable	Questionnaire Item <sup>a</sup>
Affective Evaluation of Family Life (Life 3)	Mean of 1.3a and 9.1
Affective Evaluation of Life-As-A-Whole (Life 3)	Mean of 1.1 and 9.2
Affective Evaluation of Family Life by Satisfaction with:	
Your husband or wife	6.1a
Your children	6.1b
The love and affection you experience	6.1c
The closeness and sense of belonging you feel	6.1d
The amount of respect you receive	6.1e
How comfortable it feels to be at home	6.1f
Your marriage	6.1g
Affective Evaluation of Family Life-- Your Marriage, Husband or Wife and Children by Satisfaction with:	
The way money is used	6.2a
The amount of money available for personal use	6.2b
The material goods it enables you to own	6.2c
The way decisions are made	6.2d
The things you do together	6.2e

TABLE 1.--Continued

Variable	Questionnaire Item <sup>a</sup>
Affective Evaluation of Family Life by Satisfaction with:	
The mutual helpfulness of family members	6.3a
The way household work is divided/ accomplished	6.3b
How openly and honestly you can express feelings	6.3c
The kind of communication you have	6.3d
The amount of time the family spends together	6.3e
Your sexual relationship	6.3f
The time you spend with your children	6.3g
The time you spend with your husband or wife	6.3h
Employment status	13.9b

<sup>a</sup>See appendix for complete questionnaire.

analyses. Particularly with sensitivity to public and social policy issues, it would seem important to identify whether the independent variables present in the subgroup of families with autistic children could significantly impact on overall life quality. In keeping with the Andrews and Withey (1974) model, the statistic for this variable was a simple mean of the responses on Life 1 and Life 2-- identical questions asked approximately thirty minutes apart on the questionnaire.

People/Shared Time Resources.--Rettig (1980) conceptualized the quality of shared time in the family as being a necessary condition for the exchange of resources. Since this research deals with families who by definition include a severely handicapped person, it was felt important to evaluate whether a collection of variables which reflected specific people and shared time with those people might reveal a significant effect on the satisfaction with family life. Also called the "People Scale," these independent variables are drawn from items developed by Rettig (1980) and included:

How would you feel about your own family life if you considered only:

Your husband or wife?  
 Your children?  
 The amount of time the family spends together?  
 The time you spend with your children?  
 The time you spend with your husband or wife?

Rettig Resources.--The remaining independent variables were drawn from research by Rettig (1980) and include individual evaluations

on the Terrible-Delighted Scale of satisfaction with resources conceptualized as reflecting the Foa and Foa resource classes of love, status, services, information, goods and money. These include:

How would you feel about your own family life if you considered only:

The love and affection you experience? (love)  
 The closeness and sense of belonging you feel? (love)  
 The amount of respect you receive? (respect)  
 How comfortable it feels to be at home? (services)  
 The way money is used? (goods and money)  
 The amount of money available for your personal use? (goods and money)  
 The material goods it enables you to own? (goods and materials)  
 The way decisions are made? (information)  
 The things you do together? (shared time)  
 The mutual helpfulness of family members? (services)  
 The way housework is divided/accomplished? (services)  
 How openly and honestly you can express feelings? (information)  
 The kind of communication you have? (information)  
 Your sexual relationship? (love-services)

### Data Analysis

Research data were analyzed on the Control Data Corporation 6500 Model Computer at the Michigan State University computer laboratory. Programs were drawn from the Statistical package for the Social Sciences (Nie, Hull, Jenkins, Steinbrenner, and Brent, 1975) and consulting assistance from the Office of Research Consultation in the College of Education.

### Statistical Methods and Assumptions

The statistical methods which were used in the analysis included: T-Tests of Means, paired T-Tests of Means, Cross Tabulations, Pearson product moment correlations, and the forward method of multiple regression.

### T-Tests of Means and Paired T-Tests

The following hypotheses<sup>1</sup> were tested by simple T-tests of means or paired T-tests of means:

- H3: Parents of autistic children will report lower mean scores of evaluations of family life, marriage, children, and spouse than will parents of non-handicapped children.
- H3a: Mothers of autistic children will report lower mean scores of overall evaluations of life, family life, children and spouse than mothers of non-handicapped children.
- H3b: Fathers of autistic children will report lower mean scores of overall evaluation of life, family life, marriage, children and spouse than will fathers of non-handicapped children.
- H20: In families with autistic children, mothers' evaluations of overall life, family life, children, marriage and spouse are significantly lower than fathers' evaluations of these same dimensions.
- H22: Mothers of autistic children who work for pay out of the home show the same mean evaluations of selected

---

<sup>1</sup>All hypotheses are stated in the predicted form.

resources received in the family as mothers of autistic children who do not work for pay out of the home.

The T-test for sample means tests the significance of the difference between two sample means for specified variables or, for paired observations, arranged casewise. A significance level for the t statistic is chosen which is then used to test the null hypothesis that there are no differences between the population means on that variable. In this analysis of an exploratory nature, a Type II error (accepting the null when it is false) was judged to be more serious and therefore the significance level for the T-tests was set at .05. Variances of each of the samples are computed or approximated for utilization in the t statistical test:

$$t_d = \frac{(x_1 - x_2) - \mu_1 - \mu_2}{S_d}$$

Where  $t_d$  is the t for the difference in means

$S_d$  is the difference in sample variances

The two-tailed probability is computed which represents the occurrence of a value greater or equal to t, sign ignored, and is then utilized to accept or reject the null hypothesis.

In the paired observations analysis, the difference between husbands' and wives' means for each variable is utilized. This technique attempts to reduce extraneous influences on the variable; for purposes of this study it highlights the pattern of agreement/disagreement between spouses for specific variables. The T-test assumes a normal distribution of the variable.

### Pearson Product Moment Correlation

The following questions were investigated through the use of Pearson product moment correlations:

Q1: Do parents of autistic children show the same pattern of relationship between evaluations of specific resources and evaluation of family life as do parents of non-handicapped children?

Q2: Do parents of autistic children show the same pattern of relationship between evaluations of shared time and people resources and their evaluation of family life as do parents of non-handicapped children?

Correlational analysis provides a method of examining the statistical results to identify patterns in the responses of sub-groups. The Pearson correlation coefficient  $r$  is the test statistic which provides a measure of the degree to which the variation observed in one interval variable is related to the variation observed in a second interval variable. The numerical value can range from -1 to +1 with a perfect positive linear correlation designated as +1. The  $r$  statistic assumes linearity of measurement, random sampling and a bivariate normal distribution (Nie et al; 1975). Violations of the assumptions yield a statistic which is robust according to Nie (1975). The squared correlation coefficient describes the relative percent of common variance between two variables. The significance level of  $r$  is reflective of its distance from zero. The mathematical formula for  $r$  is:



$$r = \frac{\sum_{i=1}^N (X_i - \bar{X})(Y_i - \bar{Y})}{\{ [\sum_{i=1}^N (X_i - \bar{X})^2] [\sum_{i=1}^N (Y_i - \bar{Y})^2] \}^{1/2}}$$

Where  $X_i$  =  $i$  th observation of variable  $X$

$Y_i$  =  $i$  th observation of variable  $Y$

$N$  = number of observations

$\bar{X} = \sum_{i=1}^N X_i / N$  = mean of variable  $X$

$\bar{Y} = \sum_{i=1}^N Y_i / N$  = mean of variable  $Y$

Pairwise deletion was used for all of the correlations; a case is omitted from the compilation of a given coefficient if the value of either of the two variables being considered is missing.

### Cross Tabulations

The following hypothesis was tested by cross tabulation analysis:

$H_{3c}$ : Mothers and fathers of autistic children will show no differences in the pattern of spouse agreement of evaluations of life-as-a-whole, family life, marriage, spouse, and children when compared to mothers and fathers of non-handicapped children.

Cross tabulation is simply a descriptive technique which produces a joint frequency distribution of cases according to at least two variables. In this analysis, the wife variables for life-as-a-whole, family life, children, marriage and spouse were plotted against the husband variables on these same measures to produce

five joint frequency tables. The measure of association between the two variables can then be computed by the following formula for Gamma:

$$\text{Gamma} = \frac{P - Q}{P + Q}$$

where P is the number of concordant pairs and Q is the number of discordant pairs. Both variables must be least be measured at ordinal level. A positive value indicates a predominance of concordant pairs, and values which move toward 1, sign ignored, show fairly strong trends. The value of gamma can be taken as the probability of correctly guessing the order of a pair of cases on one variable once the ordering on the other variable is known.

#### Multiple Regression

The following hypotheses were investigated by multiple regression analysis with forward stepwise deletion:

- H4: In families with autistic children, the mothers' evaluations of marriage do not contribute significantly to the prediction of evaluation of family life.
- H5: In families with autistic children, the mothers' evaluations of love and affection do not contribute significantly to the prediction of evaluation of family life.
- H6: In families with autistic children, the mothers' evaluation of how comfortable it feels to be at home do not

contribute significantly to the prediction of evaluation of family life.

- H7: In families with autistic children, the mothers' evaluations of how openly and honestly feelings can be expressed do not contribute significantly to the prediction of evaluations of family life.
- H8: In families with autistic children, the mothers' evaluations of the amount of respect received do not contribute significantly to the prediction of evaluations of family life.
- H9: In families with autistic children, the fathers' evaluations of marriage do not contribute significantly to the prediction of evaluations of family life.
- H10: In families with autistic children, the fathers' evaluations of "things done together" do not contribute significantly to the prediction of evaluations of family life.
- H11: In families with autistic children, the fathers' evaluations of how comfortable it feels to be at home do not contribute significantly to the prediction of evaluation of family life.
- H12: In families with autistic children, the fathers' evaluation of the sexual relationship do not contribute significantly to the prediction of evaluation of family life.
- H13: In families with autistic children, the fathers' evaluations of love and affection received do not contribute significantly to the prediction of evaluation of family life.

- H14: In families with autistic children, mothers' and fathers' evaluations of marriage contribute at the same level to their evaluations of family life as those of mothers and fathers of non-handicapped children.
- H15: In families with autistic children, mothers' and fathers' evaluations of children contribute to the prediction of evaluation of family life at the same level as mothers and fathers of non-handicapped children.
- H16: In families with autistic children, mothers' and fathers' evaluations of spouse contribute to the prediction of evaluations of family life at a level equal to that of mothers and fathers of non-handicapped children.
- H17: In families with autistic children, the mothers' and fathers' evaluations of time spent with children contribute to the prediction of evaluations of family life at the same levels as those of mothers and fathers of non-handicapped children.
- H18: In families with autistic children, the mothers' and fathers' evaluations of time with spouse contribute to the prediction of their evaluations of family life at a level equal to that of mothers and fathers of non-handicapped children.
- H19: In families with autistic children, the people and shared time resources are stronger predictors of affective evaluations of family life than are the identified Rettig resources.

The intention of multiple regression procedures is to identify the minimum number or the most powerful set of independent variables which account for the variance in the identified dependent variables of interest. Furthermore, the forward stepwise inclusion method is appropriate when the researcher is interested in making as good a prediction to a criterion as possible on the basis of several predictor variables. In this analysis, the dependent variables were either life-as-a-whole or family life.

In the forward stepwise solution, tests are performed at each step to ascertain the contribution of the variable under consideration if it were to enter the equation of prediction last. The calculated F ratio is obtained at each step. In the final equation, the F-to-remove represents the loss caused to R by removing a given variable. The independent variable which has the highest zero correlation with the dependent variable enters the equation first, followed by the variable which has the highest partial correlation to the dependent variable until all variables which meet the pre-specified level of significance have entered. The statistical multiple regression model is:

$$Y_i = \beta_0 + \sum_{k=1}^{P-1} X_{ik} \beta_k + e_i$$

where:  $Y_i$  is the dependent variable value on the  $i$ th trial

$\beta_0$  is the Y intercept which is a constant in the multiple regression table

$\beta_k$  is the change in the mean response of the dependent variable with a unit increase in the

independent variable  $k$  when all other independent variables in the equation are held constant;  
 $i1 \dots, x_i, p-1$  are the values of the independent variables in the  $i$ th trial;  
 $e_i$  is the random error.

The assumptions of the multiple regression procedure are as follows:

1. Random sampling
2. Normal Distribution
3. Equality of variance
4. Additivity
5. Linearity
6. Independence of observations
7. Interval measurements.

The  $F$  test statistics associated with multiple regression are considered to be "robust" with regard to violation of these assumptions (Kerlinger, 1973). The overall accuracy of the prediction equation is reflected by  $R^2$ , the proportion of variation explained by the variables included in the regression equation. List wise deletion of data was used for the regression analysis to ensure that all computations of the regression equation are carried out on the same universe of data. The  $F$  ratio for the overall equation tests the null hypothesis that the sample has been drawn from a population where the multiple correlation is equal to zero. Therefore the tests for specific regression coefficients are necessary to ascertain whether certain variables can be legitimately deleted from the regression equation. Direct examination of residuals through a scatter plot will reveal only random patterns if the regression equation accounts for

all the significant patterns between the independent and dependent variables.

## FINDINGS

The statistical procedures and test statistics are detailed in Chapter III. In this chapter, the hypotheses and questions are taken in order. The frequency data for the autism and Oakland populations are presented where appropriate and the summary statistics from the statistical tests used are included.

### Objective A

Obtain demographic information on a volunteer population of parents of autistic children for comparison to published information in the literature.

### Hypothesis for Objective A

H1: The sample of autistic families used in this study is enough representative of the universe of autistic families reported in the literature to permit meaningful inferential statements about autistic families known to other researchers.

As reported in Chapter II, the demographic information for the autism sample supports meaningful comparison to the DeMyer (1979) information and the figures reported by Lotter (1976), Rutter (1978) and Paluszny (1979). Descriptive tables are contained in the appendix and reveal similarities in family size, age of parents, race, sex, verbal behavior, and presence of multihandicaps in the autistic



child. The autism sample in this study includes mothers with a slightly higher level of education, and families with somewhat higher prestige scores for their occupations than those described in previous studies.

In addition, comparisons between the autism sample used for this study and those not selected from the original College of Education Survey reveal that the autism parents are somewhat more experienced with a variety of agencies, and feel good support from professionals and extended family members. In a study in which the concern is quality of life, the literature would suggest, therefore, the greater possibility of a Type II error in hypotheses testing. In other words, these autism families may show characteristics which would be expected to raise their means of evaluation of overall life and family life in comparison to the universe of families with autistic children. In an initial exploratory effort, this tendency would not be viewed in the negative.

H2: The sample of autistic families used in this study is enough similar to families in the Oakland Quality of Life Study to permit meaningful comparisons of data.

Tables in the appendix illustrates these comparisons and can be summarized in the following manner: ages of men and women are quite comparable, the men in the autism sample include a greater proportion with education beyond a bachelor's degree and tend to hold jobs in somewhat higher managerial levels than men in the Oakland sample. The women in the autism group show higher levels of

education and a slightly higher percentage work for pay out of the home. While the age ranges of children in the two groups are comparable, a larger proportion of the autism families have only two children. The per capita income reveals the Oakland group to be slightly higher. Again, one might suspect that aside from their handicapped child, the autism group represents parents who might show more satisfaction with their life quality. In summary, it would seem that meaningful comparisons can be made between the two samples studied.

#### Objective B

Compare the relationships between parent reporting of overall evaluations of life, family life, marriage, children, and spouse in families of autistic children with families of non-handicapped children.

#### Hypotheses for Objective B

H3: Parents of autistic children will report lower mean scores of evaluations of family life, marriage, children, and spouse than will parents of non-handicapped children.

In Table 2, the descriptive statistics comparing the autism and Oakland mothers and fathers on these variables are shown. It appears that there is great similarity between the two groups on these variables. The autism parents show a higher mean affective evaluation of spouse, and marriage; neither of these differences

**TABLE 2.--Descriptive Statictics for Means of Autism and Oakland  
Parents on Affective Evaluations of Satisfaction with  
Family Life and People Resources**

<b>Variable</b>	<b>Autism</b>	<b>Oakland</b>
<b>Spouse</b>	<b>5.909</b>	<b>5.786</b>
<b>Children</b>	<b>5.682</b>	<b>5.876</b>
<b>Marriage</b>	<b>6.000</b>	<b>5.903</b>
<b>Family Life</b>	<b>5.738</b>	<b>5.742</b>

achieve significance level. The Oakland parents show slightly higher means on affective evaluations of satisfaction with children, and family life. Neither of these differences again, achieve significance. By pooling the men and women from each sample, no significant differences are revealed on any of the variables. The directional hypothesis is rejected by these data.

H3a: Mothers of autistic children will show lower mean scores of affective evaluations of family life, marriage, children, and spouse than will mothers of non-handicapped children.

Table 3 reveals that women in the autism group show lower mean scores for affective evaluations of spouse, children and family life, and higher mean scores for affective evaluations of marriage than the Oakland women. However, the T-tests do not reach significance on any of these variables and the directional hypotheses is rejected. The test for the mean of satisfaction with children is the only one which begins to approach significance.

H3b: Fathers of autistic children will report lower mean scores of overall evaluation of life, family life, marriage, children, and spouse than will fathers of non-handicapped children.

From Table 4 it can be seen that the means of the autism fathers are higher than the Oakland fathers on affective evaluations of spouse, children, marriage and family life; only on satisfaction with spouse is the significance level approached (.058). Therefore, the directional hypotheses for fathers should be rejected.

**TABLE 3.--T-Tests of Means of Affective Evaluations of Selected Domains and Resources for Women in Autism and Oakland Groups**

Satisfaction with	Means		T Value	Significance
	Autism	Oakland		
Children	5.409	5.803	-1.81	.081
Spouse	5.591	5.721	- .44	.666
Marriage	5.864	5.835	.11	.916
Family Life	5.571	5.636	- .21	.781
Life	5.336	5.437	- .36	.820

TABLE 4.--T-Tests of Means of Affective Evaluations of Selected  
Domains and Resources for Men in Autism and Oakland Groups

Satisfaction with	Means		T Value	Significance
	Autism	Oakland		
Children	5.955	5.949	.03	.978
Spouse	6.227	5.851	1.97	.058
Marriage	6.136	5.970	.73	.469
Family Life	5.905	5.848	.12	.969
Life	5.581	5.476	.56	.612

H3c: Mothers and fathers of autistic children will show no differences in the pattern of spouse agreement of evaluations of life-as-a-whole, family life, marriage, spouse and children when compared to mothers and fathers of non-handicapped children.

Cross tabulations for this hypotheses are presented in Tables D-1 through D-10 (Appendix D) for autism and Oakland husband-wife pairs separately. Table 5 summarizes these findings. Absolute concordance for couples is quite similar for both samples on affective evaluations of family life, children, and marriage. There are approximately ten percent fewer autism couples who agree on evaluations of life-as-a-whole and fourteen percent more autism couples who agree on affective evaluations of spouse. When the figures are compared for absolute concordance or one category difference, approximately equal agreement is seen for life-as-a-whole, and children. Seven percent less agreement is seen in autism couples for evaluation of spouse, and thirteen percent less agreement for affective evaluations of family life and marriage.

### Objective C

Explore the relationships between parent evaluations of selected dimensions of family life in families with autistic children and families of non-handicapped children.

Sub C.1: Identify the resources which are the most powerful predictors of family life evaluation for parents of autistic children in comparison to parents of non-handicapped children.

TABLE 5.--Summary of Spousal Agreement for Life-As-A-Whole, Family Life, Marriage, Spouse and Children in Oakland and Autism Groups.

Domain	Spouse Agreement		One Category Difference	
	Autism	Oakland	Autism	Oakland
Life-As-A-Whole	33.3%	43.4%	83.8%	85.8%
Family Life	40.9%	43.2%	77.1%	90.2%
Marriage	36.3%	42.6%	67.1%	80.8%
Spouse	59.1%	45.6%	72.7%	80.9%
Children	50.0%	47.2%	85.3%	83.4%



Sub C.2: Identify the evaluations of shared time and people resources in families of autistic children which are the strongest predictors of parent evaluations of family life in comparison to families of non-handicapped children.

#### Hypotheses and Questions for Objective C

Q1: Do parents of autistic children show the same pattern of resources as predictors of their evaluation of family life as do parents of non-handicapped children?

Hypotheses for Mothers:

H4: In families with autistic children, the mothers' evaluations of marriage do not contribute significantly to the prediction of evaluation of family life.

H5: In families with autistic children, the mothers' evaluations of love and affection experienced do not contribute significantly to the prediction of evaluation of family life.

H6: In families with autistic children, the mothers' evaluations of how comfortable it feels to be at home do not contribute significantly to the predictions of evaluation of family life.

H7: In families with autistic children, the mothers' evaluations of how openly and honestly feelings can be expressed do not contribute significantly to the prediction of evaluations of family life.

H8: In families with autistic children, the mothers' evaluations of the amount of respect received do not contribute significantly to the prediction of evaluations of family life.

Rettig (1980) has identified marriage, love and affection, comfortableness at home, honest expression of feelings and respect received as the most powerful predictors in descending order of affective evaluations of family life by women in the Oakland group. The  $R^2$  values from the regression analysis values for these resources are reported by Rettig to be 54% for marriage and an additional 7% for love and affection. Comfortableness at home, open and honest expression of feelings, and respect received contributed an additional 2% to the predictions of variance in family life. The entire set accounted for 63% of the variance. Table 6 summarizes the regression results for women in the autism group. Most notable is the fact that marriage did not even enter the equation with  $T$  set at .001. In other words, marriage was not able to account for even .1% of the variance in evaluation of family life not accounted by the other four. For the remaining four resources, only 42% of the variance in family life is explained. Love and affection accounts for 35%, the next two account for an additional 4½%. The fourth adds only .001 and takes the overall  $F$  above the critical value to .055. Examination of the scatterplot of residuals reveals a completely randomized pattern, which reinforces the prediction equation and confirms the assumption of normality. It would appear that hypotheses 4 and 8 should be retained and hypotheses 5, 6 and 7 are rejected. In other words, love and affection experienced, open and honest expression of feelings, and comfortableness at home appear to contribute significantly to the prediction of affective evaluation of family life

TABLE 6.--Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Marriage and Resources Received, order not specified for Women in Autism Group<sup>a</sup>

Step	Variable Entered	F to Enter	Multiple R	R <sup>2</sup>	R <sup>2</sup> Change	Significance
1.	The love and affection you experience (Love)	11.35864	.61168	.37415	.37415	.003
2.	How openly and honestly you can express feelings. (Information)	.57002	.62718	.39336	.01921	.011
3.	How comfortable it feels to be at home. (Services)	.80118	.64859	.42066	.02730	.023
4.	The amount of respect you receive. (Status)	.02968	.64941	.42174	.00107	.055

<sup>a</sup>The variable "Your Marriage" did not enter the equation at T = .001.

in women in the autism group. In view of the relative position of marriage in the regression equation for both groups and the total variance accounted for by the five resources for the Oakland women, it appears that the pattern of resources is significantly different for the autism group of women.

#### Hypotheses for Fathers:

H9: In families with autistic children, the fathers' evaluations of marriage do not contribute significantly to the prediction of evaluations of family life.

H10: In families with autistic children, the fathers' evaluations of things done together do not contribute significantly to the prediction of evaluations of family life.

H11: In families with autistic children the fathers' evaluations of how comfortable it feels to be at home do not contribute significantly to the prediction of evaluation of family life.

H12: In families with autistic children, the fathers' evaluations of the sexual relationship do not contribute significantly to the prediction of evaluation of family life.

H13: In families with autistic children, the fathers' evaluations of love and affection received do not contribute significantly to the prediction of evaluations of family life.

Rettig (1980) identified a series of resources which were the most powerful predictors of evaluation of family life for the Oakland men. These resources and their relative contribution to the regression equation for Oakland men in descending order are

as follows: marriage - 48%; things done together added 7%, comfortableness at home added 4%; sexual relationship added 1% and love and affection added .3%. The entire set of resources accounted for 60% of the variance in the Oakland men's evaluations of family life.

Table 7 represents the summary statistics for the men in the autism group. This set of five resources accounted for 82% of the variance in the autism men's evaluation of family life, with the greatest contributions attributable to marriage (77%) and sexual relationship (2%). The next three resources add an additional 4% with the overall F significance remaining at  $p < .001$ . Examination of the residuals reveals a completely random pattern. Evidently, for men in the autism group, these resources are significant and powerful predictors of evaluation of family life. Therefore, hypotheses 9, 10, 11, 12 and 13 should be rejected.

Q2: Do parents of autistic children show the same pattern of shared time and people resources as predictors of their evaluation of family life as do parents of non-handicapped children?

H14: In families with autistic children, mothers' and fathers' evaluations of shared time as a family, contribute to evaluation of family life at the same level as those of mothers and fathers of non-handicapped children.

H15: In families with autistic children, mothers' and fathers' evaluations of children contribute to the prediction of their evaluation of family life at the same level as mothers and fathers of non-handicapped children.

TABLE 7.--Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Marriage and Resources Received, order not specified, for Men in Autism Group

Step	Variable Entered	F to Enter	Multiple R	R <sup>2</sup>	R <sup>2</sup> Change	Significance
1.	Your marriage	62.91225	.87638	.76804	.76804	.0000
2.	Your sexual relationship.	2.15430	.89041	.79284	.02479	.0000
3.	The things you do together	1.79142	.90144	.81259	.01975	.0000
4.	The love and affection you experience.	.88153	.90685	.82237	.00979	.0000
5.	How comfortable it feels to be at home.	.04235	.90712	.82287	.00050	.0000

H16: In families with autistic children, mothers' and fathers' evaluations of spouse contribute to the prediction of their evaluations of family life at levels equal to those of mothers and fathers of non-handicapped children.

H17: In families with autistic children, the mothers' and fathers' evaluations of time spent with children contribute to the prediction of their evaluations of family life at the same levels as that of mothers and fathers of non-handicapped children.

H18: In families with autistic children, the mothers' and fathers' evaluations of time spent with spouse contribute to the prediction of their evaluation of family life at levels equal to those of mothers and fathers of non-handicapped children.

Question 2 is reflective of an exploratory interest in the power of the satisfaction with "people resources" to explain variance in the affective evaluations of family life. Since a prerequisite for the existence of a family is identified members, it is theorized that satisfaction with these people and time shared with them would constitute a valid way to predict evaluation of family life. Since the sample of autism families is defined by a quality of one of its members it is suggested that evaluations of people and shared time may discriminate more clearly between the two groups than the identified Rettig resources.

Table 8 presents the summary of the regression analysis on the people and shared time resources against family life for women in the Oakland group. The five resources account for 53%

TABLE 8.--Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Satisfaction with People and Shared Time, order not specified, for Women in the Oakland Group.

Step	Variable Entered	F to Enter	Multiple R	R <sup>2</sup>	R <sup>2</sup> Change	Significance
1.	Satisfaction with spouse.	147.50577	.63182	.39920	.39920	.000
2.	Satisfaction with shared time with children.	37.53591	.69744	.48643	.08723	.000
3.	Satisfaction with children.	9.91581	.71314	.50858	.02215	.000
4.	Satisfaction with shared time with family.	7.63873	.72466	.52514	.01656	.000
5.	Satisfaction with shared time with spouse.	.81847	.72589	.52691	.00178	.000



of the variance in family life, ordered in the following manner; spouse - 40%, shared time with children - 9%, children - 2%, shared time as family - 1.6%, and shared time with spouse - .1%. The significance levels for each step are all less than .01. Table 9 summarizes these same variables in the regression equation for the Oakland men. The results are very similar in ordering,  $R^2$  change per step, and overall  $R^2$  except for the reversal of positioning of shared time with spouse and shared time with children in comparison to the Oakland women. The women's equation included shared time with children at step 2 and shared time with spouse at step 5; in the men's equation the positions reversed. However, for the Oakland sample of both men and women, the Rettig resources account for approximately 10% more variance in evaluation of family life.

In Table 10, the women's regression equation for the autism group is shown. Here the patterning shows satisfaction with children and shared time with children entering at steps 1 and 2 respectively. Shared time with family enters at the intermediate step 3, while spouse and shared time with spouse enter at steps 4 and 5. The total variance of evaluation of family life accounted for by these 5 variables is 52% which is comparable to the 53% for Oakland women, but represents an increase of 10% from the variance accounted for by the Rettig resources in the women's autism group. For men in the autism group, Table 11 shows that the variable "shared time with family" does not reach the specified level to enter the equation. The other four account for 63% of the variance in family life with

TABLE 9.--Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Satisfaction with People and Shared Time, order not specified, for Men in the Oakland Group.

Step	Variable Entered	F to Enter	Multiple R	R <sup>2</sup>	R <sup>2</sup> Change	Significance
1.	Satisfaction with spouse.	158.51586	.64543	.41658	.41658	.000
2.	Satisfaction with shared time with spouse.	154.37871	.72924	.53179	.11521	.000
3.	Satisfaction with children	8.92995	.74165	.55005	.01826	.000
4.	Satisfaction with shared time with family.	2.85121	.74554	.55583	.00578	.000
5.	Satisfaction with time with children.	2.6207	.74908	.56112	.00529	.000

TABLE 10.--Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Satisfaction with People and Shared Time, order not specified, for Women in Autism Group.

Step	Variable Entered	F to Enter	Multiple R	R <sup>2</sup>	R <sup>2</sup> Change	Significance
1.	Satisfaction with children	12.48316	.61923	.38344	.38344	.002
2.	Satisfaction with time shared with children	3.02151	.68413	.46804	.08460	.002
3.	Satisfaction with shared time with family	1.57090	.71466	.51074	.04270	.004
4.	Satisfaction with spouse.	.05315	.71573	.51226	.00153	.012
5.	Satisfaction with time shared with spouse.	.23745	.72069	.51939	.00713	.026

TABLE 11.--Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Satisfaction with People and Shared Time, order not specified, for Men in Autism Group<sup>a</sup>

Step	Variable Entered	F to Enter	Multiple R	R <sup>2</sup>	R <sup>2</sup> Change	Significance
1.	Satisfaction with spouse	15.11105	.65603	.43038	.43038	.001
2.	Satisfaction with children	7.19004	.76600	.58676	.15638	.000
3.	Satisfaction with children	1.60223	.78774	.62054	.03378	.000
4.	Satisfaction with shared time with spouse	.57491	.79558	.63295	.01241	.001

<sup>a</sup>The variable "Satisfaction with shared time with family" did not enter the equation at T = .001.

the largest power found in the first two steps; spouse - 43% and shared time with children - 16%. Children and shared time with spouse contribute 3% and 1.3% respectively. Thus, the men in the autism group utilize spouse and time with children as important considerations in family life evaluation--a pattern also seen in women in the Oakland group. For the autism men, the regression equation utilizing the Rettig variables accounts for 20% more of the variance of affective evaluations of family life than do people and shared time resources

In summarizing the hypotheses concerned with people and shared time, Hypothesis 14 is rejected because shared time with family does not even enter the regression equation for autism men. Women in the autism group and men and women in the Oakland group all ranked this variable quite comparably. Hypothesis 15 dealt with evaluation of children and is rejected. Children entered at step 3 for men in the Oakland group and at step 2 for both Oakland women and autism men, but it enters the equation at step one for women in the autism group and thus accounts for 38% of the variance in family life for that group. It contributed only 2-3% to the variance for the other three groups.

Hypothesis 16 deals with evaluation of spouse which enters at step 1 accounting for 39-42% of the variance in family life for men and women in the Oakland group and men in the autism group. However, for the women in the autism group, spouse enters at step 4 carrying only a .2% increase in the  $R^2$ . Hypothesis 16 is, therefore, rejected.

Hypothesis 17 deals with shared time with children and represents the closest similarity in ordering across all groups. This variable for autism men and women and Oakland women entered at step 2. In both women's equations, it adds 8%. This variable enters last for Oakland men and offers only .6% change in the  $R^2$ . For the autism men, this variable contributes 15% to the  $R^2$  at step 2. Thus, shared time with children shows significant differences for men across the two groups and thus Hypothesis 17 should be rejected.

Hypothesis 18 deals with evaluation of spouse and is rejected because of the contrasting pattern shown by the autism women where it entered at step 4 and contributed only .1% to the  $R^2$ . For the other three groups, spouse enters at step 1 and accounts for 39-42% of the variance in evaluation of family life. Thus, there are significantly different patterns shown by mothers and fathers in the autism and Oakland groups across each of the variables on this scale. There is a general pattern of the autism women being most consistently different from the three other groups. Oakland men and women are more alike than are autism men and women for this scale.

H19: In families with autistic children, the people and shared time resources are stronger predictors of affective evaluations of family life than are the Rettig resources.

The results of the regression equations for the Rettig resources (Tables 8-11) show that 82% of the variance for affective evaluations of family life by autism men are accounted for; 42% of the variance in autism women's affective evaluations of family life are accounted

for by the Rettig resources. The people and shared time resources account for 63% of the variance in affective evaluations of family life by men and 52% by women. Therefore, these results would suggest that the directional hypothesis for autism men should be rejected, but accepted for autism women; the Rettig resources explain 82% of the autism men's variance in affective evaluations of family life, and the people and shared time resources explain only 52% of the variance in affective evaluations of family life for women. Women appear to be more directly impacted by the people in the family, but other variables not herein selected account for more variance in women's affective evaluations of family life than is true for men.

#### Objective D

Explore the relationships between evaluations of selected dimensions of family life by fathers of autistic children in comparison to mothers of autistic children.

#### Hypotheses for Objective D

H20: In families with autistic children, mothers' evaluations of overall life, family life, children, marriage, and spouse are significantly lower than fathers' evaluations of these same dimensions.

Table 12 shows the means and significance levels of the 2-Tailed paired T-test for women and men in the autism group. For all five of these variables, women's scores are lower than men's, but only for evaluation of children and spouse are these differences significant.

TABLE 4.--T-Tests of Means of Affective Evaluations of Selected  
Domains and Resources for Men in Autism and Oakland Groups

Satisfaction with	Means		T Value	Significance
	Autism	Oakland		
Children	5.955	5.949	.03	.978
Spouse	6.227	5.851	1.97	.058
Marriage	6.136	5.970	.73	.469
Family Life	5.905	5.848	.12	.969
Life	5.581	5.476	.56	.612



H3c: Mothers and fathers of autistic children will show no differences in the pattern of spouse agreement of evaluations of life-as-a-whole, family life, marriage, spouse and children when compared to mothers and fathers of non-handicapped children.

Cross tabulations for this hypotheses are presented in Tables D-1 through D-10 (Appendix D) for autism and Oakland husband-wife pairs separately. Table 5 summarizes these findings. Absolute concordance for couples is quite similar for both samples on affective evaluations of family life, children, and marriage. There are approximately ten percent fewer autism couples who agree on evaluations of life-as-a-whole and fourteen percent more autism couples who agree on affective evaluations of spouse. When the figures are compared for absolute concordance or one category difference, approximately equal agreement is seen for life-as-a-whole, and children. Seven percent less agreement is seen in autism couples for evaluation of spouse, and thirteen percent less agreement for affective evaluations of family life and marriage.

### Objective C

Explore the relationships between parent evaluations of selected dimensions of family life in families with autistic children and families of non-handicapped children.

Sub C.1: Identify the resources which are the most powerful predictors of family life evaluation for parents of autistic children in comparison to parents of non-handicapped children.

TABLE 5.--Summary of Spousal Agreement for Life-As-A-Whole, Family Life, Marriage, Spouse and Children in Oakland and Autism Groups.

Domain	Spouse Agreement Autism	Spouse Agreement Oakland	One Category Difference Autism	One Category Difference Oakland
Life-As-A-Whole	33.3%	43.4%	83.8%	85.8%
Family Life	40.9%	43.2%	77.1%	90.2%
Marriage	36.3%	42.6%	67.1%	80.8%
Spouse	59.1%	45.6%	72.7%	80.9%
Children	50.0%	47.2%	85.3%	83.4%

Sub C.2: Identify the evaluations of shared time and people resources in families of autistic children which are the strongest predictors of parent evaluations of family life in comparison to families of non-handicapped children.

### Hypotheses and Questions for Objective C

Q1: Do parents of autistic children show the same pattern of resources as predictors of their evaluation of family life as do parents of non-handicapped children?

Hypotheses for Mothers:

H4: In families with autistic children, the mothers' evaluations of marriage do not contribute significantly to the prediction of evaluation of family life.

H5: In families with autistic children, the mothers' evaluations of love and affection experienced do not contribute significantly to the prediction of evaluation of family life.

H6: In families with autistic children, the mothers' evaluations of how comfortable it feels to be at home do not contribute significantly to the predictions of evaluation of family life.

H7: In families with autistic children, the mothers' evaluations of how openly and honestly feelings can be expressed do not contribute significantly to the prediction of evaluations of family life.

H8: In families with autistic children, the mothers' evaluations of the amount of respect received do not contribute significantly to the prediction of evaluations of family life.

Rettig (1980) has identified marriage, love and affection, comfortableness at home, honest expression of feelings and respect received as the most powerful predictors in descending order of affective evaluations of family life by women in the Oakland group. The  $R^2$  values from the regression analysis values for these resources are reported by Rettig to be 54% for marriage and an additional 7% for love and affection. Comfortableness at home, open and honest expression of feelings, and respect received contributed an additional 2% to the predictions of variance in family life. The entire set accounted for 63% of the variance. Table 6 summarizes the regression results for women in the autism group. Most notable is the fact that marriage did not even enter the equation with  $T$  set at .001. In other words, marriage was not able to account for even .1% of the variance in evaluation of family life not accounted by the other four. For the remaining four resources, only 42% of the variance in family life is explained. Love and affection accounts for 35%, the next two account for an additional 4½%. The fourth adds only .001 and takes the overall  $F$  above the critical value to .055. Examination of the scatterplot of residuals reveals a completely randomized pattern, which reinforces the prediction equation and confirms the assumption of normality. It would appear that hypotheses 4 and 8 should be retained and hypotheses 5, 6 and 7 are rejected. In other words, love and affection experienced, open and honest expression of feelings, and comfortableness at home appear to contribute significantly to the prediction of affective evaluation of family life

TABLE 6.---Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Marriage and Resources Received, order not specified for Women in Autism Group

Step	Variable Entered	F to Enter	Multiple R	R <sup>2</sup>	R <sup>2</sup> Change	Significance
1.	The love and affection you experience (Love)	11.35864	.61168	.37415	.37415	.003
2.	How openly and honestly you can express feelings. (Information)	.57002	.62718	.39336	.01921	.011
3.	How comfortable it feels to be at home. (Services)	.80118	.64859	.42066	.02730	.023
4.	The amount of respect you receive. (Status)	.02968	.64941	.42174	.00107	.055

<sup>a</sup>The variable "Your Marriage" did not enter the equation at T = .001.

in women in the autism group. In view of the relative position of marriage in the regression equation for both groups and the total variance accounted for by the five resources for the Oakland women, it appears that the pattern of resources is significantly different for the autism group of women.

#### Hypotheses for Fathers:

H9: In families with autistic children, the fathers' evaluations of marriage do not contribute significantly to the prediction of evaluations of family life.

H10: In families with autistic children, the fathers' evaluations of things done together do not contribute significantly to the prediction of evaluations of family life.

H11: In families with autistic children the fathers' evaluations of how comfortable it feels to be at home do not contribute significantly to the prediction of evaluation of family life.

H12: In families with autistic children, the fathers' evaluations of the sexual relationship do not contribute significantly to the prediction of evaluation of family life.

H13: In families with autistic children, the fathers' evaluations of love and affection received do not contribute significantly to the prediction of evaluations of family life.

Rettig (1980) identified a series of resources which were the most powerful predictors of evaluation of family life for the Oakland men. These resources and their relative contribution to the regression equation for Oakland men in descending order are

as follows: marriage - 48%; things done together added 7%, comfortableness at home added 4%; sexual relationship added 1% and love and affection added .3%. The entire set of resources accounted for 60% of the variance in the Oakland men's evaluations of family life.

Table 7 represents the summary statistics for the men in the autism group. This set of five resources accounted for 82% of the variance in the autism men's evaluation of family life, with the greatest contributions attributable to marriage (77%) and sexual relationship (2%). The next three resources add an additional 4% with the overall F significance remaining at  $p < .001$ . Examination of the residuals reveals a completely random pattern. Evidently, for men in the autism group, these resources are significant and powerful predictors of evaluation of family life. Therefore, hypotheses 9, 10, 11, 12 and 13 should be rejected.

Q2: Do parents of autistic children show the same pattern of shared time and people resources as predictors of their evaluation of family life as do parents of non-handicapped children?

H14: In families with autistic children, mothers' and fathers' evaluations of shared time as a family, contribute to evaluation of family life at the same level as those of mothers and fathers of non-handicapped children.

H15: In families with autistic children, mothers' and fathers' evaluations of children contribute to the prediction of their evaluation of family life at the same level as mothers and fathers of non-handicapped children.

TABLE 7.--Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Marriage and Resources Received, order not specified, for Men in Autism Group

Step	Variable Entered	F to Enter	Multiple R	R <sup>2</sup>	R <sup>2</sup> Change	Significance
1.	Your marriage	62.91225	.87638	.76804	.76804	.0000
2.	Your sexual relationship.	2.15430	.89041	.79284	.02479	.0000
3.	The things you do together	1.79142	.90144	.81259	.01975	.0000
4.	The love and affection you experience.	.88153	.90685	.82237	.00979	.0000
5.	How comfortable it feels to be at home.	.04235	.90712	.82287	.00050	.0000



H16: In families with autistic children, mothers' and fathers' evaluations of spouse contribute to the prediction of their evaluations of family life at levels equal to those of mothers and fathers of non-handicapped children.

H17: In families with autistic children, the mothers' and fathers' evaluations of time spent with children contribute to the prediction of their evaluations of family life at the same levels as that of mothers and fathers of non-handicapped children.

H18: In families with autistic children, the mothers' and fathers' evaluations of time spent with spouse contribute to the prediction of their evaluation of family life at levels equal to those of mothers and fathers of non-handicapped children.

Question 2 is reflective of an exploratory interest in the power of the satisfaction with "people resources" to explain variance in the affective evaluations of family life. Since a prerequisite for the existence of a family is identified members, it is theorized that satisfaction with these people and time shared with them would constitute a valid way to predict evaluation of family life. Since the sample of autism families is defined by a quality of one of its members it is suggested that evaluations of people and shared time may discriminate more clearly between the two groups than the identified Rettig resources.

Table 8 presents the summary of the regression analysis on the people and shared time resources against family life for women in the Oakland group. The five resources account for 53%

TABLE 8.---Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Satisfaction with People and Shared Time, order not specified, for Women in the Oakland Group.

Step	Variable Entered	F to Enter	Multiple R	R <sup>2</sup>	R <sup>2</sup> Change	Significance
1.	Satisfaction with spouse.	147.50577	.63182	.39920	.39920	.000
2.	Satisfaction with shared time with children.	37.53591	.69744	.48643	.08723	.000
3.	Satisfaction with children.	9.91581	.71314	.50858	.02215	.000
4.	Satisfaction with shared time with family.	7.63873	.72466	.52514	.01656	.000
5.	Satisfaction with shared time with spouse.	.81847	.72589	.52691	.00178	.000

of the variance in family life, ordered in the following manner; spouse - 40%, shared time with children - 9%, children - 2%, shared time as family - 1.6%, and shared time with spouse - .1%. The significance levels for each step are all less than .01. Table 9 summarizes these same variables in the regression equation for the Oakland men. The results are very similar in ordering,  $R^2$  change per step, and overall  $R^2$  except for the reversal of positioning of shared time with spouse and shared time with children in comparison to the Oakland women. The women's equation included shared time with children at step 2 and shared time with spouse at step 5; in the men's equation the positions reversed. However, for the Oakland sample of both men and women, the Rettig resources account for approximately 10% more variance in evaluation of family life.

In Table 10, the women's regression equation for the autism group is shown. Here the patterning shows satisfaction with children and shared time with children entering at steps 1 and 2 respectively. Shared time with family enters at the intermediate step 3, while spouse and shared time with spouse enter at steps 4 and 5. The total variance of evaluation of family life accounted for by these 5 variables is 52% which is comparable to the 53% for Oakland women, but represents an increase of 10% from the variance accounted for by the Rettig resources in the women's autism group. For men in the autism group, Table 11 shows that the variable "shared time with family" does not reach the specified level to enter the equation. The other four account for 63% of the variance in family life with

TABLE 9.--Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Satisfaction with People and Shared Time, order not specified, for Men in the Oakland Group.

Step	Variable Entered	F to Enter	Multiple R	R <sup>2</sup>	R <sup>2</sup> Change	Significance
1.	Satisfaction with spouse.	158.51586	.64543	.41658	.41658	.000
2.	Satisfaction with shared time with spouse.	154.37871	.72924	.53179	.11521	.000
3.	Satisfaction with children	8.92995	.74165	.55005	.01826	.000
4.	Satisfaction with shared time with family.	2.85121	.74554	.55583	.00578	.000
5.	Satisfaction with time with children.	2.6207	.74908	.56112	.00529	.000

TABLE 10.--Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Satisfaction with People and Shared Time, order not specified, for Women in Autism Group.

Step	Variable Entered	F to Enter	Multiple R	R <sup>2</sup>	R <sup>2</sup> Change	Significance
1.	Satisfaction with children	12.48316	.61923	.38344	.38344	.002
2.	Satisfaction with time shared with children	3.02151	.68413	.46804	.08460	.002
3.	Satisfaction with shared time with family	1.57090	.71466	.51074	.04270	.004
4.	Satisfaction with spouse.	.05315	.71573	.51226	.00153	.012
5.	Satisfaction with time shared with spouse.	.23745	.72069	.51939	.00713	.026

TABLE 11 .--Summary of Multiple Regression Analysis for the Prediction of Affective Evaluation of Family Life by Evaluation of Satisfaction with People and Shared Time, order not specified, for Men in Autism Group<sup>a</sup>

Step	Variable Entered	F to Enter	Multiple R	R <sup>2</sup>	R <sup>2</sup> Change	Significance
1.	Satisfaction with spouse	15.11105	.65603	.43038	.43038	.001
2.	Satisfaction with children	7.19004	.76600	.58676	.15638	.000
3.	Satisfaction with children	1.60223	.78774	.62054	.03378	.000
4.	Satisfaction with shared time with spouse	.57491	.79558	.63295	.01241	.001

<sup>a</sup>The variable "Satisfaction with shared time with family" did not enter the equation at T = .001.

the largest power found in the first two steps; spouse - 43% and shared time with children - 16%. Children and shared time with spouse contribute 3% and 1.3% respectively. Thus, the men in the autism group utilize spouse and time with children as important considerations in family life evaluation--a pattern also seen in women in the Oakland group. For the autism men, the regression equation utilizing the Rettig variables accounts for 20% more of the variance of affective evaluations of family life than do people and shared time resources

In summarizing the hypotheses concerned with people and shared time, Hypothesis 14 is rejected because shared time with family does not even enter the regression equation for autism men. Women in the autism group and men and women in the Oakland group all ranked this variable quite comparably. Hypothesis 15 dealt with evaluation of children and is rejected. Children entered at step 3 for men in the Oakland group and at step 2 for both Oakland women and autism men, but it enters the equation at step one for women in the autism group and thus accounts for 38% of the variance in family life for that group. It contributed only 2-3% to the variance for the other three groups.

Hypothesis 16 deals with evaluation of spouse which enters at step 1 accounting for 39-42% of the variance in family life for men and women in the Oakland group and men in the autism group. However, for the women in the autism group, spouse enters at step 4 carrying only a .2% increase in the  $R^2$ . Hypothesis 16 is, therefore, rejected.

Hypothesis 17 deals with shared time with children and represents the closest similarity in ordering across all groups. This variable for autism men and women and Oakland women entered at step 2. In both women's equations, it adds 8%. This variable enters last for Oakland men and offers only .6% change in the  $R^2$ . For the autism men, this variable contributes 15% to the  $R^2$  at step 2. Thus, shared time with children shows significant differences for men across the two groups and thus Hypothesis 17 should be rejected.

Hypothesis 18 deals with evaluation of spouse and is rejected because of the contrasting pattern shown by the autism women where it entered at step 4 and contributed only .1% to the  $R^2$ . For the other three groups, spouse enters at step 1 and accounts for 39-42% of the variance in evaluation of family life. Thus, there are significantly different patterns shown by mothers and fathers in the autism and Oakland groups across each of the variables on this scale. There is a general pattern of the autism women being most consistently different from the three other groups. Oakland men and women are more alike than are autism men and women for this scale.

H19: In families with autistic children, the people and shared time resources are stronger predictors of affective evaluations of family life than are the Rettig resources.

The results of the regression equations for the Rettig resources (Tables 8-11) show that 82% of the variance for affective evaluations of family life by autism men are accounted for; 42% of the variance in autism women's affective evaluations of family life are accounted



for by the Rettig resources. The people and shared time resources account for 63% of the variance in affective evaluations of family life by men and 52% by women. Therefore, these results would suggest that the directional hypothesis for autism men should be rejected, but accepted for autism women; the Rettig resources explain 82% of the autism men's variance in affective evaluations of family life, and the people and shared time resources explain only 52% of the variance in affective evaluations of family life for women. Women appear to be more directly impacted by the people in the family, but other variables not herein selected account for more variance in women's affective evaluations of family life than is true for men.

#### Objective D

Explore the relationships between evaluations of selected dimensions of family life by fathers of autistic children in comparison to mothers of autistic children.

#### Hypotheses for Objective D

H20: In families with autistic children, mothers' evaluations of overall life, family life, children, marriage, and spouse are significantly lower than fathers' evaluations of these same dimensions.

Table 12 shows the means and significance levels of the 2-Tailed paired T-test for women and men in the autism group. For all five of these variables, women's scores are lower than men's, but only for evaluation of children and spouse are these differences significant.

TABLE 12.--Summary of Paired T-Tests for Affective Evaluations  
of Selected People Resources by Mothers and Fathers of  
Autistic Children

Variable	Means		Significance of T-Test
	Women	Men	
Overall Life	5.114	5.4762	.256
Family Life	5.500	5.909	.236
Children	5.409	5.9545	*.004
Marriage	5.8636	6.1364	.389
Spouse	5.590	6.227	*.031

\*Significant differences.

These mean differences range from .273 (marriage) to .637 (spouse) and would seem to represent a trend of overall lower mean satisfaction with the people resources for women in families with autistic children. The hypothesis is rejected.

H21: In families with autistic children, mothers' evaluations of selected resources will form the same correlational pattern with the affective evaluation of family life as do fathers'.

In Table 13 Pearson correlations for all the independent variables with family life are produced for men and women in the Oakland and autism groups. The variables are in descending order of the correlation coefficients for the autism women. A review of the correlation coefficients reveals some meaningful differences. Clearly, the variables reflecting children are more highly correlated with the autism women's evaluation of family life than for each of the other three groups. In addition, the nineteenth place ordering for spouse and the twentieth placement for sexual relationship are in marked contrast to the other three groups, for which the correlations for these two variables were much higher. The correlation coefficient for sexual relationships for autistic men is only at level 15, while the Oakland groups place it within the first seven places. The correlation coefficient for marriage is also interesting. For women in the autism group marriage ranks tenth (.484) in order of correlation and is considerably larger than the correlation for spouse (.078). Autism men show somewhat higher correlation for marriage (.864) for spouse (.656). Oakland men and women and autism men all show marriage as the variable with the highest correlation with family life.

TABLE 13.--Pearson Correlation Coefficients (r) for Evaluations  
of Family Life by Satisfaction with Resources Received  
for Men and Women in Autism and Oakland Groups<sup>a</sup>

How would you feel about your family if you considered only:	Autism		Oakland	
	Women	Men	Women	Men
1. The closeness and sense of belonging you feel?	.701	.638	.704	.557
2. The love and affection you experience?	.645	.709	.710	.614
3. Your children?	.619	.591	.543	.456
4. The things you do together?	.589	.774	.567	.626
5. Time you spend with your children?	.586	.427	.436	.352
6. The amount of money for personal use?	.572	.397	.313	.403
7. The mutual helpfulness of family members?	.545	.564	.463	.450
8. The way decisions are made?	.543	.626	.555	.442
9. The material goods it enables you to own?	.542	.521	.304	.343
10. Your marriage?	.484	.864	.712	.695
11. The kind of communication you have?	.466	.559	.603	.615
12. The amount of respect you receive?	.460	.304	.627	.546
13. How comfortable it feels to be at home?	.458	.612	.661	.652

TABLE 13.--Continued

How would you feel about your family if you considered only:	Autism		Oakland	
	Women	Men	Women	Men
14. The time you spend with your spouse?	.447	.528	.565	.617
15. How openly and honestly you can express feelings?	.401	.075	.564	.588
16. The way household work is divided?	.307	.467	.456	.496
17. The amount of time the family spends together?	.299	.527	.551	.491
18. The way money is used?	.180	.424	.345	.412
19. Your husband or wife?	.178	.656	.641	.670
20. Your sexual relationship?	-.046	.446	.553	.610

<sup>a</sup>Ordered by ranking of autism women.

Another apparent difference is in the .075 correlation for autism men on the variable open and honest expression of feelings in contrast with autism women (.401), Oakland women (.564) and men (.588). Overall, it appears from Table 13 that Oakland men and women are much closer to each other's patterns and somewhat similar to autism men. The women in the autism group show some clear differences which appear to re-order the relative importance of children, spouse, marriage, and sexuality.

In Table 14 a comparison is made between Pearson correlation coefficients for autism women and Oakland women. The list is ordered by the autism women's correlations with the relative ranking for the Oakland groups in parentheses beside their correlations. It is apparent again that the relative importance of children is quite different for autism women, as is spouse, sex, comfortableness at home, and marriage. In addition, the higher per capita income of the Oakland group may be reflected in the low position accorded the variables affected by material wealth.

In Table 15 the men's correlations for the two groups are presented. These differences are not as great as the women's, though the same differences in relative income are seen. In addition, for the autism men the correlations for respect (.304), and expression of feelings (.075) and sexuality (.446) are notably lower than for the Oakland men.

Tables 16, 17 and 18 contain the highest correlation coefficients with family life for each of the four groups. Inspecting and

TABLE 14.--Pearson Correlation Coefficients (r) for Evaluations  
of Family Life by Satisfaction with Resources Received  
for Women in Autism and Oakland Groups<sup>a</sup>

How would you feel about your family if you considered only:	Autism	Oakland <sup>b</sup>
1. The closeness and sense of belonging you feel?	.701	.704 (3)
2. The love and affection you experience?	.645	.710 (2)
3. Your children?	.619	.543 (14)
4. The things you do together?	.589	.567 (8)
5. Time you spend with your children?	.586	.436 (17)
6. The amount of money for personal use?	.572	.313 (19)
7. The mutual helpfulness of family members?	.545	.463 (15)
8. The way decisions are made?	.543	.555 (11)
9. The material goods it enables you to own?	.542	.304 (20)
10. Your marriage?	.484	.712 (1)
11. The kind of communication you have?	.466	.603 (7)
12. The amount of respect you receive?	.460	.627 (6)
13. How comfortable it feels to be at home?	.458	.661 (4)

TABLE 14.--Continued

How would you feel about your family if you considered only:	Autism	Oakland <sup>b</sup>
14. The time you spend with your spouse?	.447	.565 (9)
15. How openly and honestly you can express feelings?	.401	.565 (10)
16. The way household work is divided?	.307	.456 (16)
17. The amount of time the family spends together?	.299	.551 (13)
18. The way money is used?	.180	.345 (18)
19. Your husband or wife?	.178	.641 (5)
20. Your sexual relationship?	-.046	.553 (12)

<sup>a</sup>Ordered by Autism women's ranking.

<sup>b</sup>Number in parentheses represents Oakland women's rank order for that variable.



TABLE 15. --Pearson Correlation Coefficients (r) for Evaluations of Family Life by Satisfaction with Resources Received for Men in Autism and Oakland Groups<sup>a</sup>

How would you feel about your family if you considered only:	Autism	Oakland <sup>b</sup>
1. The closeness and sense of belonging you feel?	.864	.695 (1)
2. The love and affection you experience?	.774	.626 (4)
3. Your children?	.709	.614 (7)
4. The things you do together?	.656	.670 (2)
5. Time you spend with your children?	.638	.557 (10)
6. The amount of money for personal use?	.626	.442 (16)
7. The mutual helpfulness of family members?	.612	.652 (3)
8. The way decisions are made?	.591	.456 (14)
9. The material goods it enables you to own?	.564	.450 (15)
10. Your marriage?	.559	.615 (6)
11. The kind of communication you have?	.528	.617 (5)
12. The amount of respect you receive?	.527	.491 (13)
13. How comfortable it feels to be at home?	.521	.343 (20)

TABLE 15.--Continued

How would you feel about your family if you considered only:	Autism	Oakland <sup>b</sup>
14. The time you spend with your spouse?	.467	.496 (12)
15. How openly and honestly you can express feelings?	.446	.610 (8)
16. The way household work is divided?	.427	.352 (19)
17. The amount of time the family spends together?	.424	.412 (17)
18. The way money is used?	.397	.403 (18)
19. Your husband or wife?	.304	.546 (11)
20. Your sexual relationship?	.075	.588 (9)

<sup>a</sup>Rank ordered by Autism Men.

<sup>b</sup>Figures in parentheses are rank order for Oakland men.

TABLE 16. --Summary of Highest Pearson Correlation Coefficients for Evaluations of Family Life by Satisfaction with Resources Received for Women in Autism and Oakland Groups

Resource		r
Autism	1. Closeness/Sense of Belonging	.701
	2. Love/Affection	.645
	3. Children	.619
	4. Things done together	.589
	5. Time with Children	.586
	6. Money personally available	.572
Oakland	1. Marriage	.712
	2. Love/Affection	.710
	3. Closeness/Sense of Belonging	.704
	4. Comfortableness at Home	.661
	5. Spouse	.641
	6. Respect	.627

TABLE 17. --Summary of Highest Pearson Correlation Coefficients for Evaluations of Family Life by Satisfaction with Resources Received for Men in Autism and Oakland Groups

Group	Resource	r
Autism	1. Marriage	.864
	2. Things done together	.774
	3. Love/affection	.709
	4. Spouse	.656
	5. Closeness/Sense of Belonging	.638
	6. Way decisions made	.626
Oakland	1. Marriage	.695
	2. Spouse	.670
	3. Comfortableness at home	.652
	4. Things done together	.626
	5. Time with Spouse	.617
	6. Communication	.615

TABLE 18.--Summary of Highest Pearson Correlation Coefficients for  
Evaluations of Family Life by Satisfaction with Resources  
Received for Men and Women in Autism Group

Group	Resource	r
Women	1. Closeness/Sense of Belonging	.701
	2. Love/affection	.645
	3. Children	.619
	4. Things done together	.589
	5. Time with Children	.586
	6. Money personally available	.572
Men	1. Marriage	.864
	2. Things done together	.774
	3. Love/Affection	.709
	4. Spouse	.656
	5. Closeness/Sense of Belonging	.638
	6. Ways Decisions are Made	.626

comparing these correlations reveals clear differences in areas of concern.

In Table 19, the means for the variables chosen by Rettig (1980) to most parsimoniously represent the Foa and Foa (1974) resource classes are presented for the Oakland and autism samples. The Pearson correlation coefficients with evaluation of family life are presented in Table 20. Once more, the relative discounting of the importance of material resources for a group which is somewhat more affluent is seen in the Oakland groups. The low correlation for status/respect with evaluations of family life is again seen for the men in the autism group. Overall, the women in the autism group show weaker correlational coefficients than the other three groups, indicating that variables not included in this selection may be more important for their evaluation of family life.

Tables 21 and 22 present the paired T-tests of means for the Oakland group and the Autism group for the people and shared time resources utilized in the regression equations. While both groups reveal significant difference for evaluation of spouse, with the mean for men higher in each group, the Oakland group shows a significant difference for shared time with children, and the autism group for evaluation of children. Except for the lowered mean for autism women's evaluations of children, the means are quite similar in the parallel, i.e. same sex groups. The time with children and time with family are the two variables for which the means for women are higher than those for men in both groups.

TABLE 19. --Means of Evaluations of Selected Resources Received<sup>a</sup> by  
Men and Women in Autism and Oakland Groups

How would you feel about your family if you considered only:	Autism Women	Men	Oakland Women	Men
1. Love/affection?	5.546	5.955	5.663	5.804
2. Services received?	6.091	6.409	5.963	5.996
3. Status/respect?	5.182	6.000	5.443	5.593
4. Information?	5.318	5.682	5.202	5.230
5. Money for personal use?	4.591	5.182	4.660	4.767
6. Goods?	5.136	5.500	4.951	4.983
7. Companionship?	5.046	5.182	5.340	5.231

<sup>a</sup>Resources selected from Rettig.

TABLE 20. --Pearson Correlation Coefficients of Evaluations of Family Life with Evaluations of Selected Resources Received<sup>a</sup> for Men and Women by Autism and Oakland Groups.

How would you feel about your family if you considered only:	Autism		Oakland	
	Women	Men	Women	Men
1. Love/affection?	.64	.71	.71	.61
2. Services received?	.46	.61	.65	.65
3. Status/respect?	.46	.30	.63	.62
4. Information?	.47	.56	.60	.62
5. Money for personal use	.57	.40	.31	.40
6. Goods	.52	.52	.30	.34
7. Companionship	.45	.53	.57	.62

<sup>a</sup>Resources identified by Rettig.



TABLE 2].--Paired T-Tests of Means of People and Shared Time Resources for Men and Women in the Oakland Group.

Variable	Means		2-Tailed Significance
	Women	Men	
Spouse	5.5856	5.8198	*.013
Children	5.8108	5.9234	.143
Time with Spouse	5.1735	5.1872	.888
Time with Children	5.3394	5.0724	*.009
Time as Family	5.2915	5.2691	.818

\*Significant difference.

TABLE 22.--Paired T-Tests of Means of People and Shared Time Resources  
for Men and Women in the Autism Group

Variable	Means		2-Tailed Significance
	Women	Men	
Spouse	5.5909	6.2273	*.031
Children	5.4091	5.9545	*.004
Time with Spouse	5.0455	5.1818	.633
Time with Children	5.4091	5.3636	.905
Time with Family	5.2273	5.1818	.880

\*Significant differences.

### Objective E

Explore the evaluations of specific dimensions of family life by mothers of autistic children who work for pay out of the home and those who do not.

### Hypotheses for Objective E

H22: Mothers of autistic children who work for pay out of the home show the same mean evaluations of selected resources received in the family as mothers of autistic children who do not work for pay out of the home.

Separating the women in the autism group into two groups based on employment status yields a group of 12 women who are employed for pay out of the home and 8 women who are full time housewives. With such a small N, any hypothesis testing will rarely approach significance. Table 23 illustrates the variables on which the means for employed women are higher than unemployed women. The Pooled T values and significance levels show that only affective evaluations of sexual relationship and life-as-a-whole meet the test of significance. It is noteworthy that the means of life-as-a-whole are 1.370 points apart. These results are in contrast to Jackson (1979) who analyzed the Oakland sample comparing employed versus unemployed women. She found the Oakland women had means of 5.4 on overall life for both groups. Table 24 shows that for the remainder of the variables, unemployed women show higher means than do employed women. The absolute differences range from .3 to .9 with only two variables--respect/status and mutual helpfulness of

TABLE 23. --Summary of T-Tests of Means of Affective Evaluations of Life-As-A-Whole, Family Life by Satisfaction with People, Shared Time, and Resources Received; Means for Employed Women in Autism Group Higher Than Unemployed Women in Autism Group.

Variable	Means		Pooled T Value	Significance
	Employed N = 12	Unemployed N = 8		
1. Life-As-A-Whole	5.750	4.38	-2.67	* .015
2. Way money is used	4.917	4.6250	- .46	.635
3. Material goods you own	5.083	5.000	- .14	.891
4. Sexual relationship	5.833	4.500	-2.55	* .020

\*Significant differences

TABLE 24.--Summary of T-Tests of Means of Affective Evaluations of Family Life by Satisfaction with People, Shared Time, and Resources Received; Means for Unemployed Women in Autism Group Higher than Employed Women in Autism Group.

Variable	Means		Pooled T Value	Significance
	Employed N = 12	Unemployed N = 8		
1. Spouse	5.167	6.000	1.38	.186
2. Children	5.250	5.500	.54	.593
3. Love/affection	5.1667	5.875	1.15	.264
4. Closeness/Belonging	5.333	5.750	.73	.475
5. Respect/Status	4.833	5.625	1.76	*.096
6. Comfortableness at home	5.833	6.375	1.20	.245
7. Marriage	5.500	6.250	1.41	.176
8. Amount of money- personal	4.583	4.750	.25	.805
9. Way Decisions Made	5.167	5.375	.36	.726
10. Things done together	4.667	5.375	1.03	.315
11. Mutual helpfulness	4.250	5.625	2.07	*.053
12. Way housework is divided	4.667	5.250	1.02	.320
13. Openly/honestly express feelings	5.333	5.875	.93	.367
14. Communication	5.167	5.625	.92	.371

TABLE 24. --Continued

Variable	Means		Pooled T Value	Significance
	Employed N = 12	Unemployed N = 8		
15. Amount of shared family time	5.083	5.500	.85	.408
16. Shared time with children	5.083	5.750	1.06	.305
17. Shared time with spouse	4.667	5.375	1.06	.303

\*Only Respect/Status and Mutual Helpfulness approach significance level.

family members approaching significance. The differences in means for spouse, marriage, and shared time with spouse are all more than .7 points apart. Since there are significant results on the two variables of sexual relationship and life-as-a-whole, hypothesis 22 can be rejected.

### Summary of the Findings

The descriptive data for the independent variables show that the autism group evaluated their life fairly consistently with other studies (see Table 25). The mean for overall life 3 was 5.114 for autism women and 5.476 for autism men. Rettig (1980) found both men and women to show a mean score of 5.3 for overall life 3; which is similar to previous studies (Andrews and Withey, 1976; Campbell et al., 1976).

The mean scores for affective evaluations of family life were 5.500 for autism women and 5.909 for autism men. These results of a higher mean for family life than for overall life are consistent with findings in previous studies (Rettig, 1980; Campbell et al., 1976; and Andrews and Withey, 1976).

Feelings about marriage were highly related to evaluations of family life for the men in the autism group ( $r = .86$ ), but were not for women in the autism group ( $r = .484$ ). In the regression equation for the Rettig identified resources, marriage accounted for 77% of the variance in family life for autism men, but did not even enter the equation for autism women.

TABLE 25 .--Summary Statistics for Men and Women in Autism Group  
on Affective Evaluation of Independent Variables

Satisfaction With	Women		Men	
	Mean	S.D.	Mean	S.D.
1. Spouse	5.591	1.777	6.227	.660
2. Children	5.409	.920	5.955	.807
3. Love/Affection	5.545	1.784	5.955	.998
4. Closeness/Belonging	5.591	1.491	6.182	.823
5. Respect	5.182	1.203	6.000	.571
6. Comfortableness	6.091	.944	6.409	.539
7. Marriage	5.864	1.361	6.136	.981
8. Money Use	4.864	1.742	5.545	.831
9. Money Available Personally	4.591	1.968	5.182	1.775
10. Material Goods	5.136	1.552	5.500	1.881
11. Way Decisions Made	5.273	1.446	5.455	1.022
12. Things Done Together	4.955	2.141	5.500	1.405
13. Mutual Helpfulness	4.773	2.851	5.500	.738
14. Way Housework Divided	4.727	2.113	5.364	.909
15. Open/Honest Expres- sion of Feelings	5.591	1.587	5.727	.970
16. Communication	5.318	1.465	5.682	.894
17. Time as Family	5.227	1.422	5.182	2.823
18. Sexual Relationship	5.409	1.682	5.333	2.033



TABLE 25. --(Continued)

Satisfaction With	Women		Men	
	Mean	S.D.	Mean	S.D.
19. Time with Children	5.409	1.872	5.364	1.957
20. Time with Spouse	5.045	2.141	5.182	2.061

Feelings about spouse were related to feelings about family life for autism men ( $r = .646$ ) but only negligibly for women ( $r = .178$ ). The regression equation for the people and shared time resources showed evaluation of spouse to contribute 43% to the variance in family life for autism men, but only added .7% to the explanation of the variance in family life for autism women.

Further differences between husbands and wives are illustrated by the difference in relative importance of children. Satisfaction with children and satisfaction with shared time with children enter the regression equation at steps 1 and 2 and account for 47% of the variance in evaluation of family life for autism women. For autism men, they enter at steps 2 and 3, accounting for 19% of the variance in affective evaluation of family life.

For the autism women, the people and shared time scale accounted for 52% of the variance in evaluation of family life. For autism men, 82% of the variance in evaluation of family life is accounted for by the Rettig resources.

In reviewing spouse agreement patterns, the autism couples show the highest agreement for evaluation of children and least agreement on evaluation of life-as-a-whole and marriage. The employed women show significantly higher means for sexual relationship and life-as-a-whole in comparison with unemployed women.

The hypotheses were accepted or rejected as follows:

Hypotheses 1 and 2 were accepted. Characteristics of the sample of autism families were similar to autism families described in the literature; and were similar to the Oakland families.

Hypotheses 3, 3a and 3b were rejected. Autism parents did not have significantly lower mean scores of evaluation of family life, marriage, children and spouse compared with parents of non-handicapped children.

Hypothesis 3c was rejected. There were differences in the pattern of spouse agreement on evaluations of life-as-a-whole, family life, marriage, spouse and children in the autism and Oakland samples.

Hypotheses 4 and 8 were accepted. Autism women's evaluations of marriage and respect received did not contribute significantly to the prediction of their evaluations of family life.

Hypotheses 5, 6 and 7 were rejected. Love and affection, comfortableness at home, open and honest expression of feelings did contribute significantly to autism women's evaluation of family life.

Hypotheses 9-13 were rejected. Autism men's evaluation of marriage, things done together, comfortableness at home, sexual relationship, and love and affection did contribute significantly to evaluation of family life.

Hypotheses 14-18 were rejected. Evaluation of shared time with family, shared time with spouse, shared time with children, children and spouse by men and women in the autism group showed different levels of prediction of evaluation of family life than in the Oakland group.

Hypothesis 19 was accepted for autism women but rejected for autism men. People and shared time resources were stronger than

the Rettig resources as predictors of evaluation of family life for women in the autism group. The Rettig resources were stronger predictors for men.

Hypothesis 20 was rejected. Autism women's mean evaluations of overall life, family life, children, marriage, and spouse were lower than men's but the differences were significant only for children and spouse.

Hypothesis 21 was rejected. Autism women's affective evaluations of selected resources did not form the same correlational patterns for evaluation of family life as did men's.

Hypothesis 22 was rejected. The mean evaluations of selected resources by employed women in the autism group were significantly different from the unemployed women's evaluations of resources.

## LIMITATIONS, CONCLUSIONS, DISCUSSION AND IMPLICATIONS

This research used a sample of families with autistic children as representative of families dealing with severely handicapped members and compared them with the families of the Oakland Quality of Life study to investigate parents' self-reporting of quality of life. Overall, certain repetitive themes in the statistical results, were found. However, conclusions drawn must be interpreted in light of the limitations of the study.

### Limitations

This research is basically a static survey design which asks respondents to evaluate relationships and interchanges which by definition must be dynamic. It, therefore, is reflective of the "true" state of affairs only inasmuch as we accept the "truth" as what people are willing and able to report on such an instrument. It has been hypothesized by Seashore (Jackson, 1979) that when individuals are coping with an unsatisfactory situation, they utilize the following coping techniques to change or rationalize their situation: repression; accommodation by changing the environment, goal reduction, cognitive distortion, resignation or withdrawal. If the presence of an autistic child in the family is perceived to be an unsatisfactory situation, any of the coping techniques would

tend to depress the revealed dissatisfaction with life for those parents. Lewis et al. (1976) describes the incongruity pattern seen in some families where a semi-conscious, shared denial of painful realities is seen as the family attempts to deal with daily problems. As mentioned in Chapter I, some family workers servicing parents of special education children (Seligman, 1970; Love, 1970; and Graziano, 1974) have suggested that the developmental process of a family's coping with a severely impaired member includes a stage of denial of the problem. This process would be conceptualized as also "blunting" the "true" reflection of parent reporting of quality of life.

The low incidence of autism and the complex of variables felt by the researcher to be operating in new autism programs led to a sample which proceeded through two stages of self-selection. As such, it cannot meet requirements for randomness, but the demographic information supported meaningful inferences to a population of autism families described in the literature. The somewhat higher socioeconomic level of the autism sample has been found by other researchers (Spence, 1965; Wing, 1976; Rutter, 1978) and remains a controversial topic that Schopler et al. (1979) have suggested has roots in the identification/diagnostic processes for severely handicapped populations.

It is generally acknowledged by survey research teams that people tend to answer in socially desirable ways and emphasize positive experiences more than the negative ones. Andrews and Withey

(1976) suggested that respondents' evaluations of family measures were so positive as to be disbelieved. They suggested that the willingness to use even the category "mostly satisfied" should suggest serious reservations. Furthermore, Andrews and Withey (1976) suggest that individuals themselves "add up" their joys and sorrows in arriving at a feeling about general well-being. Therefore, sorrows in some areas of life may be compensated for by joys in other areas. Furthermore, parents of autistic children may be willing to reveal more dissatisfaction with quality of family life if there are compensations in other areas, or the principle of reciprocal relationships in families might positively impact family life with positive experiences from other areas. Rutter and Brown (1966) suggest that when people know things are psychologically inconsistent, they will attempt to believe they can be consistent.

Problems dealing with concept definitions are typical in survey research. Since the researcher was present at the data collection, some of these problems were identified and clarified in ways that at least reduced the probable amount of missing data. While the questionnaire items utilized in this analysis have fewer ambiguous terms and phrases than some of the unanalyzed sections, there are still problems with individual interpretations of such terms as "respect," "comfortableness," and "mutual helpfulness."

Another limitation is presented by the data collection design during which the researcher was present. This may have encouraged socially acceptable responses to a greater degree than the design

utilized in the Oakland study. In addition, the researcher was identified to the respondents as being formerly associated with school services for the autistic. It is therefore suggested that certain affective judgments the parents associate with their own experiences with autism school programs may have mediated their responses to the questionnaire. Finally, in most homes, a measure of rapport and communication developed during the interview process between the researcher and respondents. Since the level of effort and success associated with this process cannot be absolutely equivalent across all twenty-two families, it is not known how this impacted on questionnaire responses.

The small number of respondents in the autism sample made it difficult to reach specified levels of significance for the hypothesis testing. For the regression analysis, violations of the assumptions of normality can be serious for small populations. However, in each case where a regression equation was utilized, direct examination of the residuals through scatter-plots confirmed both the assumptions of normality and linearity.

### Conclusions

The most important conclusion of the research is the repeated proposition that mothers of severely handicapped children reveal a different pattern of variables which are important for the evaluation of family life than do fathers of severely handicapped children or mothers and fathers of non-handicapped children. Other conclusions are:



1. The most significant predictors of family life evaluation for women in the autism group were: children and time with children.
2. The most significant predictors of family life evaluation for men in the autism group were: marriage, sexual relationship, and things done together.
3. The people and shared time scale (spouse, children, time with spouse, time with children, time as a family) predicted the autism women's evaluations of family life better than the resources identified by Rettig (1980) for the Oakland women (marriage, love and affection, open and honest expression of feelings, comfortableness at home and respect).
4. For autism men, the Rettig (1980) resources identified by the Oakland men (marriage, sexual relationship, things done together, love and affection, and comfortableness at home) were stronger predictors of evaluation of family life than the people and shared time scale (spouse, children, time with spouse, time with children, time as a family).
5. For men and women in the Oakland group, the Rettig (1980) identified resources were stronger predictors of evaluation of family life than the people and shared time resources.

6. Almost twice as many autism husbands and wives agree on the evaluation of spouse in comparison to their agreement on evaluation of life-as-a-whole.
7. For autism women, variables relating to children generally replaced variables relating to spouse and marriage in correlational and regression analysis, compared with autism men.
8. The selected variables in both regression equations accounted for significantly more variance in evaluation of family life for autism men than was true for autism women.
9. Autism men evaluate life-as-a-whole and family life higher than Oakland women and men, and autism women.
10. Autism women evaluate life-as-a-whole and family life lower than Oakland men and women, and autism men.
11. For autism men, satisfaction with respect received is correlated less highly with evaluation of family life than for autism women, Oakland men, and Oakland women.
12. For autism women, satisfaction with sexual relationship has a low negative correlation with evaluation of family life. Autism men, Oakland men and Oakland women show substantial correlation coefficients for this relationship.

13. For both men and women in the autism group, evaluation of how comfortable it feels to be at home showed the highest mean and smallest variance.
14. Autism women who work for pay out of the home show significantly higher evaluations of life-as-a-whole and sexual relationship in comparison to unemployed autism women.
15. Autism women who are employed, show lower mean scores for all other independent variables in comparison to autism women who are not employed.

This research has identified the impact of the child variables as being most significant for the autism women. Utilization of the resources identified by Rettig (1980) appeared helpful in predicting family life for men, but not as powerful for women. The results for employed versus unemployed women are in contrast to Jackson's (1979) findings of no significant differences for evaluation of life-as-a-whole between the employed and unemployed Oakland women.

### Discussion

In conceptualizing the presence of an autistic child in a family as a negative stress with complex reciprocal qualities, it was theorized that depressed satisfaction with spouse, marriage and family life might result for both parents. These results suggest that at least the overt results are admittedly different for fathers than for mothers. While Campbell et al. (1976) reported that feelings about children and spouse contribute a major share of the

variance in feelings about family life, this pattern is split for the autism sample. Thus, feelings about children explain most of the variance in family life for women, and feelings about spouse explain most for men. The women in the autism group thus have a stronger relationship between evaluation of family life and what could be anticipated to be one of the most stressful aspects of their lives. The men are more able to evaluate their feelings about family life by different, and supposedly, more positive criteria. These findings repeat the Sontag et al. (1979) results that the Oakland women are somewhat less satisfied than men with family life and children. Sontag et al. (1979) also reported that women, more often than men saw their children as an extension of themselves and a hope for the future. When at least one child is autistic, a mother may experience a lowering of hopes for the future. Since more women than men in the Sontag et al. (1979) study reported problems with children, and Lewis et al. (1976) describes the wife-mother as a barometer of stress or problems in the family system, these results are consistent with previous research findings. In addition, Lewis et al. (1976) learned that styles of family functioning were most accurately studied by observation, but the presence of problems within the family is most often ascertained by interviewing individual members.

In a discussion of the hypothesis testing, it is important to note differences that are probably due in part to the limitations inherent in a small sample. While evaluation of spouse and marriage

made negligible contributions to the regression equations for women's evaluation of family life, these two variables rank second and third in the mean scores of evaluation for women (marriage = 5.864, spouse = 5.591). They are ordered by men as the second and fourth highest means (spouse - 6.227, marriage - 6.136). For both men and women, therefore, the mean scores for evaluation of spouse and marriage are high, but women find that their evaluation of family life is more linked to their life with children. Since the spouse consensus pattern was highest for autism husbands and wives on their evaluations of spouse, there would appear to be reciprocal agreement in their feelings about their spouse. 60% of the autism couples agreed on their evaluation of each other. Since only one of these couples did not choose "pleased" or "delighted," these would appear to be very positive marriages. Booth and Welch (1978) suggest that spousal consensus is a complex construct which has not been adequately researched, but in which stress may be implicated as an independent variable. It is theorized that prolonged stress reduces the amount of consensus found in couples.

The patterns of variance seen in the means of the men's and women's group are more revealing. The women generally show greater variance for each of the variables with four (ways decisions are made, things done together, way housework is divided, and time with spouse) showing standard deviations greater than 2.1. The variance for men is not as great, though for them three variables (time as a family, sexual relationship, and time with spouse) show

standard deviations greater than 2.0. A larger sample might clarify patterns of variance in the sample. One wonders if the Andrews and Withey (1976) suggestion that joys in one area of life may compensate for sorrows in another area is valid when evaluations of children and spouse are considered. Women in the autism group evaluate life-as-a-whole lower than do men (mean for women is 5.114, men = 5.909) which would suggest the power of their evaluation of children. Love (1970) and Graziano (1974) have suggested that mothers, who have more intimate knowledge of handicapped children in the family, are more accurate in their assessment of the child's true abilities than are fathers.

The findings for employed mothers of autistic children are interesting. In general, they show less satisfaction with most of the variables than do unemployed women, yet significantly higher satisfaction with life-as-a-whole and sexual relationship. This may be a clear example of the "compensatory joys" theory proposed by Andrews and Withey (1976) or a greater negativism about family life as they carry a dual role. In consideration of their evaluation of sexual relationship more positively, however, a third explanation may be appropriate. If their job is able to be a source of satisfaction and accomplishment to them, they may more confidently reciprocate in the sexual relationship with the confidence to enter this love/service exchange described by Rettig (1980). The sexual relationship may not be as strong a barometer of the family relationships for employed women as it is for the unemployed women.

These research findings appear to support the conceptual framework that a severely handicapped child does impact on an individual family member's satisfaction with family life. The individual parent reflects this impact in ways which are reflective of their prioritizing of areas of concern and their fund of human and material resources. The findings suggest that employed women participate in exchanges with work systems external to the family which provide them resources to increase their satisfaction with life-as-a-whole. This result supports the "compensatory joys" concept of Andrews and Withey (1974) at least for the autism women in this sample.

An accurate understandings of ways in which the handicapped child influences specific exchanges demands sensitive interpretation of the data. For example, autism men and women show quite different correlations between evaluation of spouse and satisfaction with family life, but both autism men and women show a high degree of satisfaction with their spouse. Drawing meaningful inferences from either one of these results in isolation would be an inaccurate reflection of these parents' evaluations. Thus the dynamic and specific nature of resource exchanges and evaluations within the family is confirmed.

### Implications

Overall, it is noteworthy that there appears to be a great deal of positivism and strength among the autism families. Evaluations of variables were not remarkably different from the Oakland group, but the significant findings contribute to an understanding of the selection of criteria by which they evaluate certain domains of life. Mothers appear more constantly cognizant of child needs in their evaluations of family life. The long-term impact on the self-esteem and mental health of a women who are responsible for the majority of care of severely handicapped children is an important area of investigation. At least three of the respondent families made reference to a "crisis of role behavior" wherein mothers evidently demanded and received much greater child care input from fathers than had previously been the norm in their families. In addition, included among the 44 autism parents were 5 step parents who had knowingly married their spouses with knowledge of the autistic child. These individuals could constitute an interesting sample for ethnographic research efforts which might explore the relationship between altruistic behavior and quality of family life in families with severely handicapped individuals. Since this behavior is not rewarded in the marketplace, how and why do families sustain it?

There was some evidence that families tried not to conceptualize themselves as "different" or as needing to use a different set or prioritizing of values in family decision making. It was striking that only one of the twenty-two families made any overt



attempts to have the researcher perform some child care while the parents completed the questionnaire. In spite of the investigator's clear offer and description of her familiarity with autism, the families really "took care of their own". Most of the autistic children seen were engaged in stereotypical activities, many involving basic physiologic reward systems like rocking in front of a warm air register. While at school, such behaviors might be interrupted and discouraged, at home they provided some "organized relief" for families. In the striking aloneness of the autistic child is suggested one option for normalizing the "rest of family" through studied ignoring or compartmentalization. This tendency is not wholly appreciated by professionals working in autism; they tend to see the autistic child as a focus for organization and planning. Thus they often try to help a family better understand or manage their autistic child and attempt to provide alliances for families to meet other parents faced with the same handicap. Yet the reality may be that the push toward normalizing family life might preclude concentration on linkages with other families of autistic children. Furthermore, the intensity of the stress accounted for by an autistic child might make linkages with more similarly stressed systems not growth supporting for child or parent. These relationships have obvious implications for social policy and deserve more concentrated investigation.

Many professionals working in service to autism make valiant efforts to contact fathers and believe that only working with mothers

is supporting a sexist bias of services. Yet this research effort would suggest that it is indeed the women who are most impacted by the autistic child and much more of their family resources are linked to her care. In addition, the correlational analyses and regression equations often revealed the autism men to be more like the Oakland women than like their wives or the Oakland men. Thus the presence of a severely handicapped child in their family has, for the autism men, encouraged a more "female" prioritizing of variables of concern. The investigation of this phenomena might reveal interesting strengths in the development of a more "balanced" personality structure that combines both expressive and instrumental roles more comfortably than a traditional male role.

Obviously, longitudinal or at least, cross sectional analyses would be helpful to better understand the developmental process of these reciprocal relationship as the child and family mature. Agencies identified as supports for families with severely handicapped members may need to develop sensitive processes for evaluating an individual family's choices about their own priorities for quality of life for themselves and their autistic child.

In a study which compared the "problem prioritizing" lists of families with institutionalized severely handicapped children with families whose severely handicapped children remained at home, Skelton (1972) found the intriguing result that families of the institutionalized group placed more concern in areas relating to family needs and goals, while families whose children remained at

home tended to concentrate on the importance of achieving specific goals for/with the child. Perhaps this information is a reflection of a decision process which involves the relative importance of individual versus group goals as a family faces the possibility of institutionalizing their child. The maintenance of the child within the family may require a concentration on his/her needs to focus resources.

### Beyond Hypotheses Testing

It is obvious that these twenty-two families represent unique systems; awesome in the particularistic combining of resources to accomplish their goals. Upon reflection of experiences with these families, some hints from the literature seem confirmed; new questions are intriguing.

Family life cycle stage would appear important to family role expectations and assignments. Older couples with dependent adolescents seemed to feel the dissatisfaction with confinement, life limitations, and too much concentration on the parental roles. Also the evident disparities of their children may contribute to previously unexpressed realization of the bleak prognosis.

It would appear that the years of late latency and early adolescence are crucial in terms of the consideration to institutionalize. The society-family role of a charming young deviant can no longer be assigned a son or daughter entering adolescence. Some autistic adolescents become more aggressive or are found to exhibit seizures and these present physical dangers and proof of neurological

damage which are frightening to parents. Other adolescents may become calmer and less hyperactive than they were in early childhood, but the parent store of caring and protecting may be "burned out," to use Sullivan's (1979) term. There is no dramatic event, just the slow arrival at the recognition point that an extreme concentration of resources in their own child may not be rewarding.

As a group, the working mothers subjectively appeared more satisfied, less guilt ridden, and obviously enjoying more spouse support with the care of the autistic child. It appeared that mothers who had been most active in the parent groups were those who did not work; they may present a group with very few other resources. This phenomenon of intensive experience in one limited area of advocacy may help explain difficulties this group has with advocacy in total. The resource store of a broader, more generalized experience with system relationships may be missing, especially among the female leadership.

Mothers who were most positive appeared to have taken assertive, self-actualizing steps for themselves; this came at different stages for different women. As older normal children grew up and left the home, a mother left with the care of an autistic son or daughter must surely feel a loss of role functioning, a narrowing of her focus and responsibility back to concentration on deviancy. Not only does she feel the abandonment of help in child care, she feels less involved in the normal range of family life.

Economic resources were certainly significant; they provided more opportunities but they also were clearly disappointing by virtue

of what they could not buy. Most families were doing most of their own child care; no one could afford to independently institutionalize their child. If the family's means were limited, it was most satisfying to have lower expectations from life.

Many families could reflect on times being "better" or "worse" than they were at the time of the interviews. It would be fruitful to look at these comparisons in light of what resources the family utilized in "worse" times and what were the costs. These may prove to be patterns that are in contrast to other normal family histories, or may be extremes of the same stages.

It is obvious that families really did not feel much impact from the school program or personnel. Beyond the initial uncertainties and trauma of assisting in program establishment, it would appear that schools have not significantly impacted on these families. Numerous references were made to disagreements about curriculum goals and frustrations with school/home communication. Parents felt each report letter sounded like every one before it; "I don't need to read them anymore." Obviously, part of these feelings are a reflection of the fact that autism is a chronic disability; these children change very slowly. However, it also may be that well functioning families pass through a stage of intense school advocacy and involvement and then grow beyond the need to concentrate energy there. It would appear that the families in which both wife and husband possessed confidence, reflective abilities, and positive regard for themselves and each other, were able to strengthen their

marital relationship and create particularistic natural support systems that were not defined by "deviancy membership." Thus the services attached directly to school programs might be viewed in a more developmental framework. New autistic students need for their families to obtain human support and information regarding the disability from other parents who have survived the initial definition/acceptance crises. Beyond that, school personnel should facilitate information for the coordination of other services such as respite care, social services benefits and funding sources for living environments. However, these activities should be in such form that they can be utilized by individual families or small groups, and continually updated. It should be perceived that families of autistic children might be best served by learning of the unique ways other families made decisions to support growth in each family member while making an appropriate decision about the care of the autistic child. It is not necessary to "major" in autism to be responsible to an autistic son or daughter. When there were no school programs, parents may have felt that concentration was necessary; the parents who clearly expressed anger and grief that the "spirit" has died from the parent group may not have developed other systems of social support and nurturance for themselves. For older parents with difficult to manage children, this isolation is a very real crisis which is affecting quality of family life. The fact that there were some clear examples of well functioning step-parent families may illustrate the importance of "family decision

opportunities" where change can be facilitated and a more satisfying quality of life obtained by the infusion of new resources. If schools and social service agencies could be more attuned to family crises which involve potential opportunities for new adaptability, the appropriate human services might be prepared to cooperate with families in facilitating choices which are satisfying.

## APPENDICES



NATIONAL SOCIETY FOR AUTISTIC CHILDREN  
DEFINITION OF THE SYNDROME OF AUTISM

Submitted by Edward R. Ritvo, M.D. and B. J. Freeman, Ph.D.  
in July, 1977 and approved by the Board of Directors and the Professional Advisory Board.<sup>1</sup>

I. Essential Features: Autism is a behaviorally defined syndrome. The essential features are typically manifested prior to 30 months of age and include disturbances of: (1) developmental rates and/or sequences, (2) responses to sensory stimuli, (3) speech, language, and cognitive capacities, and (4) capacities to relate to people, events and objects.

1. Disturbances of developmental rates and sequences: Normal coordination of the three developmental pathways (motor, social-adaptive, cognitive) is disrupted. Delays, arrests, and/or regressions occur among or within one or more of the pathways: (a) within the motor pathway: for example, gross motor milestones may be normal while fine motor milestones are delayed; (b) between pathways: for example, motor milestones may be normal while social-adaptive and cognitive are delayed; (c) arrests, delays and regression: for example, motor development may be normal until the age 2 when walking stops; (d) some cognitive skills may develop at expected times while others are delayed or absent; imitative behavior and/or speech may be delayed in onset until age 3, followed by rapid acquisition to expected developmental level.
2. Disturbances of responses to sensory stimuli: There may be generalized hyper-reactivity or hypo-reactivity, and alternation of these two states over periods ranging from hours to months: For example, (a) visual symptoms: These may be close scrutiny of visual details, apparent non-use of eye contact, staring, prolonged regarding of hands or objects, attention to changing levels of illumination; (b) auditory symptoms: These may be close attention to self-induced sounds, non-response or over-response to varying levels of sound; (c) tactile symptoms: These may be over- or under-response to touch, pain, and temperatures, prolonged rubbing of surfaces, and sensitivity to food textures; (d) vestibular symptoms: These may be over- or under-reactions to gravity stimuli, whirling without dizziness, and preoccupation with spinning objects; (e) olfactory and gustatory symptoms: These may be repetitive sniffing, specific food preferences,

and licking of inedible objects; (f) proprioceptive symptoms: These may be posturing, darting-lunging movements, hand flapping, gesticulations and grimaces.

3. Disturbance of speech, language-cognition, and nonverbal communication: Symptoms may include: (a) speech: for example, mutism, delayed onset, immature syntax and articulation, modulated but immature inflections; (b) language-cognition: for example, absent or limited symbolic capacity, specific cognitive capacities such as rote memory and visual-spatial relations intact with failure to develop the use of abstract terms, concepts, and reasoning; immediate, delayed, negative echolalia with or without communicative intent; non-logical use of concepts; neologisms; (c) nonverbal communication: for example, absence or delayed development of appropriate gestures, dissociation of gestures from language, and failure to assign symbolic meaning to gestures.
4. Disturbances of the capacity to appropriately relate to people, events, and objects, manifested by failure to develop appropriate responsivity to people and assignment of appropriate symbolic meaning to objects. For example, (a) People: absence, arrests and/or delays of smiling response, stranger anxiety, anticipatory response to gestures, playing "peek-a-boo", playing "patty-cake", and waving "bye-bye", reciprocal use of eye contact and facial responsivity, and appropriate reciprocal responsiveness to physical contact; failure to develop a relationship with significant caretakers or excessive reliance on caretakers. For example, caretakers may be treated indifferently, interchangeable, with only mechanical clinging, or with panic or separation. Cooperative play and friendships (usually appearing between two and four) may not develop. Expected responses to adults and peers (usually appearing between five and seven) may develop, but are superficial, immature, and only in response to strong social cues. (b) Objects: absent, arrested and/or delayed capacities to utilize objects and/or toys in an age-appropriate manner and/or to assign them symbolic and/or thematic meaning. Objects are often used in idiosyncratic, stereotypic and/or perseverative ways. Interference with this use of objects often results in expressions of discomfort and/or panic. (c) Events: There may be a particular awareness of the sequence of events and disruption of this sequence may result in expressions of discomfort and/or panic.

II. Associated features: Associated clinical features vary with age and include other disturbances of thought, mood, and behavior. Mood may be labile; crying may be unexplained or inconsolable; there may be giggling or laughing without identifiable stimuli. Delusions and hallucinatory experiences have been reported. There may be a lack of appreciation of real dangers, such as moving vehicles and heights as well as inappropriate fears. Self-injurious behaviors such as hair pulling and hitting or biting parts of the body, may be present, and stereotypic and repetitive movements of limbs or the entire body are common.

Current research estimates are that approximately 60 percent of autistic children have measured I.Q.'s below 50; 20 percent between 50-70, and 20 percent of 70 or more. The majority show extreme variability of intellectual functioning on formal I.Q. testing. They perform poorest on tasks requiring abstract thought, symbolism or sequential logic, and best on those assessing manipulative or visual-spatial skills and rote memory.

Recent studies indicate that the incidence of EEG abnormalities increases with age as does the possible onset of seizures.

III. Impairment: The syndrome is severely incapacitating. Periodic medical, neurological, psychological, educational, and behavioral reassessments are necessary. One must monitor the course of the syndrome to keep treatment planning apace with physiological and behavioral changes. Special educational facilities are almost always required. Behaviorally structured, functional, individualized programs have been demonstrated to be most helpful. Counseling families regarding total living planning is often desirable. Individual supportive psychotherapy and symptomatically targeted pharmacologic therapy may enhance social-adaptive functioning in selected persons. The severe form of the syndrome may include the most extreme forms of self-injurious, repetitive, highly unusual and aggressive behaviors. Such behaviors may be persistent and highly resistant to change, often requiring unique management, treatment, or teaching strategies.

IV. Age of onset: The exact age of onset is unknown, but symptoms have been reported and observed during the first months of life. Families may be unaware of early symptoms until the child fails to pass major developmental milestones (i.e., onset of walking, speech, socialization with peers). They may then date the onset of the syndrome to these missed milestones, whereas careful history taking may reveal that subtle symptoms were present earlier.

V. Etiology: The symptoms are best explained as expressive of a physical dysfunction within the central nervous system (CNS) - the exact nature and type of which has yet to be determined. This physical dysfunction of the CNS occurs independently or in association

with other disorders which directly affect the central nervous system (i.e., maternal rubella, PKU, Down's Syndrome, epilepsy). In such cases, the diagnosis of Autism is made on Axis One, and the coexisting organic condition coded on Axis Three.

VI. Incidence and Sex Ratio: The syndrome has been identified in all parts of the world. It is very rare, with an incidence of approximately 4 or 5 per 10,000 births. It is found four or five times more commonly in males.

VII. Complications: Major complications are self-induced physical injuries, infections related to improper hygiene, dental problems related to persistent bruxism, and physical injuries due to inadvertent exposures.

#### VIII. Differential diagnosis:

1. Mental retardation, etiology unknown and known:  
Here developmental delays usually occur in all areas, and developmental sequences (motor, social, and cognitive) remain coordinated. Responses to sensory inputs, people and objects, and speech and language development are appropriate to the overall developmental level of cognitive functioning.
2. Specific sensory deficits (e.g., deafness, blindness):  
Here compensatory behaviors may be confused with symptoms indicative of autism (e.g., hyperreactivity to auditory, proprioceptive and tactile stimuli in blind children (i.e., blindness); hyperresponsivity to visual, proprioceptive (i.e., head shaking), and tactile stimuli in deaf children). When auditory and visual deficits are accompanied by mental retardation, speech, language, and the ability to relate to people and objects are appropriate to the overall developmental level of cognitive functioning.
3. Congenital, developmental, and acquired disorders of central processing of language (aphasia): Here disturbances in language development and central processing are not accompanied by disturbances of responses to sensory inputs, disassociation of other developmental courses (motor, social), relatedness to people and objects. Aphasics may imitate and use gestures and other means to communicate symbolic content. If these disorders are accompanied by mental retardation then it must be assessed independently of the disturbances of central processing of language.

4. Sequelae of physical or psychological trauma (e.g., syndromes previously described as hospitalism, maternal deprivations, anaclitic depression, sequelae of a chronically traumatizing environment): Here syndromes include failure to thrive, infantile apathy and withdrawal, physical illnesses secondary to malnutrition or toxin ingestions and physical abuse, specific psychological fixations (psychogenic psychoses, severe neuroses, pathological character development), and all degrees of mental retardation. The pattern of symptoms and developmental delays are specific to the syndromes described, are related to specific etiologic factors in psychological and social environments, and respond to specific therapies if instituted before permanent changes have resulted.
5. Schizophrenia, childhood type: Here, the disorder is characterized by the presence of a thought disorder (see the definition of thought disorder in the American Psychiatric Association's Diagnostic Standards Manual, Third Edition). Certain persons with the syndrome of autism as defined in DSM category 299.00 also may fit the criteria for childhood schizophrenia, particularly at a later age (ages 5-12). In this case, both diagnoses should be listed so that subsequent researchers can objectively test the two main hypotheses regarding the relationship between these two syndromes, i.e., autism is the earliest form of schizophrenia as manifested in late childhood or early adulthood or that autism and schizophrenia are distinct syndromes with different etiologies, family histories, and courses.
6. Degenerative organic brain syndromes (e.g., Schilder's Disease, Heller's Syndrome) with or without mental retardation: Here the clinical course is characterized by progressive regressions in all or some areas of development (motor, social-adaptive, and cognitive). In the early stages, these regressions may mimic symptoms indicative of autism but are distinguishable by their relatively specific times of onset, characteristic signs and symptoms on neurological, psychological, and cognitive testing, and unremitting deteriorating course.

IX. Predisposing factors: None known.

X. Family factors: None known. The syndrome has been identified in all parts of the world. Recent studies have revealed no correlation between autism and parental psychopathology.

XI. Operational criteria: A, B, C, D, and E are required.

- A. Signs and symptoms present prior to 30 months of age.
- B. Disturbances of developmental rate and/or sequences.
- C. Disturbances of responsiveness to sensory stimuli.
- D. Disturbances of speech, language and cognitive capacities.
- E. Disturbances of relation to people, events and objects.

---

<sup>1</sup>Edward R. Ritvo and B. J. Freeman, "National Society for Autistic Children Definition of the Syndrome of Autism," NSAC Newsletter, May 1978, pp. 16-19.

NEEDS ASSESSMENT SURVEY FOR  
PARENTS OF AUTISTIC CHILDREN

--WHY A "NEEDS ASSESSMENT?"

With the apparent growing concern and frustration between parents and service agencies of the population of autistic children, we have developed a needs assessment survey. The survey consists of a series of questions related to issues involved with home, school, and supportive services.

--HOW WILL THIS SURVEY BE CONDUCTED?

The initial step will be to contact a sample of parents whose autistic children currently attend public schools in Michigan and request that they complete a comprehensive questionnaire. We plan to reach these parents with the assistance of the schools and agencies who serve autistic children, and by meeting with several local NSAC chapters. After we have received these initial responses, we will contact a random follow-up group of parents who indicate that they would be willing to participate in a personal interview. All information gathered will then be organized for study.

--HOW WILL THE SURVEY INFORMATION BE USED?

The completed needs assessment should result in a compiled summary of those needs that parents feel are still lacking, and those needs they feel are being met by those agencies that service autistic children. The finished study which would result will become available for any group or persons' use. The study results could hopefully be used by professionals in planning program goals, and could be used by parent or advocacy groups as a basis for obtaining more effective services for autistic children and their families.

## GLOSSARY OF TERMS

This short glossary has been included as a reference for your use. If you feel that a term has been omitted which would be helpful to you, please call us.

**AUDIOLOGICAL TESTING** - Professional testing, usually with specialized instruments, to determine the presence and extent of hearing impairment in a child.

**BIOCHEMICAL THERAPY** - The therapeutic use of drugs, supervised by a medical doctor, which aims to remediate a physically caused problem.

**GROUP HOME** - A home-like dwelling in a residential community supervised and run by a public service agency for the purpose of providing a more normal living environment for handicapped persons.

**NON-VERBAL** - A person who does not use verbal language as a systematic means of communicating with other persons.

**RESPIRE CARE** - Supervision and care of handicapped persons, usually by a public service agency, with the purpose of providing relief for the handicapped person's family. This relief may extend for several hours, or up to several weeks.

**SHELTERED WORKSHOP** - A commercial establishment maintained for the purpose of providing handicapped persons with an environment in which they may receive wages and work successfully. These are usually run by a public service agency.





7. Number of children in your family \_\_\_\_\_ 8
- Ages of children: 1) \_\_\_\_\_ years 9
- 2) \_\_\_\_\_ years 10
- 3) \_\_\_\_\_ years 11
- 4) \_\_\_\_\_ years 12
8. Is your autistic child verbal or non-verbal? 13  
(check one)
- \_\_\_\_\_ verbal \_\_\_\_\_ non-verbal 14

\*We will begin making randomly picked telephone interviews during the month of April, 1979.

We will only be calling consenting parents.

If you consent to a telephone interview, we will need the following optional information:

Parents' names: Father \_\_\_\_\_  
Mother \_\_\_\_\_

Telephone number: (\_\_\_\_\_) \_\_\_\_\_ - \_\_\_\_\_  
area

When would be the best time to call?

\_\_\_\_\_ days \_\_\_\_\_ weekends  
\_\_\_\_\_ evenings \_\_\_\_\_ other \_\_\_\_\_  
\_\_\_\_\_

Some items assume more than one child in a family. If you have only one child please complete these items as if you had other children.

## II. AREAS OF CONCERN

The following section consists of statements concerning the quantity and quality of services provided for your child. Also included are statements which allow us to assess your feelings about these services.

In SECTION A, a line of boxes will follow each statement. Check the box which corresponds to the way you feel about that statement.

(see EXAMPLE)

EXAMPLE	STRONGLY AGREE	STRONGLY DISAGREE								
Example 1. Playing in the snow is a good experience for a child.	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 20px; height: 20px; text-align: center;">✓</td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> </table>	✓								
✓										
Example 2. My child should play with matches when alone.		<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px; text-align: center;">✓</td> </tr> </table>								✓
							✓			

In Example 1 we agreed that playing in the snow is a good experience for a child. We therefore checked a box close to "strongly agree."

In Example 2 we did NOT agree with a child should play with matches when he is alone. We therefore checked a box close to the "strongly disagree."

Please complete each of the following questions in the same way.

SECTION	STRONGLY AGREE	STRONGLY DISAGREE								
1. We believe that our other children should help in the care of our autistic child.	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> </table>									
2. We currently have available to us adequate information concerning biochemical therapies.	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> </table>									

	STRONGLY AGREE	STRONGLY DISAGREE
3. We would like to see more group homes for autistic persons.	<input type="checkbox"/>	<input type="checkbox"/>
4. We believe that the public should have more opportunity to learn about autism.	<input type="checkbox"/>	<input type="checkbox"/>
5. Our autistic child prevents our home from running smoothly.	<input type="checkbox"/>	<input type="checkbox"/>
6. We found it was necessary to go to many professionals before we had a clear picture of our child's impairment.	<input type="checkbox"/>	<input type="checkbox"/>
7. We are presently getting enough time to ourselves away from our autistic child to satisfy us.	<input type="checkbox"/>	<input type="checkbox"/>
8. We found it hard to obtain information concerning financial benefits for our autistic child.	<input type="checkbox"/>	<input type="checkbox"/>
9. Our other children feel we spend too much time with our autistic child.	<input type="checkbox"/>	<input type="checkbox"/>
10. We feel that schools are beginning to program adequately for autistic children in our area.	<input type="checkbox"/>	<input type="checkbox"/>
11. We believe that competent audiology testing is readily available to us.	<input type="checkbox"/>	<input type="checkbox"/>
12. We believe that competent visual testing is readily available to us.	<input type="checkbox"/>	<input type="checkbox"/>

	STRONGLY AGREE	STRONGLY DISAGREE
13. Our relatives give us a great amount of emotional support with regard to our autistic child.	<input type="checkbox"/>	<input type="checkbox"/>
14. We feel that our family doctor is aware of the problems of autistic children.	<input type="checkbox"/>	<input type="checkbox"/>
15. We feel that it is important to belong to a parents' organization.	<input type="checkbox"/>	<input type="checkbox"/>
16. We feel that parental organizations are active in improving services for autistic children.	<input type="checkbox"/>	<input type="checkbox"/>
17. We feel comfortable going to the teaching staff in our autistic child's program with any concerns we might have.	<input type="checkbox"/>	<input type="checkbox"/>
18. We have in the past received a very adequate amount of respite care.	<input type="checkbox"/>	<input type="checkbox"/>
19. We are currently receiving a very adequate amount of respite care.	<input type="checkbox"/>	<input type="checkbox"/>
20. We feel that our family has been strengthened by our child's handicapping condition.	<input type="checkbox"/>	<input type="checkbox"/>
21. We feel that community service agencies are able to effectively program for autistic children.	<input type="checkbox"/>	<input type="checkbox"/>
22. We think that verbal autistic children have a better chance in the world than non-verbal autistic children.	<input type="checkbox"/>	<input type="checkbox"/>

	STRONGLY AGREE	STRONGLY DISAGREE
23. We would like to become more directly involved in our child's education.	<input type="checkbox"/>	<input type="checkbox"/>
24. The education laws of the State of Michigan that effect our child are fair and relevant to his/her needs.	<input type="checkbox"/>	<input type="checkbox"/>
25. Elected representatives are responsive to the needs of autistic children.	<input type="checkbox"/>	<input type="checkbox"/>
26. We feel that the teachers that are teaching our autistic child have been very well trained.	<input type="checkbox"/>	<input type="checkbox"/>
27. As parents, we both have similar philosophies about how to raise our autistic child.	<input type="checkbox"/>	<input type="checkbox"/>
28. We know how to obtain information on current legislation pertaining to autistic children.	<input type="checkbox"/>	<input type="checkbox"/>
29. We are currently receiving as much information from the school concerning our autistic child as we would like.	<input type="checkbox"/>	<input type="checkbox"/>
30. We generally accept what psychologists tell us about our autistic child.	<input type="checkbox"/>	<input type="checkbox"/>
31. We generally feel that psychologists have been competent in their diagnoses of our autistic child.	<input type="checkbox"/>	<input type="checkbox"/>
32. Our autistic child's current school program provides strong language instruction.	<input type="checkbox"/>	<input type="checkbox"/>

STRONGLY  
DISAGREE

33. We feel that we would benefit from more professional help in communicating with our autistic child.
34. We generally feel that social workers are flexible enough to work with autistic children and their families.
35. We feel comfortable enough with our social worker to contact him/her in a crisis situation.
36. We would like to see more sheltered workshops for autistic persons.
37. There is a need for pre-vocational programs for autistic students.
38. Autistic students can benefit from vocational education.
39. There are sufficient vocational education programs now which can meet the needs of autistic students.

In SECTION B, a line of boxes will again follow each statement. Please note that the scale runs from RARELY to OFTEN, with the extreme boxes being labeled NEVER and CONTINUOUSLY.

(see EXAMPLE)

#### EXAMPLE

NEVER

RARELY

OFTEN

CONTINUOUSLY

Example 1. My child finds pennies on the floor.

						✓	
--	--	--	--	--	--	---	--

Example 2. A ghost was seen in our house.

✓							
---	--	--	--	--	--	--	--

In Example 1 we felt that our child OFTEN finds pennies on the floor. We therefore checked a box close to "OFTEN."

In Example 2 a ghost has NEVER been seen in our house. We therefore checked the box under "NEVER."

Please complete each of the following questions in the same way.

#### SECTION B

NEVER

RARELY

OFTEN

CONTINUOUSLY

40. Information has been easily attainable from service agencies to help with our autistic child.

--	--	--	--	--	--	--	--

41. Our other children help in the care of our autistic child.

--	--	--	--	--	--	--	--

42. The school makes a concerted effort to help us plan for our autistic child at home.

--	--	--	--	--	--	--	--

43. We receive support from our family doctor.

--	--	--	--	--	--	--	--



	NEVER	RARELY	OFTEN	CONTINUOUSLY
44. We have found that professionals will refuse to service our autistic child and send us to someone else.				
45. Teachers keep us informed about our autistic child's progress.				
46. Our other children get upset with our autistic child.				
47. Our family freely shares concerns and frustrations encountered in living with our autistic child.				
48. We are consulted with about the nature of our autistic child's educational plan by his teacher.				
49. Our neighbors are supportive of our situation with our autistic child.				
50. We allow our autistic child to do as much for him/herself as possible.				
51. We have had contact with a professional advocacy organization.				
52. Our other children are ridiculed about their autistic sibling.				

Thank you so much for completing our survey!

If you have any further questions, or desire any information whatsoever, please contact us at:

David Paige and Linda Petersen  
c/o Dr. Ronald Wolthuis  
346 Erickson Hall  
Michigan State University  
East Lansing, Michigan 48824

(517) 355-6549

Number \_\_\_\_\_

Date \_\_\_\_\_

## PARENT QUESTIONNAIRE ON QUALITY OF LIFE

January, 1980

Dear Parent,

Your agreement to participate in this study investigating the relationships between quality of life and having an autistic child in the family is gratefully appreciated.

A great deal has been written about parents and families of autistic children which has not asked questions directly of those families. This study will ask about various aspects of your life such as spare time activities and neighborhood, and many questions about your family life. As I explained on the phone, this information will be used for comparison to families who do not have handicapped children to see if we can understand these differences better. It is your experience and information that is valuable. There are no "wrong" answers.

I will come to your house at \_\_\_\_\_ on \_\_\_\_\_  
with a questionnaire for each of you. I will be glad to supervise or play with your autistic child while you complete the questionnaire.

By signing the consent form, you agree to the confidential utilization of this information for purposes of research and study. No individuals will be identified. A report which summarizes the findings will be sent to you upon completion of the study.

If you have any questions or concerns, do not hesitate to call me at home (517-355-5861) or at the office (517-355-4545). I look forward to meeting with you.

Sincerely,



Mary M. Gray  
Graduate Student  
Family Ecology

Consent Form

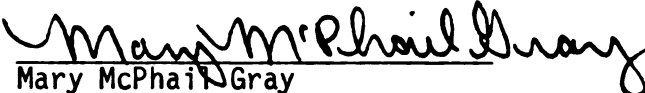
We, the undersigned willingly consent to participate in this study about quality of life in families with autistic children. We do so understanding that our names will in no way be identified with the answers we have given and we reserve the right to withdraw from this study at any time.

The goals of the research project have been explained to us. We feel that our participation will support research efforts to understand how the quality of family life is impacted by an autistic child.

We desire to participate in this study and consent and agree.

_____	_____	_____	_____
Wife's Signature	Date	Husband's Signature	Date
_____	_____	_____	_____
Street	City, State	Zip	

I, the undersigned student researcher, guarantee complete anonymity to the persons whose signature appears above. I will be happy to answer any questions at 517-355-5861 or 517-355-4545

  
\_\_\_\_\_  
Mary McPhail Gray  
Ph.D. Student  
Family Ecology

### GENERAL DIRECTIONS

Please read the directions at the beginning of each section before answering the questions. It is very important that you answer each question as carefully and as accurately as you can. Be sure to respond to all the questions on each page. Both you and your spouse are asked to complete separate questionnaires. Please do not discuss your answers before both of you have finished the entire questionnaire. When you have completed the questionnaire, return it to the manila envelope provided.

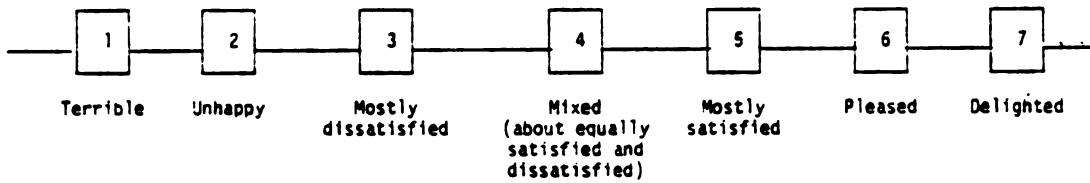
### YOUR FEELINGS ABOUT LIFE CONCERNS

In this section of the questionnaire, we want to find out how you feel about various parts of your life. Please include the feelings you have now, taking into account what has happened in the last year and what you expect in the near future.

All of the items are answered simply by writing on the line to the left of each question one of the following numbers OR letters to indicate how you feel. For example write in "1" for "terrible", "4" for mixed feelings about some question (this is, you are about equally satisfied and dissatisfied with some part of your life), and so forth on to the "7" if you feel delighted about it. If you have no feelings at all on the question, write, "A". If you have never thought about something, write in "B." If some question does not apply to you, write in "C."

For two of the questions we also ask you to write in some important reasons for why you feel as you do. Please finish this section before going on to the next section.

I feel:



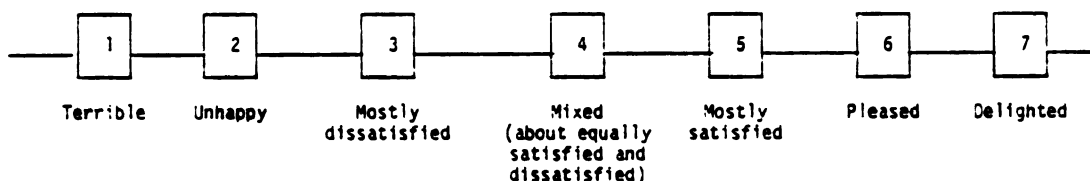
☐ A Neutral--neither satisfied nor dissatisfied

☐ B Never thought about it

☐ C Does not apply to me

- \_\_\_\_\_ 1.1 How do you feel about your life as a whole?
- \_\_\_\_\_ 1.2 How do you feel about the freedom you have from being bothered and annoyed?
- \_\_\_\_\_ 1.3a How do you feel about your own family life; your husband or wife, your marriage, and, your children?
- \_\_\_\_\_ 1.3b What are some of the most important reasons for why you feel as you do about your family?
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_ 1.5 How do you feel about your independence or freedom--the chance you have to do what you want?
- \_\_\_\_\_ 1.6 How do you feel about how much you are accepted and included by others?
- \_\_\_\_\_ 1.7 How do you feel about your job?
- \_\_\_\_\_ 1.11 How do you feel about how much fun you are having?
- \_\_\_\_\_ 1.12 How do you feel about your house or apartment?
- \_\_\_\_\_ 1.13 How do you feel about what you are accomplishing in your life?

I feel:



☐ A Neutral--neither satisfied nor dissatisfied

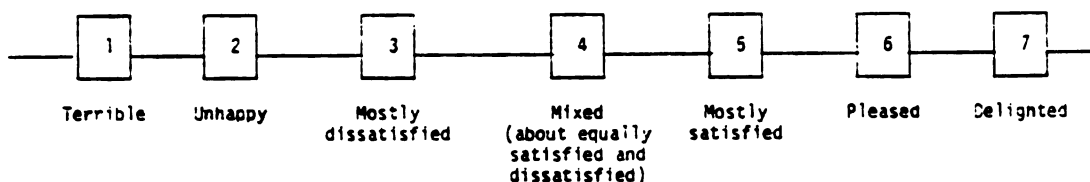
☐ B Never thought about it

☐ C Does not apply to me

- \_\_\_\_\_ 1.14 How do you feel about your particular neighborhood as a place to live?
- \_\_\_\_\_ 1.16 How do you feel about the way you spend your spare time, your non-working activities?
- \_\_\_\_\_ 1.17 How do you feel about yourself?
- \_\_\_\_\_ 1.20 How do you feel about how interesting your day to day life is?
- \_\_\_\_\_ 1.22 How do you feel about the extent to which your social and emotional needs (for example friends, acceptance by others, belonging and affection) are met?
- \_\_\_\_\_ 1.23 How do you feel about your own health?
- \_\_\_\_\_ 1.25 How do you feel about how creative and expressive you are?
- \_\_\_\_\_ 1.26 How do you feel about the chance you have to learn new things or be exposed to new ideas?
- \_\_\_\_\_ 1.18 How do you feel about your home environment if you considered only the heating/cooling system?
- \_\_\_\_\_ 1.19 How do you feel about your home environment if you considered only the safety of your autistic child?
- \_\_\_\_\_ 1.20 How do you feel about your home environment if you considered only the safety for the rest of the family?



I feel:



☐ A Neutral--neither satisfied nor dissatisfied

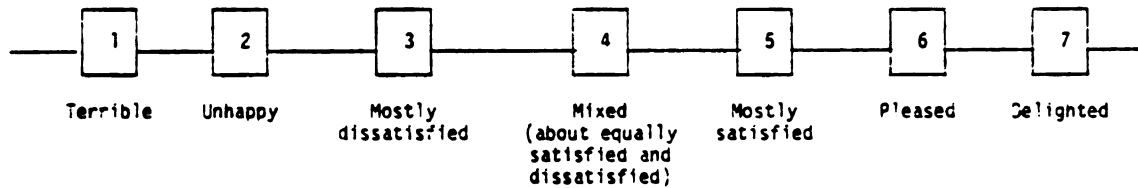
☐ B Never thought about it

☐ C Does not apply to me

- \_\_\_\_\_ 1.21 How would you feel about your home environment if you considered only the room or space you have?
- \_\_\_\_\_ 1.22 How do you feel about your home environment if you considered only the distance to stores and shopping areas?
- \_\_\_\_\_ 1.23 How do you feel about your home environment if you considered only the distance to your friends?
- \_\_\_\_\_ 1.24 How do you feel about your home environment if you considered only the distance to your relatives?
- \_\_\_\_\_ 1.25 How would you feel about your home environment if you considered only your distance from schools?
- \_\_\_\_\_ 1.26 How would you feel about your environment if you considered only your distance from medical services?

The questions on this page ask you to give your reactions to how you would feel about your family life.

About my FAMILY LIFE I would feel:



☐ A Neutral--neither satisfied nor dissatisfied

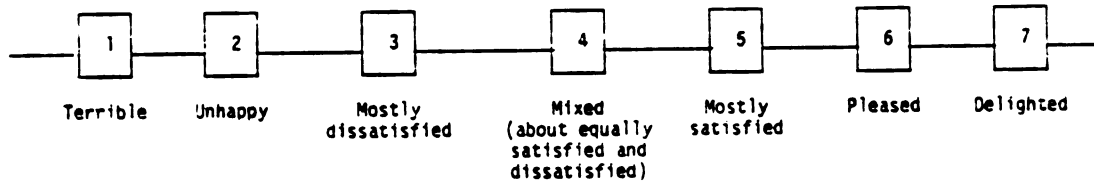
☐ B Never thought about it

☐ C Does not apply to me

- \_\_\_\_\_ 2.4a How would you feel about your own family life--your marriage, husband or wife, and children--if you considered only its effect on your standard of living?
- \_\_\_\_\_ 2.4b How would you feel about your own family life if you considered only the fun it enables you to have?
- \_\_\_\_\_ 2.4c How would you feel about your own family life if you considered only the effect on your independence o freedom--the chance you have to do what you want?
- \_\_\_\_\_ 2.4d How would you feel about your own family life if you considered only the attractiveness and beauty it enables you to enjoy?
- \_\_\_\_\_ 2.4e How would you feel about your own family life if you considered only the freedom from bother and annoyance that it enables you to have?
- \_\_\_\_\_ 2.4f How would you feel about your own family life if you considered only the safety it enables you to have?
- \_\_\_\_\_ 2.4g How would you feel about your own family life if you considered only how it enables you to accomplish what you want?
- \_\_\_\_\_ 2.4h How would you feel about your family life if you considered only its effect on your acceptance and inclusion by other people?

The questions on this page ask you to give your reactions to how you would feel about your neighborhood.

About my NEIGHBORHOOD as a place to live I would feel:



☐ A Neutral--neither satisfied nor dissatisfied

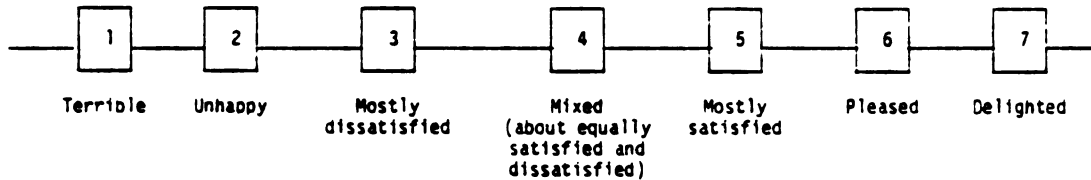
☐ B Never thought about it

☐ C Does not apply to me

- \_\_\_\_\_ 2.5a How would you feel about your own neighborhood as a place to live if you considered only the standard of living it enables you to have?
- \_\_\_\_\_ 2.5b How would you feel about your own neighborhood as a place to live if you considered only the fun you have?
- \_\_\_\_\_ 2.5c How would you feel about your own neighborhood as a place to live if you considered only its effect on your independence or freedom--the chance you have to do what you want?
- \_\_\_\_\_ 2.5d How would you feel about your own neighborhood as a place to live if you considered only the amount of beauty and attractiveness it enables you to enjoy?
- \_\_\_\_\_ 2.5e How would you feel about your own neighborhood as a place to live if you considered only the freedom you have from bother and annoyance?
- \_\_\_\_\_ 2.5f How would you feel about your own neighborhood as a place to live if you considered only your own safety?
- \_\_\_\_\_ 2.5g How would you feel about your own neighborhood as a place to live if you considered only how it enables you to accomplish things?
- \_\_\_\_\_ 2.5h How would you feel about your own neighborhood as a place to live if you considered only how much you are accepted and included by other people?

The questions on this page ask you to give your reactions to how you would feel about your spare time.

About my SPARE TIME I would feel:



☐ A    Neutral--neither satisfied nor dissatisfied

☐ B    Never thought about it

☐ C    Does not apply to me

- \_\_\_\_\_ 2.6a How would you feel about the way you spend your spare time, your non-working activities, if you considered only its effect on your standard of living?
- 2.6b How would you feel about the way you spend your spare time, your non-working activities, if you considered only how much fun you have?
- \_\_\_\_\_ 2.6c How would you feel about the way you spend your spare time if you considered only your independence or freedom--the chance you have to do what you want?
- \_\_\_\_\_ 2.6d How would you feel about the way you spend your spare time if you considered only the beauty and attractiveness you enjoy?
- \_\_\_\_\_ 2.6e How would you feel about the way you spend your spare time if you considered only the freedom you have from being bothered and annoyed?
- \_\_\_\_\_ 2.6f How would you feel about the way you spend your spare time if you considered only your safety?
- \_\_\_\_\_ 2.6g How would you feel about the way you spend your spare time if you considered only how it enables you to accomplish things?
- \_\_\_\_\_ 2.6h How would you feel about the way you spend your spare time if you considered only how much you are accepted by others?

Now we have some questions of a different kind. For each of the following four questions check one of the two responses that best describes how you feel.

- 4.1 Have you usually felt pretty sure your life would work out the way you want it to, or have there been times when you haven't been sure about it?  
CHECK ONE:
- (        ) I have felt pretty sure life would work out the way I want it to.
- (        ) There have been times when I haven't been sure about it.
- 4.2 Do you think it's better to plan your life a good way ahead, or would you say life is too much a matter of luck to plan ahead very far?  
CHECK ONE:
- (        ) I think it's better to plan my life a good way ahead.
- (        ) I think life is too much a matter of luck to plan ahead very far.
- 4.3 When you do make plans ahead, do you usually get to carry things out the way you expected, or do things usually come up to make you change your plans?  
CHECK ONE:
- (        ) I usually get to carry things out the way I expected.
- (        ) Things usually come up to make me change my plans.
- 4.4 Some people feel that they run their lives pretty much the way they want to; others feel the problems of life are sometimes too big for them. Which one are you most like?
- (        ) I feel I can run my life pretty much the way I want to.
- (        ) I feel the problems of life are sometimes too big for me.

### More Feelings About Your Family Life

Circle the Number that best describes your feelings about your own family life. For example, circle "1" if you feel terrible about something, circle "4" if you have mixed feelings (that is, you are about equally satisfied and dissatisfied), and circle "7" if you feel delighted about it.

	<u>Terrible</u>	<u>Unhappy</u>	<u>Mostly dissatisfied</u>	<u>Mixed (about equally satisfied * dissatisfied)</u>	<u>Mostly satisfied</u>	<u>Pleased</u>	<u>Delighted</u>
6.1 How would you feel about your own family life if you considered only:							
6.1a Your husband or wife?	1	2	3	4	5	6	7
6.1b Your children?	1	2	3	4	5	6	7
6.1c The love and affection you experience?	1	2	3	4	5	6	7
6.1d The closeness and sense of belonging you feel?	1	2	3	4	5	6	7
6.1e The amount of respect you receive?	1	2	3	4	5	6	7
6.1f How comfortable it feels to be at home?	1	2	3	4	5	6	7
6.1g Your marriage?	1	2	3	4	5	6	7
6.2 How would you feel about your own family life--your marriage, husband or wife and children--if you considered only:							
6.2a The way money is used	1	2	3	4	5	6	7
6.2b The amount of money available for your personal use?	1	2	3	4	5	6	7
6.2c The material goods it enables you to own	1	2	3	4	5	6	7
6.2d The way decisions are made?	1	2	3	4	5	6	7
6.2e The things you do together?	1	2	3	4	5	6	7

	<u>Terrible</u>	<u>Unhappy</u>	<u>Mostly dissatisfied</u>	<u>Mixed (about equally satisfied * dissatisfied)</u>	<u>Mostly satisfied</u>	<u>Pleased</u>	<u>Delighted</u>
6.3 How would you feel about your own family life if you considered only:							
6.3a The mutual help- fulness of family members?	1	2	3	4	5	6	7
6.3b The way house- hold work is divided/accomplished	1	2	3	4	5	6	7
6.3c How openly and honestly you can express feelings?	1	2	3	4	5	6	7
6.3d The kind of com- munication you have?	1	2	3	4	5	6	7
6.3e The amount of time the family spends together?	1	2	3	4	5	6	7
6.3f Your sexual rela- tionship?	1	2	3	4	5	6	7
6.3g The time you spend with your children?	1	2	3	4	5	6	7
6.3h The time you spend with your husband or wife?	1	2	3	4	5	6	7
6.3i The friends it enables you to enjoy?	1	2	3	4	5	6	7

6.4a Have you had any children born to you?

(       ) NO

(       ) YES

Number of children  
born to you: \_\_\_\_\_

6.4b If you had it to do over again would you have children?

(       ) NO

(       ) YES

6.4c How strongly do you feel about the answer you have to the  
above question?

(       ) Very strongly

(       ) Somewhat strongly

(       ) Not strongly

6.4d What are some of the reasons you feel as you do about having  
children?

---

---

---

---



CIRCLE THE NUMBER corresponding to the category which most accurately estimates how often the following events occur. For example, circle "1" if something never happens, circle "4" if it happens about once each month, and circle "8" if it happens about two to three times each day.

	Never	About once a year	About 6 times each year	About once each month	About once each week	About 3-4 times a week	About once each day	About 2-3 times each day
7.1 How often do you and your mate:								
7.1a Spend time together-- just the two of you?	1	2	3	4	5	6	7	8
7.1b Spend an hour or more just talking?	1	2	3	4	5	6	7	8
7.1c Discuss personal feelings?	1	2	3	4	5	6	7	8
7.1d Work together on a pro- ject?	1	2	3	4	5	6	7	8
7.1e Take a drive or walk?	1	2	3	4	5	6	7	8
7.1f Eat at a restaurant?	1	2	3	4	5	6	7	8
7.1g Entertain friends at home?	1	2	3	4	5	6	7	8
7.1h Visit friends?	1	2	3	4	5	6	7	8
7.1i Go to a movie or other entertainment?	1	2	3	4	5	6	7	8
7.1j Attend a sports event?	1	2	3	4	5	6	7	8
7.2 How often does your mate:								
7.2a Make you feel like an important person?	1	2	3	4	5	6	7	8
7.2b Tell or show you that he/she admires and respects you?	1	2	3	4	5	6	7	8
7.2c Let you know he/she has confidence in your abilities?	1	2	3	4	5	6	7	8
7.2d Tell or show you his/her love?	1	2	3	4	5	6	7	8
7.2e Let you know she/he enjoys your company?	1	2	3	4	5	6	7	8
7.2f Enjoy a laugh or a joke with you?	1	2	3	4	5	6	7	8
7.2g Give you a hug or kiss?	1	2	3	4	5	6	7	8
7.2h Do an errand for you?	1	2	3	4	5	6	7	8
7.2i Make him/herself avail- able to do work for you?	1	2	3	4	5	6	7	8
7.2j Do something to give you energy or make you com- fortable?	1	2	3	4	5	6	7	8
7.2k Give you new information?	1	2	3	4	5	6	7	8
7.3l Give you his/her opinion?	1	2	3	4	5	6	7	8

	<u>Never</u>	<u>About once a year</u>	<u>About 6 times each year</u>	<u>About once each month</u>	<u>About once each week</u>	<u>About 3-4 times a week</u>	<u>About once each day</u>	<u>About 2-3 times each day</u>
7.2 How often does your mate:								
7.2m Give you something you need or want?	1	2	3	4	5	6	7	8
7.2n Give you money for personal use?	1	2	3	4	5	6	7	8
7.2o Help you solve a problem or make a decision?	1	2	3	4	5	6	7	8
7.2p Support you in the guidance and discipline of the children?	1	2	3	4	5	6	7	8
7.4 How often does the entire family group:								
7.4a Sit together for a meal?	1	2	3	4	5	6	7	8
7.4b Have a discussion of ideas?	1	2	3	4	5	6	7	8
7.4c Discuss a decision or a problem?	1	2	3	4	5	6	7	8
7.4d Work on a project together?	1	2	3	4	5	6	7	8
7.4e Play a game?	1	2	3	4	5	6	7	8
7.4f Go to a movie or other entertainment?	1	2	3	4	5	6	7	8
7.4g Attend church services or activities?	1	2	3	4	5	6	7	8
M7.5 As an individual, how often do you:								
M7.5a Visit a friend or a relative?	1	2	3	4	5	6	7	8
M7.5b Speak by phone with a friend or relative?	1	2	3	4	5	6	7	8
M7.5c Speak with a friend or relative about your autistic child?	1	2	3	4	5	6	7	8
M7.5d Speak with a school representative about your autistic child?	1	2	3	4	5	6	7	8
M7.5e Visit your autistic child's school?	1	2	3	4	5	6	7	8
M7.5f Talk with another parent of an autistic child?	1	2	3	4	5	6	7	8
M7.5g Take your autistic child to appointments with professionals?	1	2	3	4	5	6	7	8

M7.6 Are you a member of NSAC? \_\_\_\_\_ Yes \_\_\_\_\_ NO MSAC? \_\_\_\_\_ Yes  
\_\_\_\_\_ No.

M7.7 Are you a member of another group for parents of special  
children? \_\_\_\_\_ No \_\_\_\_\_ Yes \_\_\_\_\_ Name the  
group.

		<u>Never</u>	<u>About once a year</u>	<u>About 6 times each year</u>	<u>About once each month</u>	<u>About once each week</u>	<u>About 3-4 times a week</u>	<u>About once each day</u>	<u>About 2-3 times each day</u>
M7.8	How often do you see a professional (teacher, minister, social worker, counselor, psychologist, etc.) to discuss:								
M7.8a	Concerns about your autistic child?	1	2	3	4	5	6	7	8
M7.8b	Concerns about your family?	1	2	3	4	5	6	7	8
M7.8c	Concerns about yourself?	1	2	3	4	5	6	7	8
M7.9	How often do you read a book or an article about autism?	1	2	3	4	5	6	7	8
M7.10	How often do you attend an <u>informational</u> meeting on autism?	1	2	3	4	5	6	7	8
M7.11	How often do you attend a <u>support</u> meeting for parents or families of autistic persons?	1	2	3	4	5	6	7	8
M7.12	How often do you use a baby-sitter (not an immediate family member) for your autistic child?	1	2	3	4	5	6	7	8
M7.13	How often do you use respite care services for your autistic child?	1	2	3	4	5	6	7	8

Most people have disagreements in their relationships. Please CIRCLE THE NUMBER under the category that indicates the approximate extent of agreement or disagreement between you and your mate for each of the following items. For example, circle "1" if you always disagree on a subject, circle "3" if you frequently disagree, and circle "6" if you always agree on it.

	<u>Always disagree</u>	<u>Almost always disagree</u>	<u>Frequently disagree</u>	<u>Occasionally disagree</u>	<u>Almost always agree</u>	<u>Always agree</u>
8.1 Handling family finances	1	2	3	4	5	6
8.2 Matters of recreation	1	2	3	4	5	6
8.3 Religious matters	1	2	3	4	5	6
8.4 Demonstration of affection	1	2	3	4	5	6
8.5 Friends	1	2	3	4	5	6
8.6 Sex relations	1	2	3	4	5	6
8.7 Conventionality (correct or proper behavior)	1	2	3	4	5	6
8.8 Philosophy of life	1	2	3	4	5	6
8.9 Ways of dealing with parents or in-laws	1	2	3	4	5	6
8.10 Aims, goals, and things believed important	1	2	3	4	5	6
8.11 Amount of time spent together	1	2	3	4	5	6
8.12 Making major decisions	1	2	3	4	5	6
8.13 Household tasks	1	2	3	4	5	6
8.14 Leisure time interests and activities	1	2	3	4	5	6
8.15 Career decisions	1	2	3	4	5	6
M8.16 Ways to raise autistic child	1	2	3	4	5	6
M8.17 Ways to raise our "other" children	1	2	3	4	5	6
M8.18 Influence our autistic child will have on our future	1	2	3	4	5	6

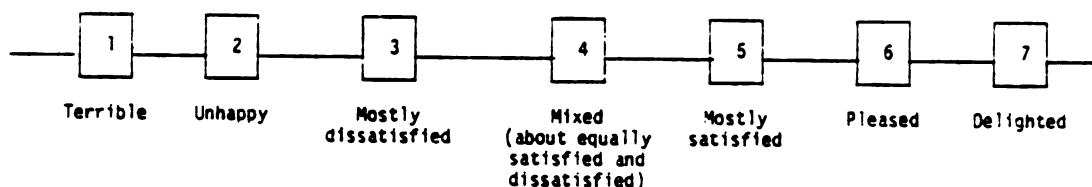
This section takes a look at the unique demands for care and supervision that autistic children require. The questions can be answered by circling the number which best represents your judgement of how much time you spend on an average for that task.

	Never	About once a year	About once each month	About once each week	Under 30 minutes each day	30-60 minutes per day	1 - 2 hours per day	2 - 4 hours per day	4 - 8 hours per day	Constantly
M10.1 How much time do you spend in the following activi- ties for your autistic child:										
M10.1a Special medical care care (exercises, diet, etc.)	1	2	3	4	5	6	7	8	9	10
M10.1b Playing with	1	2	3	4	5	6	7	8	9	10
M10.1c Caring for (dress- ing, bathing, feeding)	1	2	3	4	5	6	7	8	9	10
M10.1d Cleaning up after	1	2	3	4	5	6	7	8	9	10
M10.1e Worrying about	1	2	3	4	5	6	7	8	9	10
M10.1f Enjoying	1	2	3	4	5	6	7	8	9	10
M10.1g Trying to get babysitters for	1	2	3	4	5	6	7	8	9	10
M10.1h Teaching	1	2	3	4	5	6	7	8	9	10
M10.1i Supervising to protect from danger	1	2	3	4	5	6	7	8	9	10
M10.1j Supervising to protect from "mischief" or "messes"	1	2	3	4	5	6	7	8	9	10

This section asks you to consider how many things you can do at the same time that you are caring for your autistic child. CIRCLE THE NUMBER which best represents your estimation of how often other activities take place at the same time you are caring for your autistic child.

	<u>Never</u>	<u>About once a year</u>	<u>About once each month</u>	<u>About once each week</u>	<u>Under 30 minutes each day</u>	<u>30-60 minutes per day</u>	<u>1 - 2 hours per day</u>	<u>2 - 4 hours per day</u>	<u>4 - 8 hours per day</u>	<u>Constantly</u>
M11.1 When your autistic child is at home, how often can you do any of the following activities:										
M11.1a Household maintenance (repairs, cleaning, etc.)	1	2	3	4	5	6	7	8	9	10
M11.1b Household care (meal preparation, laundry, etc.)	1	2	3	4	5	6	7	8	9	10
M11.1c Leisure or hobby activities	1	2	3	4	5	6	7	8	9	10
M11.1d Socializing with other family members	1	2	3	4	5	6	7	8	9	10
M11.1e Entertaining	1	2	3	4	5	6	7	8	9	10
M11.1f Household management (shopping, meal planning, running errands, etc.)	1	2	3	4	5	6	7	8	9	10
M11.1g Homework from job or studies	1	2	3	4	5	6	7	8	9	10
M11.1h Thinking, planning daydreaming	1	2	3	4	5	6	7	8	9	10

Now that you have done some thinking about your family life and your life in general, we would like to ask you how you feel about them. Please write on the line to the left of each question one of the following numbers or letters to indicate how you feel. For example, if you feel terrible about it write in "1", if you have mixed feelings about it (that is, you are about equally satisfied and dissatisfied) write in "4" and if you feel delighted about it write in "7." If you feel neutral about it (that is, you are neither satisfied or dissatisfied), write in "A." If you have never thought about it, write in "B." If it does not apply to you, write in "C."



A      Neutral--neither satisfied nor dissatisfied

B      Never thought about it

C      Does not apply to me

\_\_\_\_\_ 9.1      How do you feel about your own family life--your husband or wife, your marriage, and your children?

\_\_\_\_\_ 9.2      How do you feel about your life as a whole?

9.3      This study has asked you to tell us how you feel about various parts of life. Are there things which affect your quality of life which have not been included. If so, please write them below?

---



---



---



---



---



---



YOUR FAMILY SITUATION

This study is about the quality of life of family members. Therefore, we are interested in knowing some things about yourself and your family. As you answer the questions, please consider only yourself and the family members now living in your household.

FOR EACH QUESTION, PLACE A CHECK MARK IN THE BRACKETS (    ) OR WRITE IN THE ANSWER ON THE LINE PROVIDED.

13.1 What is your sex?

(    ) Male

(    ) Female

13.2a How old were you on your last birthday?

\_\_\_\_\_ Age at last birthday.

13.2b What is the month, day, and year of your birth?

\_\_\_\_\_                      \_\_\_\_\_                      \_\_\_\_\_  
Month                      Day                      Year of Birth

13.3 What is your religion, if any?

(    ) Protestant: \_\_\_\_\_  
(Please specify)

(    ) Catholic

(    ) Jewish

(    ) None

(    ) Other: \_\_\_\_\_  
(Please specify)

13.4 What is your race?

(    ) White

(    ) Black/Negro/Afro-American

(    ) Other: \_\_\_\_\_  
(Please specify)

13.5 Do you (or does a member of your family who lives with you) own your home, do you rent, or what? (CHECK ONE)

( ) Own or buying

( ) Renting

( ) Other: \_\_\_\_\_  
(Please specify)

13.6a Is this your first marriage?

( ) YES-----In what year were you married? \_\_\_\_\_

( ) NO-----

13.6b In what year did your  
present marriage begin? \_\_\_\_\_

13.6c How did your last marriage end? CHECK ONE

( ) Death-----Year of death: \_\_\_\_\_

( ) Divorce-----Year of divorce: \_\_\_\_\_

( ) Annulment\_\_\_Year of annulment: \_\_\_\_\_

13.7a What is the highest level of formal schooling that you have completed? CHECK ONE

( ) Less than 8 grades of elementary school

( ) 8 grades of elementary school

( ) 1 - 3 years of high school

( ) Completed high school and received diploma or passed high school equivalency exam.

( ) 1 - 3 years of college

( ) College graduate, bachelor's degree

( ) Post bachelor's course work

( ) Master's degree

( ) Ph.D., Ed.D.

( ) Other professional degree (such as MD, DO, JD, DDS):

\_\_\_\_\_  
please specify

13.7b Are you NOW attending or enrolled in one of the programs listed above?

(        ) YES-----13.7c If YES, is that full-time or part-time?

(        ) NO

(        ) Full-time student

(        ) Part-time student

13.7d Please specify in which one of the above programs you are now enrolled (such as high school, college master's program).

Type of school or program: \_\_\_\_\_

13.9b If you are working now OR are temporarily laid off OR on strike OR on sick leave, what kind of work do you do? What is your main occupation called? (If you have two jobs, your main occupation is the job on which you spend the most time. If you spend an equal amount of time on two jobs, it is the one which provides the most income.)

Main occupation \_\_\_\_\_

13.9c What do you actually do in that job? What are some of your main duties?

Duties \_\_\_\_\_

13.9d What kind of business, industry or organization is your job in? What do they do or make at the place where you work?

Kind of business, industry or organization \_\_\_\_\_

What they make or do \_\_\_\_\_

13.9e About how many hours a week do you do this work? CHECK ONE

- (        ) Less than 30 hours per week
- (        ) 20 hours per week
- (        ) 21-39 hours per week
- (        ) 40 hours per week
- (        ) 41-50 hours per week
- (        ) 51-60 hours per week
- (        ) More than 60 hours per week

13.9f Do you do this work inside your home, outside your home but on your own property, or away from your home and property? CHECK THE ONE PLACE IN WHICH YOU DO MOST OF THIS WORK.

- (        ) Inside my home
- (        ) Outside my home but on my own property
- (        ) Away from my home and property

13.9g Are you an hourly wage worker, salaried, on commission, self-employed, or what? CHECK ONE

- (        ) Hourly wage worker
- (        ) Salaried
- (        ) Work on commission, tips
- (        ) Self-employed in own business, professional practice, or farm
- (        ) Work without pay in family business or farm

13.9 How long have you been in your present job?

\_\_\_\_\_ years and \_\_\_\_\_ months

13.9i Is this your first job?

(        ) NO-----13.9j

(        ) YES

What kind of work did you do in your first full-time job after completing your education or training? What was occupation called?

Occupation \_\_\_\_\_

13.9k What did you actually do in that job? What were some of your main duties?

Duties \_\_\_\_\_

19.3l Would you be satisfied to stay in your present position indefinitely?

(        ) YES

(        ) NO

13.9m Do you anticipate a change from your present occupation or your position within the near future?

(        ) YES-----13.9n

(        ) NO

If YES, please describe your anticipated new position, what your title will be and what you will do.

Anticipated new position \_\_\_\_\_

Title \_\_\_\_\_

Duties \_\_\_\_\_

13.9o Are you currently employed in a second job:

(        ) YES-----13.9p

(        ) NO

If YES, about how many hours a week do you do this work?

(        ) Less than 20 hours per week

(        ) 20 hours per week

(        ) 21-39 hours per week

(        ) 40 hours per week

- 13.11a What do you estimate will be your total family income before taxes in 1980? Please include income from all sources before taxes, including income from wages, property, stocks, interest, welfare, Aid to Families with Dependent Children, child support from a previous marriage, and any other money income received by you and all family members who live with you.

ESTIMATED TOTAL FAMILY YEARLY INCOME, 1980

- |                          |                          |
|--------------------------|--------------------------|
| (    ) Under \$3,000     | (    ) \$12,000 - 14,999 |
| (    ) \$ 3,000 - 3,999  | (    ) \$16,000 - 19,999 |
| (    ) \$ 4,000 - 4,999  | (    ) \$20,000 - 24,999 |
| (    ) \$ 5,000 - 5,999  | (    ) \$25,000 - 29,999 |
| (    ) \$ 6,000 - 6,999  | (    ) \$30,000 - 34,999 |
| (    ) \$ 7,000 - 7,999  | (    ) \$35,000 - 49,999 |
| (    ) \$ 8,000 - 9,999  | (    ) \$50,000 - 74,999 |
| (    ) \$10,000 - 11,999 | (    ) \$75,000 and over |

- 13.11b About how much of this total family yearly income do you estimate that YOU will earn in 1980:

ESTIMATED PORTION OF TOTAL FAMILY INCOME, 1980, EARNED BY YOURSELF

- |   |                          |
|---|--------------------------|
| (    ) Does not apply, not employed in 1980 |                          |
| (    ) Under \$3,000                        | (    ) \$12,000 - 14,999 |
| (    ) \$ 3,000 - 3,999                     | (    ) \$15,000 - 19,999 |
| (    ) \$ 4,000 - 4,999                     | (    ) \$20,000 - 24,999 |
| (    ) \$ 5,000 - 5,999                     | (    ) \$25,000 - 29,999 |
| (    ) \$ 6,000 - 6,999                     | (    ) \$30,000 - 34,999 |
| (    ) \$ 7,000 - 7,999                     | (    ) \$35,000 - 49,999 |
| (    ) \$ 8,000 - 9,999                     | (    ) \$50,000 - 74,999 |
| (    ) \$10,000 - 11,999                    | (    ) \$75,000 and over |

13.12 In the coming year, would you say your financial situation  
will get worse, stay about the same, or get better?  
CHECK ONE

(     ) Get worse

(     ) Stay about the same

(     ) Get better

IMPORTANCE OF LIFE CONCERNS

All of us have an idea of what we think is important in life. Now that you have done a lot of thinking about various parts of your life, we would like to ask you how important you think various life concerns are. Take a few moments to think about what is important to you. CIRCLE THE NUMBER in the column that best represents the degree of importance of each life concern to you. For example, circle "1" if it is of no importance, circle "3" if it is of some importance, and circle "5" if it is of very high importance.

		No importance at all	Little importance	Some importance	High importance	Very high importance
14.1	Having freedom from bother and annoyance	1	2	3	4	5
14.2	My family life	1	2	3	4	5
14.3	Beauty and attractiveness in my day to day life	1	2	3	4	5
14.3	My independence or freedom	1	2	3	4	5
14.5	Being accepted and included by others	1	2	3	4	5
14.6	My job	1	2	3	4	5
14.7	My standard of living--the things I have like housing, car, furniture, recreation, and the like	1	2	3	4	5
14.10	Having Fun	1	2	3	4	5
14.11	My house or apartment	1	2	3	4	5
14.12	Accomplishing something	1	2	3	4	5
14.13	My neighborhood	1	2	3	4	5
14.15	The way I spend my spare time, my non-working activities	1	2	3	4	5
14.16	Myself	1	2	3	4	5
14.18	Having financial security	1	2	3	4	5
14.19	Having an interesting day to day life	1	2	3	4	5
14.20	Having my physical needs met	1	2	3	4	5
14.21	Having my social and emotional needs met	1	2	3	4	5
14.22	My own health	1	2	3	4	5
14.23	Our total family income	1	2	3	4	5
14.24	Being creative or expressive	1	2	3	4	5
14.25	Our children	1	2	3	4	5
14.26	Having the opportunity to learn new things	1	2	3	4	5
14.27	Having love and affection	1	2	3	4	5



- 14.28 What other things are very important to you? Please list them below.

---

---

---

- 15.1a We would like to know something about the people who live in your household. In the chart below, please list for ALL PERSONS LIVING IN YOUR HOUSEHOLD NOW: their birth date, age at last birthday, sex and marital status. Do not list any person more than once.

Please use the following numbers to indicate marital status:

- |                              |                               |
|------------------------------|-------------------------------|
| ( 1 ) Never married          | ( 4 ) Separated               |
| ( 2 ) Married                | ( 5 ) Divorced, not remarried |
| ( 3 ) Widowed, not remarried | ( 6 ) Don't know              |

	Date of birth mo./day/yr.	Age of last birthday	Sex (circle M or F)	Marital Status
<hr/>				
SPOUSE (husband or wife)			M    F	
<hr/>				
CHILDREN BORN TO THIS MARRIAGE, LIVING IN THIS HOUSEHOLD  Please list in order from oldest to youngest	1.		M    F	
	2.		M    F	
	3.		M    F	
	4.		M    F	
	5.		M    F	
	6.		M    F	
	7.		M    F	
	8.		M    F	
	9.		M    F	
<hr/>				

	Date of birth mo./day/yr.	Age of last birthday	Sex (circle M or F)	Marital Status
CHILDREN BORN TO WIFE PRIOR TO THIS MARRIAGE, LIVING IN THIS HOUSE- HOLD	1.		M   F	
	2.		M   F	
	3.		M   F	
	4.		M   F	
	5.		M   F	
Please list in order from oldest to young- est				
CHILDREN BORN TO HUS- BAND PRIOR TO THIS MARRIAGE, LIVING IN THIS HOUSEHOLD	1.		M   F	
	2.		M   F	
	3.		M   F	
	4.		M   F	
	5.		M   F	
Please list in order from oldest to young- est				
ADOPTED CHILDREN NOT BORN TO EITHER SPOUSE, LIVING IN THIS HOUSE- HOLD	1.		M   F	
	2.		M   F	
	3.		M   F	
	4.		M   F	
	5.		M   F	
Please list in order from oldest to young- est				
OTHER RELATIVES LIVING IN THIS HOUSEHOLD (such as niece, nephew, grandchild, parent, sister, uncle, brother, brother-in-law, mother-in-law, hus- band's uncle)	1.		M   F	
	2.		M   F	
	3.		M   F	
	4.		M   F	
	5.		M   F	
	6.		M   F	

	Date of birth mo./day/yr.	Age of last birthday	Sex (circle M or F)	Marital Status
OTHER PERSONS LIVING IN THIS HOUSEHOLD (such as foster child, friend, household help, boarders)	1.		M    F	
	2.		M    F	
	3.		M    F	
	4.		M    F	
	5.		M    F	
	6.		M    F	
	7.		M    F	

NOTE: If there are not enough spaces, please finish the list on the last page.

15.1b Counting yourself, how many people live in your household?  
\_\_\_\_\_ people

15.2a Are there any other children born to you and/or your spouse (including children from previous marriages) who are not listed in the preceding chart?

(        ) YES-----15.2b If YES, how many?

(        ) NO                \_\_\_\_\_ males

\_\_\_\_\_ females

15.2c Please list their ages at last birthday from oldest to youngest by sex.

Males \_\_\_\_\_

Females \_\_\_\_\_

THANK YOU VERY MUCH for completing this questionnaire. We will send you a summary of results from this study.

If you wish to make any comments about how you felt while filling out this questionnaire, please do: \_\_\_\_\_

---

---

---

---

---

TABLE C-1.--Age of Autistic Child in Two Autism Groups.

Ages	Gray N = 22		Non-Selected N = 88	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
1 - 5 years	4	18.2	10	11.4
6 - 10 years	7	31.8	26	29.5
11 - 15 years	6	27.3	32	36.4
16 and over	4	18.2	18	20.5
Missing	1	4.5	2	Missing
MEAN AGE	10		11	

TABLE C-2.--Presence of Other Handicapping Conditions' in Two Autism Groups

Ages	Gray N = 22		Non-Selected N = 88	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
No other Handicap	13	59.1	62	70.5
Presence of Other Handicap (i.e., seizure disorder, aphasia, mental retardation)	9	40.9	26	29.5

TABLE C-3.--Presence of Verbal Ability in Two Autism Groups.

	Gray (N = 22)		Non-Selected (N = 88)	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
Verbal Ability	8	36.4	29	33.0
Non-Verbal	13	59.1	45	51.1
Missing	1	4.5	14	15.9
	<u>22</u>	<u>100.0</u>	<u>88</u>	<u>100.0</u>

TABLE C-4.--Number of Children in Families of Two Autism Groups

Number of Children in Family	Gray (N = 22)		Non-Selected (N = 88)	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
1	4	18.1	16	18.2
2 - 3	13	59.1	38	43.2
4 and over	4	18.2	25	28.4
Missing	1	4.5	9	10.2
	<u>22</u>	<u>100.0</u>	<u>88</u>	<u>100.0</u>

TABLE C-5.--Age of Mothers in Two Autism Groups.<sup>a</sup>

Age of Mother	Gray		Non-Selected	
	N	%	N	%
18 - 25	1	4.5	7	8.8
26 - 35	8	36.4	30	37.5
36 - 50	11	50.0	39	48.7
51 and up	2	9.1	4	5.0
Missing			8	
TOTAL	22	100.0	88	100.0

<sup>a</sup>Data from the 1979 College of Education Survey.

TABLE C-6.--Ages of Fathers in Two Autism Groups.

Age of	Gray		Non-Selected	
	N	%	N	%
18 - 25			3	4.1
26 - 35	5	22.7	20	27.0
36 - 50	10	45.5	38	51.4
51 and up	7	31.8	13	17.6
Missing			14	15.9
TOTAL	22	100.0	88	100.0



TABLE C-7.--Distance from Nearest Relative in Miles for Two Autism Groups.

	Gray N = 22		Non-Selected N = 88	
	N	%	N	%
1 - 5 miles	15	68.2	50	60.2
6 - 20 miles	3	13.6	11	13.3
21 - 50 miles			6	7.2
51 - 100 miles	2	9.1	46	4.8
Over 100 miles	1	4.5	12	14.5
Missing	1	4.5	5	Missing
TOTAL	22	100.0	88	100.0

TABLE C-8.--Selected Indices for Gray Autism Sample and DeMyer Sample.<sup>a</sup>

	DeMyer	Gray
Mean Age		
Child	5	10
Mother	33	31
Father	36	37
Sex Autistic Child		
Male	76%	73%
Female	24%	27%
Race		
White	83%	86.4%
Black	17%	13.6%
Number of Siblings		
0	15%	18.1%
1 or 2	61%	59.1%
3 or More	24%	18.2%
Missing Data	-	4.5
Verbal Behavior		
Non-Verbal	65%	59.1%
Verbal (Range of Communicative Intent)	36%	36.4%

<sup>a</sup>Source: Marian K. DeMyer. Parents and Children in Autism. (New York: John Wiley & Sons, 1979), p. 2.

TABLE C-9.--Education and Socioeconomic Status of Gray Sample and DeMyer Sample.<sup>a</sup>

	DeMyer	Gray
Education		
Below High School		
Mother	19%	4.5%
Father	20%	9.1%
High School Grad		
Mother	66%	68.2%
Father	40%	50.0%
College Graduate and above		
Mother	15%	27.3%
Father	39%	40.7%
Socioeconomic Status		
High	20%	
Middle	70%	
Low	10%	
Occupational Status of Fathers		
Professional/Managerial		49.9%
Sales/craftsman/Operatives		55.6%
Laborers/Private Household		4.5%

<sup>a</sup>Source: Marian K. DeMyer, Parents and Children in Autism, (New York: John Wiley Sons, 1979), p. 3.

TABLE C-10.--Age of Respondents - Oakland.

<u>OAKLAND SAMPLE</u>				
Age	Women		Men	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
30 and younger	46	18.9	31	13.1
31 - 35	61	25.0	44	18.6
36 - 40	56	23.0	56	23.6
41 - 45	34	13.9	42	17.7
47 - 55	42	17.2	50	21.1
Over 55	2	.8	13	5.5
Missing Data	3	1.2	1	.4
	<u>244</u>	<u>100.0</u>	<u>237</u>	<u>100.0</u>
TOTAL	244	100.0	237	100.0
MEAN	37.5		40.2	
RANGE	22 - 59		24 - 63	

TABLE C-11.--Age of Respondents - Autism.

<u>AUTISM SAMPLE</u>				
Age	Women		Men	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
30 and younger	4	18.2	4	19.0
31 - 35	6	27.2	4	19.0
36 - 40	5	22.7	3	13.5
41 - 45	3	13.5	1	4.5
46 - 55	4	18.1	7	31.8
Over 55	0	0	2	9.1
Missing Data	0	0	1	4.5
TOTAL	22	100.0	22	100.0
MEAN	37.8		41.7	
RANGE	25 - 52		27 - 61	

TABLE C-12.--Race of Respondents.

<u>OAKLAND SAMPLE</u>					
Age	Women		Men		
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>	
White	194	79.5	196	82.7	
Black	46	18.9	41	17.3	
Mexican American	1	.4	--	--	
Other	3	1.2	--	--	
	<u>      </u>	<u>      </u>	<u>      </u>	<u>      </u>	
TOTAL	244	100.0	237	100.0	

<u>AUTISM SAMPLE</u>					
Age	Women		Men		
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>	
White	19	86.4	18	81.9	
Black	3	13.6	3	13.6	
Mexican American	0	0	0	0	
Other	0	0	1	4.5	
	<u>      </u>	<u>      </u>	<u>      </u>	<u>      </u>	
TOTAL	22	100.0	22	100.0	

TABLE C-13.--Household Composition for Autism and Oakland Groups.

Composition	OAKLAND		AUTISM	
	N	%	N	%
Husband and wife with one or more children living at home	237	97.1	22	100.0
- No other persons living with family	214	87.7	20	90.1
- One or more relatives <sup>a</sup> living with family	18	7.4	2	9.9
- One or more unrelated <sup>b</sup> persons living with family	4	1.6		
- One related and one unrelated person living with family	1	.4		
Female single parent with one or more children living at home	7	2.9		
- No other persons living with family	5	2.1		
- One relative <sup>a</sup> living with family	1	.4		
- One unrelated <sup>b</sup> person living with family	1	.4		
	244	100.0%	22	100.0

<sup>a</sup>Relatives living with various families include: grandchildren, nieces, nephews, parents, siblings and an aunt of the husband or wife, and a daughter-in-law.

<sup>b</sup>Unrelated persons living with various families include: foster children, friends, an exchange student and a boarder.

TABLE C-14.--Number of Own or Adopted Children Living in Household  
for Autism and Oakland Groups.

No. of Children	Oakland		Autism	
	N	%	N	%
1	33	13.5	3	13.6
2	86	35.2	10	45.5
3	66	26.2	6	27.3
4	38	15.6	-	-
5	12	4.9	2	9.1
6 or More	11	4.5	1	4.5
TOTAL	244	100.0	22	100.0
MEAN	2.8		2.6	
RANGE	1 - 9		1 - 6	



TABLE C-15.--Number of People Living in Household for Autism and Oakland Groups

	Oakland		Autism	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
2 Persons	1	.4	0	0
3 Persons	31	12.7	3	13.6
4 Persons	81	33.2	10	45.5
5 Persons	64	26.2	6	27.3
6 Persons	43	17.6	0	0
7 Persons	10	4.1	2	9.1
8 or Above	14	5.7	1	4.5
	<u>244</u>	<u>100.0</u>	<u>22</u>	<u>100.0</u>
MEAN	4.9		4.6	
RANGE	2 - 11		3 - 9	

TABLE C-16.--Age Range of Children Living in Household - Oakland

OAKLAND	Age of Youngest Child		
	1-5 years	6-12 years	13-18 years
Age of Oldest Child			
1 - 5 years	12 (4.9%)	0	12 (4.9%)
6 - 12 years	51 (20.9%)	36 (14.8%)	87 (35.7%)
13 - 18 years	19 (7.8%)	53 (21.7%)	99 (40.6%)
19 - 22 years	4 (1.6%)	13 (5.3%)	39 (16.0%)
23 years or over	1 (.4%)	2 (.8%)	7 (2.9%)
	87 (35.7%)	104 (42.6%)	53 (21.7%)
			244 (100.0%)

TABLE C-17.--Age Range of Children Living in Household - Autism.

AUTISM <sup>a</sup>	Age of Youngest Child		
	1-5 years	6-12 years	13-18 years
Age of Oldest Child			
1 - 5 years	2 10.5%	0	2 (10.5%)
6 - 12 years	3 15.8%	4 21.2%	7 (46.0%)
13 - 18 years	0	4 21.2%	6 (31.7%)
19 - 22 years	0	0	2 (10.5%)
23 years or over	0	0	2 (10.5%)
	5 (26.3%)	8 (42.4%)	2 (31.5%)
			2 (100.0%)

<sup>a</sup>Two families had only the autistic child and no siblings.

TABLE C-18.--Ages of Children Listed as Not Living in the Household<sup>a</sup>  
for Autism and Oakland Groups.

Age Group	OAKLAND		AUTISM <sup>b</sup>	
	No. of Children	% of Families	No. of Children	% of Families
5 years and under	4	6.4	0	0
6-12 years	4	6.4	0	0
13-18 years	16	25.4	3	60.0
19-22 years	27	42.7	5	60.0
23-30 years	47	74.6	3	40.0
Over 30 years	8	12.8	0	0
Missing data	13	20.6	0	0
TOTALS	119	100.0%	11	100.0

<sup>a</sup> These data pertain only to the 63 Oakland families and the 5 autism families who reported children not living in the household including children from previous marriages. In other words 25.8% of Oakland families and 23.7% of autism families reported children not living at home.

<sup>b</sup> Some families reported children from more than one age group not living at home.

TABLE C-19.--Highest Level of Formal Education for Women in Autism and Oakland Groups.

	Oakland		Autism	
	N	%	N	%
Less than 8 grades of elementary school	1	.4	1	4.5
Completed 8 years of elementary school	6	2.5	-	-
1-3 years of high school	33	13.5	-	-
Completed high school	119	48.8	8	36.4
1-3 years of college	45	18.4	7	31.8
Bachelor's degree	17	7.0	2	9.1
Post Bachelor course work	14	5.7	2	9.1
Master's degree	6	2.5	2	9.1
Post Master's course work	2	.8	0	-
Ph.D., Ed.D.	-	-	0	-
Other Prof.	-	-	0	-
Missing Data	1	.4		
TOTAL	244	100.0	22	100.0

TABLE C-20.--Highest Level of Formal Education for Men<sup>a</sup> in Autism and Oakland Group.

	Oakland		Autism	
	N	%	N	%
Less than 8 grades of elementary school	6	2.5	-	-
Completed 8 years of elementary school	8	3.4	-	-
1-3 years of high school	33	13.9	2	9.1
Completed high school (high school diploma)	66	27.9	9	40.9
1-3 years of college	55	23.2	2	9.1
Bachelor's degree	23	9.7	1	4.5
Post Bachelor's course work	18	7.6	1	4.5
Master's degree	18	7.6	3	13.6
Post master's course work	2	.8	1	4.5
Ph.D., Ed.D.	3	1.3	1	4.5
Other professional degree (such as MD, DO, JD, DDS)	3	1.3	2	9.1
Missing data	2	.8	-	-
TOTAL	237	100.0	22	100.0

<sup>a</sup>In the Oakland sample, 19.4 of the men held degrees beyond a Bachelor's. In the Autism fathers, 36.4 held degrees beyond the Bachelor's.

TABLE C-21.--Employment Status of Women in Autism and Oakland Groups.

	Oakland		Autism	
	N	%	N	%
Housewife or Househusband not employed or looking for work	112	46.0	8	36.4
Employed away from home	95	39.0	14	63.6
Unemployed, looking for work, on strike, or on sick leave	24	10.0	-	-
Retired or Disabled	1	4.0	-	-
Student Not Employed	9	4.0	-	-
Missing Data	3	1.0	0	
	<hr/> 244	<hr/> 100.0	<hr/> 22	<hr/> 100.0

TABLE C-22.--Employment Status for Men in Autism and Oakland Groups.

	Oakland		Autism	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
Housewife of Househusband not employed or looking for work	1	4.0	-	-
Employed away from home	218	92.0	20	90.9
Unemployed, looking for work, on strike, or on sick leave	10	4.0	1	4.5
Retired or Disabled	8	3.0	1	4.5
Student Not Employed	-	-	-	-
Missing Data	-	-	-	-
	<u>237</u>	<u>100.0</u>	<u>22</u>	<u>100.0</u>



TABLE C-23.--Types of Occupations Held by Women in Autism and Oakland Groups.

	Oakland		Autism	
	N	%	N	%
Professional, Technical, and Kindred Workers	25	10.2	4	18.1
Managers and Administrators, except Farm	6	2.5	1	4.5
Sales Workers	10	4.1	2	9.1
Clerical and Kindred Workers	25	10.2	1	4.5
Craftsmen and Kindred Workers	1	.4	-	-
Operatives, except trans- port	9	3.7	1	4.5
Transport Equipment Opera- tives	4	1.6	1	4.5
Laborers, Except farm	1	.4	-	-
Service Workers, except Private Household	16	6.6	4	18.1
Private Household Workers	5	2.1	0	-
Not Employed for Pay (e.g., Homemakers, retired, dis- abled)	139	57.0	8	36.4
Missing Data	3	1.2	-	-
TOTAL	244	100.0	22	100.0

TABLE C-24.--Types of Occupations Held by men in Autism and Oakland Groups.

	Oakland		Autism	
	N	%	N	%
Professional, Technical, and Kindred Workers	6	2.5	7	31.8
Managers and Administrators, except Farm	8	3.4	4	18.1
Sales Workers	33	13.9	3	13.6
Clerical and Kindred Workers	66	27.9	-	-
Craftsmen and Kindred Workers	55	23.2	2	9.1
Operatives, except trans- port	23	9.7	2	9.1
Transport Equipment Opera- tives	18	7.6	1	4.5
Laborers, Except farm	18	7.6	1	4.5
Service Workers, except Private Household	2	.8	1	4.5
Private Household Workers	3	1.3	-	-
Not Employed for Pay (e.g., Homemakers, retired, dis- abled)	3	1.3	1	4.5
Missing Data	2	.8	-	-
TOTAL	237	100.0	22	100.0

TABLE C-25.--Total Family Income<sup>a</sup> before Taxes for Autism and Oakland Group.<sup>b</sup>

Income	OAKLAND		AUTISM	
	N	%	N	%
Under \$5,000	5	2.0	-	-
\$ 5,000 - \$ 9,900	19	7.8	1	4.5
\$10,000 - \$14,999	14	5.7	1	4.5
\$15,000 - \$19,999	37	15.2	3	13.6
\$20,000 - \$24,999	49	20.1	4	18.2
\$25,000 - \$29,999	45	18.5	3	13.6
\$30,000 - \$34,999	31	12.7	3	13.6
\$35,000 - \$49,999	32	13.1	3	13.6
Over \$50,000	10	4.1	4	18.2
Missing data	2	.8	-	-
TOTALS	244	100.0	22	100.0

<sup>a</sup>Including wages, property, stocks, interest, welfare, Aid to Families with Dependent Children, Child Support from a previous marriage, and any other money income received by all family members in the household.

<sup>b</sup>The Oakland figures represent income received in 1977, while the Gray figures refer to 1979 income. With the inflation rate, it would appear that the Gray sample represents a slightly lower average income except for the higher percentage in the highest income level.

TABLE D-1.--Cross Tabulations of Women's and Men's Affective Evaluations of Life-As-A-Whole in the Oakland Group<sup>a</sup>

Husbands	Wives						Row Total	
	Terrible	Unhappy	Mostly Dissatisfied	Mixed	Mostly Satisfied	Pleased		Delighted
Terrible	0	0	0	0	1 (.4%)	0	0	1 (.4%)
Unhappy	0	0	0	0	0	1 (.4%)	0	1 (.4%)
Mostly Dissatisfied	0	0	0	1 (.4%)	3 (.13%)	3 (.13%)	1 (.4%)	8 (3.5%)
Mixed	0	0	2 (.8%)	6 (3.5%)	12 (5.3%)	7 (3.1%)	0	27 (1.21%)
Mostly Satisfied	0	0	3 (.13%)	20 (8.8%)	61 (26.75%)	33 (14.5%)	1 (4.0%)	118 (51.8%)
Pleased	0	0	0	7 (3.1%)	20 (8.8%)	29 (12.8%)	6 (2.6%)	62 (27.2%)
Delighted	0	0	0	1 (.4%)	2 (.8%)	5 (2.2%)	3 (13%)	11 (4.8%)
Column Total	0	0	5 (2.2%)	35 (15.4%)	99 (43.4%)	78 (34.27%)	11 (4.8%)	228 (100.0%)

<sup>a</sup>43.4% of Husbands and Wives agree on evaluation of Life-As-A-Whole. 85.5% agree or are only one point discrepant.

TABLE D-2.--Cross Tabulations of Women's and Men's Affective Evaluations of Life-As-A-Whole in the Autism Group<sup>a</sup>

Husbands	Wives							Row Total
	Terrible	Unhappy	Mostly Dissatisfied	Mixed	Mostly Satisfied	Pleased	Delighted	
Terrible	0	0	0	0	0	0	0	0
Unhappy	0	0	0	0	0	0	0	0
Mostly Dissatisfied	0	0	0	0	2 ( 9.5%)	0	0	2 ( 9.5%)
Mixed	0	0	0	0	0	0	0	0
Mostly Satisfied	0	0	0	2 ( 9.5%)	2 ( 9.5%)	4 (19.0%)	0	8 ( 38.1%)
Pleased	0	0	0	0	4 (19.0%)	5 (23.8%)	0	9 ( 42.9%)
Delighted	0	0	0	1 ( 4.5%)	1 ( 4.5%)	0	0	2 ( 9.5%)
Column Total	0	0	0	3 (14.3%)	9 (42.9%)	9 (42.9%)	0	21 (100.0%)

<sup>a</sup>33.3% of Husbands and Wives agree on Evaluation of Life-As-A-Whole. 83.8% agree or are only one category discrepant.

TABLE D-3.--Cross Tabulations of Women's and Men's Evaluations of Family Life in the Oakland Group<sup>a</sup>

Husbands	Wives					Row Total
	Terrible	Unhappy	Mostly Dissatisfied	Mixed	Mostly Satisfied	
Terrible	0	0	0	0	1 (.4%)	1 (.4%)
Unhappy	0	0	0	0	0	2 (.9%)
Mostly Dissatisfied	0	1 (.4%)	1 (.4%)	1 (.4%)	0	3 (1.2%)
Mixed	0	0	1 (.4%)	7 (3.0%)	7 (3.0%)	17 (7.5%)
Mostly Satisfied	0	0	0	17 (7.5%)	23 (10.1%)	60 (26.4%)
Pleased	0	1 (.4%)	0	12 (5.3%)	27 (11.9%)	13 (5.7%)
Delighted	0	0	0	0	21 (9.0%)	16 (6.9%)
Column Total	0	2 (.9%)	2 (.9%)	37 (16.2%)	62 (27.2%)	29 (12.7%)
Total	0	2	2	37	95	227 (100.0%)

<sup>a</sup>43.2% of Husbands and Wives agree on evaluation of Family Life. 90.2% agree or are only one point discrepant.

TABLE D-4. --Cross Tabulations of Women's and Men's Affective Evaluation of Family Life for Autism Group<sup>a</sup>

Husbands	Wives					Row Total
	Terrible	Unhappy	Mostly Dissatisfied	Mixed	Mostly Satisfied	
Terrible	0	0	0	0	0	0
Unhappy	0	0	0	0	0	0
Mostly Dissatisfied	0	0	0	0	1 ( 4.5%)	1 ( 4.5%)
Mixed	0	0	0	0	0	0
Mostly Satisfied	0	0	0	1 ( 4.5%)	2 ( 9.1%)	3 ( 9.1%)
Pleased	0	0	0	2 ( 9.1%)	7 (31.8%)	9 ( 50.0%)
Delighted	0	0	0	0	4 (18.2%)	4 ( 18.2%)
Column Total	0	0	0	3 (13.6%)	4 (18.1%)	7 (100.0%)

<sup>a</sup>40.9% of husbands and wives agree on evaluation of family life. 77.1% agree or are only one point discrepant.

TABLE D-5.--Cross Tabulations of Women's and Men's Evaluations of Marriage in the Oakland Group.<sup>a</sup>

Husbands	Wives							Row Total
	Terrible	Unhappy	Mostly Dissatisfied	Mixed	Mostly Satisfied	Pleased	Delighted	
Terrible	1 (.4%)	0	0	2 (.9%)	1 (.4%)	0	1 (.4%)	5 (2.1%)
Unhappy	0	0	0	0	0	3 (1.3%)	0	3 (1.3%)
Mostly Dissatisfied	0	0	2 (.9%)	1 (.4%)	3 (1.3%)	1 (.4%)	1 (.4%)	8 (3.4%)
Mixed	0	2 (.9%)	3 (1.3%)	2 (.9%)	7 (3.0%)	2 (.9%)	4 (1.7%)	20 (8.5%)
Mostly Satisfied	1 (.4%)	1 (.4%)	0	2 (.9%)	13 (5.5%)	15 (6.4%)	7 (3.0%)	39 (16.6%)
Pleased	1 (.4%)	1 (.4%)	0	1 (.4%)	11 (4.7%)	32 (13.6%)	36 (15.3%)	82 (34.9%)
Delighted	0	0	0	0	7 (3.0%)	21 (8.9%)	50 (21.3%)	78 (33.2%)
Column Total	3 (1.3%)	4 (1.7%)	5 (2.1%)	8 (3.4%)	42 (17.9%)	74 (31.5%)	99 (42.1%)	235 (100.0%)

<sup>a</sup>42.6% of Husbands and Wives agree upon the evaluation of marriage. 80.8% agree or are only one point discrepant.



TABLE D-6.--Cross Tabulations of Women's and Men's Affective Evaluation of Marriage in the Autism Group<sup>a</sup>

Husbands	Wives							Row Total
	Terrible	Unhappy	Mostly Dissatisfied	Mixed	Mostly Satisfied	Pleased	Delighted	
Terrible	0	0	0	0	0	0	0	0
Unhappy	0	0	0	0	0	0	0	0
Mostly Dissatisfied	0	0	0	0	0	0	1 ( 4.5%)	1 ( 4.5%)
Mixed	0	0	1 (4.5%)	0	0	0	1 ( 4.5%)	2 ( 9.1%)
Mostly Satisfied	0	0	0	0	1 ( 4.5%)	2 ( 9.1%)	1 ( 4.5%)	4 ( 18.2%)
Pleased	0	0	0	0	0	4 (18.2%)	3 (13.6%)	7 ( 31.8%)
Delighted	0	0	0	0	2 ( 9.1%)	3 (13.6%)	3 (13.6%)	8 ( 36.4%)
Column Total	0	0	1 (4.5%)	0	3 (13.6%)	9 (40.9%)	9 (40.9%)	22 (100.0%)

<sup>a</sup>36.3% of husbands and wives agree on evaluations of marriage. 67.1% agree or are only one point discrepant.

TABLE D-7.--Cross Tabulations of Women's and Men's Evaluations of Spouse in Oakland Group<sup>a</sup>

Husbands	Wives							Row Total
	Terrible	Unhappy	Mostly Dissatisfied	Mixed	Mostly Satisfied	Pleased	Delighted	
Terrible	0 (.4%)	1 (.4%)	0	0	1 (.4%)	0	0	2 (.9%)
Unhappy	1 (.4%)	0	0	1 (.4%)	1 (.4%)	4 (1.7%)	1 (.4%)	8 (3.4%)
Mostly Dissatisfied	0	0	3 (1.3%)	0	2 (.9%)	2 (.9%)	1 (.4%)	8 (3.4%)
Mixed	0	1 (.4%)	1 (.4%)	7 (3.0%)	7 (3.0%)	4 (1.7%)	5 (2.1%)	25 (10.6%)
Mostly Satisfied	1 (.4%)	1 (.4%)	2 (.9%)	3 (1.3%)	16 (6.8%)	9 (3.8%)	7 (3.0%)	39 (16.6%)
Pleased	0	0	0	2 (.9%)	10 (4.3%)	43 (18.3%)	30 (12.8%)	85 (36.2%)
Delighted	0	1 (.4%)	1 (.4%)	0	7 (3.0%)	21 (8.9%)	38 (16.2%)	68 (28.9%)
Column Total	2 (.5%)	4 (1.7%)	7 (3.0%)	13 (5.5%)	44 (18.7%)	83 (35.3%)	82 (34.9%)	235 (100.0%)

<sup>a</sup>45.6% of husbands and wives agree on their evaluations of each other as spouse. 80.9% agree or are only one point discrepant.

TABLE D-8.--Cross Tabulations of Women's and Men's Affective Evaluation of Spouse in the Autism Group<sup>a</sup>

Husbands	Wives							Row Total
	Terrible	Unhappy	Mostly Dissatisfied	Mixed	Mostly Satisfied	Pleased	Delighted	
Terrible	0	0	0	0	0	0	0	0
Unhappy	0	0	0	0	1 ( 4.5%)	0	0	1 ( 4.5%)
Mostly Dissatisfied	0	0	0	0	0	0	1 ( 4.5%)	1 ( 4.5%)
Mixed	0	0	0	1 ( 4.5%)	0	1 ( 4.5%)	0	2 ( 9.1%)
Mostly Satisfied	0	0	0	0	0	1 ( 4.5%)	2 ( 9.1%)	3 ( 13.6%)
Pleased	0	0	0	0	0	8 (36.4%)	2 ( 9.1%)	10 ( 45.5%)
Delighted	0	0	0	0	1 ( 4.5%)	0	4 (18.2%)	5 ( 22.7%)
Column Total	0	0	0	1 ( 4.5%)	2 ( 9.1%)	10 (45.5%)	9 (40.9%)	22 (100.0%)

<sup>a</sup>59.1% of husbands and wives agree on evaluation of spouse. 72.7% agree or are only one point discrepant.

TABLE D-9.--Cross Tabulations by Women and Men of Evaluations of Children in the Oakland Group<sup>a</sup>

Husbands	Wives					Row Total
	Terrible	Unhappy	Mostly Dissatisfied	Mixed	Mostly Satisfied	
Terrible	0	0	1 (.4%)	0	0	1 (.4%)
Unhappy	0	0	0	1 (.4%)	1 (.4%)	2 (.9%)
Mostly Dissatisfied	0	0	1 (.4%)	0	2 (.9%)	4 (1.7%)
Mixed	0	0	1 (.4%)	3 (1.3%)	7 (3.0%)	19 (8.1%)
Mostly Satisfied	0	1 (.4%)	1 (.4%)	4 (1.7%)	19 (8.1%)	50 (21.3%)
Pleased	0	0	1 (.4%)	5 (2.1%)	43 (18.3%)	83 (35.3%)
Delighted	0	0	0	3 (1.3%)	22 (9.4%)	76 (32.3%)
Column Total	0	1 (.4%)	5 (2.1%)	16 (6.8%)	43 *18.3%	235 (100.0%)

<sup>a</sup>47.2% of husbands and wives agree on evaluations of children. 83.4% agree or are only one point discrepant.

TABLE D-1Q --Cross<sup>a</sup> Tabulations of Women's and Men's Affective Evaluation of Children in the Autism Group<sup>a</sup>

Husbands	Wives					Row Total
	Terrible	Unhappy	Mostly Dissatisfied	Mixed	Mostly Satisfied	
Terrible	0	0	0	0	0	0
Unhappy	0	0	0	0	0	0
Mostly Dissatisfied	0	0	0	0	0	0
Mixed	0	0	0	2 ( 9.1%)	1 ( 4.5%)	5 ( 22.7%)
Mostly Satisfied	0	0	0	0	2 ( 9.1%)	5 ( 22.7%)
Pleased	0	0	0	0	6 (27.3%)	10 ( 45.5%)
Delighted	0	0	0	0	1 ( 4.5%)	2 ( 9.1%)
Column Total	0	0	0	2 ( 9.1%)	3 (13.6%)	22 (100.0%)

<sup>a</sup>50.0% of husbands and wives agree on evaluation of children. 85.3% agree or agree only one point discrepant.

## BIBLIOGRAPHY

## BIBLIOGRAPHY

- Andrews, Frank M. and Withey, Stephen B. "Developing Measures of Perceived Life Quality: Results from Several National Surveys" Social Indicators Research, 1 (1974): 1-26.
- Andrews, Frank M and Withey, Stephen B. Social Indicator of Well-Being. NY: Plenum Press, 1976.
- Azrin, N. H. and Foxx, R. M. "A Rapid Method of Toilet Training the Institutionalized Retarded." Journal of Applied Behavior Analysis 4 (1971): 4, 89-99.
- Bartlett, Donald P.; Gove, Walter; Miller, F. T. and Simpkins, Celeste G. "The Effect of Environmental Impetus on the Mood of the Individual: A Schematic Presentation." Journal of Community Psychology, 3 (1975): 3, 239-245.
- Bemporad, J. R. "Adult Recollections of a Formerly Autistic Child." Journal of Autism and Developmental Disabilities 9 (June 1979) 179-197.
- Bender, L. "Childhood Schizophrenia. Clinical Study of One-Hundred Schizophrenic Children." American Journal of Ortho-Psychiatry 17 (1947): 40-56.
- Bender, L., Gurevitz, S. "Results of Psychotherapy with Young Schizophrenic-Children." American Journal of Orthopsychiatry 25, (1955): 5.
- Bender, L. and Grugett, A. E. "A Study of Certain Epidemiological Problems in a Group of Children with Childhood Schizophrenia." American Journal of Ortho-Psychiatry, 26 (1956): 131-145.
- Bene, E. "A Rorschach Investigation into the Mothers of Autistic Children." British Journal of Medical Psychology, 38, (1958) 226-227.
- Berkowitz, B. P. and Graziano, A. M. "Training Parents as Behavior Therapists: A Review." Behavior Research and Therapy 10, (1972): 297-317.
- Berlin, I. N. and Szurek, S. A. "Psychoses of Childhood, Retrospect and Prospect." In S. A. Szurek and I. N. Berlin (Eds.) Clinical Studies in Childhood Psychoses NY: Brunner/Mazel, 1973, 3-9.

- Bernard, Jack "Cost Benefit Analysis and Mental Retardation Center Funding" Mental Retardation 17, (June 1979) 3: 156-157.
- Bettleheim, B. The Empty Fortress: Infantile Autism and the Birth of the Self. New York: Free Press, 1967.
- Bettleheim, B. A Home for the Heart. NY: Alfred A. Knopf, 1976.
- Blackstock, Edward "Cerebral Assymetry and the Development of Early Infantile Autism." Journal of Autism and Childhood Schizophrenia. 8 (1978) 3: 339-353.
- Blauler, E. (1919 "Das Autistisch-Undisziplinierte Denken under Medizrin und seine Überwindung," Berlin: Springer, 1919.
- Booth, Alan and Welch, Susan. "Spousal Consensus and its Correlates: A Reassessment." Journal of Marriage and the Family, (Feb., 1978) 23-31.
- Boulding, Kenneth E. The Economy of Love and Fear. Belmont, California: Wadsworth Publishing Co., Inc. 1973.
- Brash, B. H. "A Prevalence Investigation of Childhood Psychosis." Paper given at The 16th Scandanavian Congress of Psychiatry 1970.
- Bricker, D. and Casuso, V. "Family Involvement: A Critical Component of Early Intervention" Exceptional Child, 46, (October 1979): 108-116.
- Bronfenbrenner, Urie. The Ecology of Human Development. Cambridge, Mass.; Harvard University Press, 1979.
- Brown, George W. and Rutter, Michael. "The Measurement of Family Activities and Relationships." Human Relations, 19, 241-263, 1966.
- Browning, Robert M. Teaching and Severely Handicapped Child Basic Skills for the Developmentally Disabled. New York: Allyn & Bacon, 1980.
- Browning, Robert Mitchell and Stover, Donald O. Behavior Modification in Child Treatment: An Experimental and Clinical Approach. Chicago: Aldine-Atherton, 1971.
- Burr, W. R. Theory Construction and the Sociology of the Family. New York: John Wiley and Sons, 1973.
- Byassee, J. and Murrell, S. "Interaction Patterns in Families of Autistic, Disturbed and Normal Children." American Journal of Orthopsychiatry, 45, (1975) 473-478.



- Callias, Maria "Educational Aims and Methods." In Michael Rutter and Eric Schopler (Eds.) Autism: A Reappraisal of Concepts and Treatment. New York: Plenum Press, 1978.
- Campbell, Angus; Converse, Phillip and Rodgers, Willard L. The Quality of American Life: Perceptions, Evaluations & Satisfaction. NY: Russell Sage, 1976.
- Cantwell, D. P., Baker, L. and Rutter, M. "Family Factors." In M. Rutter and E. Schopler (Eds.) Autism: A Reappraisal of Concepts and Treatment. NY: Plenum Press, 1978.
- Cantwell, D. P., Baker L. and Rutter, M. "Families of Autistic and Dysphasic Children. II. Mother's Speech to Children." Journal of Autism and Childhood Schizophrenia, 7 (1977) 223-229.
- Cantwell, Dennis P. and Baker, Lorain. "The Language Environment of Autism & Dysphasic Children." Journal of American Academy of Child Psychiatry, 17, (Autumn 1978) 4.
- Cantwell, D. P., Baker, L. and Rutter, M. "Families of Autistic & Dyphasic Children: I. Family Life and Interaction Patterns." Unpublished Paper, 1977.
- Chess, S. "Autism in Children with Congenital Rubella." Journal of Autism and Childhood Schizophrenia 1 (1971), 33-48.
- Cohen, Donald J. "Agreement in Diagnosis" Journal of American Academy of Child Psychiatry 17 (1978) 4, 589-663.
- Cohen, Don J. "The Medical Care of Autistic Children." Pediatrics 51, (Feb. 1973) 2, 278-280.
- Copeland, James. For the Love of Anne. London: Arrow Books, 1973.
- Creak, M. and Ini, S. "Families of Psychotic Children." Journal of Child Psychology and Psychiatry, 1, (1960). 156.
- Creak, M. "Schizophrenia Syndrome in Childhood: Progress Report of a Working Party." Cerebral Palsy Bulletin, 3, (1961) 501-504.
- Culbertson, Frances M. "The Search for Help of Parents of Autistic Children or Beware of Professional 'Groupthink'." Journal of Clinical Child Psychology (Winter 1977); 63-65.
- Delacato, Carl H. The Ultimate Stranger: The Autistic Child. Garden City, N.Y.: Doubleday, 1974.
- DeMyer, Marian K. "Comments on 'Siblings' of Autistic Children" Journal of Autism and Developmental Disabilities. 9 S 1979, 3, 296-298.

- DeMyer, Marian K. Parents and Children in Autism. New York: John Wiley & Sons, 1979.
- DeMyer, M. K. "Research in Infantile Autism: A Strategy and its Results." Biological Psychiatry 10 (1975) (4), 433-452.
- Despert, J. L. "Some Considerations Relating to the Genesis of Autistic Behavior in Children." American Journal of Orthopsychiatry 21, (1951) 335-363.
- DesLauriers, Austin M. and Carlson, C. F. Your Child Is Asleep: Early Infantile Autism. Homewood, Ill.: The Dorsey Press, 1969.
- Donnellan-Walsh, Anne. Teaching Makes a Difference. San Diego: Santa Barbara Dissemination Project, 1976.
- Drotar, Dennis "Parent-child Interaction & Early Infantile Autism." Journal of Pediatric Psychology 2 (1968) 4, 164-177.
- Eisenberg, L. "Fathers of Autistic Children," American Journal of Orthopsychiatry, 112 1957. 607-612.
- Eisenberg, L. and Kanner, L. "Early Infantile Autism 1943-55." American Journal of Orthopsychiatry, 1956, 26, 556-566.
- Eyman, R. Dingman, H. and Sabagh, G. "Association of Characteristics of Retarded Patients and their Families with Speed of Institutionalization." American Journal of Mental Deficiency, 71, (1966) 93-99.
- Farber, B. and Ryckman, D. D. "Effects of Severely Mentally Retarded Children on Family Relatedness." Mental Retardation Abstracts 2 (1965) 1-28.
- Faretna, Gloria "Larretta Bender on Autism: A Review" Child Psychiatry and Human Development 10, (Winter 79) #2 118-128.
- Feetham, Suzanne Lee Bellinger The Relationship of Family Functioning to Infant, Parent and Family Environment Outcomes in the First 18 Months Following the Birth of an Infant with Myelodysphasia Unpublished Ph.D. Dissertation, Michigan State University, 1980.
- Feldman, F. L. and Scherz, F. H. Family Social Welfare Helping Troubled families NY: Atherton, 1974.
- Ferster, C. B. "The Autistic Child." In Readings in Psychology. Del Mar, Cal.: CRM Books, 1979 187-192.
- Ferster, C. B. "Positive Reinforcement & Behavioral Deficits in Autistic Children," Child Development, 32 (1961) 437-454.

- Finn, Jeremy D. A General Model for Multivariate Analysis. New York: Holt, Rinehart and Winston, Inc. 1974.
- Fleming, Juanita W. Care and Management of Exceptional Children. N.Y.: Appleton-Century-Crafts, 1973.
- Foa, V. G. and Foa, E. B. Societal Structures of the Mind. Springfield, Ill.: Charles Thomas, 1974.
- Fotheringham, John B. and Joan Morris. Understanding the Preschool Retarded Child. Toronto: University of Toronto, 1976.
- Fotheringham, J., Skelton, M. and Hoddinott, B. "The Effects on the Family of the Presence of an Mentally Retarded Child" Canadian Psychiatric Association Journal. 17 (1972), 283-290.
- Gabriel, Hugh "Management of Autistic Child Undergoing Open Heart Surgery" Pediatrics, 51, (Feb. 1973) 2, 251-253.
- Gardner, J. "Three Aspects of Childhood Autism: Mother-child Interaction, Autonomic Responsibility, and Cognitive Functioning." Ph.D. Dissertation, University of Leicester, 1977.
- Goldfarb, W. Childhood Schizophrenia, Cambridge, Mass.: Harvard University Press, 1961.
- Goldfarb, W. "The Mutual Impact of Mother and Child in Childhood Schizophrenia." American Journal of Orthopsychiatry 31, (1961) 738-747.
- Gonzales, S., Kolvin, I., Garande, R. F. and Leitch, I. M. "Characteristics of Parents of Handicapped Children. I. Preliminary Findings." Unpublished manuscript, 1977.
- Goode, W. J. "Family Disorganization." In Merton, R. K. and Nisbet, R. A. Contemporary Social Problems. N.Y.: Harcourt & Brace. 1971, 479-552.
- Graziano, Anthony M. Child Without Tomorrow. NY: Pergamon Press, 1974
- Greenfield, Josh. A Child Called Noah. New York: Warner Books, Inc. 1973.
- Haslam, J. Observations on Madness & Melancholy, London: Hayden 1809.
- Hill, Reuben Families Under Stress. NY: Harper & Row, 1949.
- Hobbo, Steven A. and Gaswick, Ruth Ann. "Behavioral Treatment of Self-Stimulation: An Examination of Alternatives to Principal Punishment." Journal of Clinical Child Psychology, Sp. 1977 20-24.

- Holroyd, Jean; Brown, Nancy; Wilker, Lyn; Simmons, James Q. III. "Stress in Families of Institutionalized and Non-Institutionalized Autistic Children." Journal of Community Psychology, 3 (1975), 26-31.
- Holroyd, Jean and McArthur, Daniel. "Mental Retardation and Stress on the Parents. A Contrast Between Down's Syndrome and Childhood Autism." American Journal of Mental Deficiency. 80 (1976) 4, 431-436.
- Howlin, P., Merchant, R., Berger, M., Rutter, M., Hersov, L. and Yule, W. "A Home Based Approach to the Treatment of Autistic Children." Journal of Autism and Childhood Schizophrenia, 3 (1973) 308-336.
- Hutt, C. and Hutt, S. J. "Stereotype, Arousal & Autism." Human Dev. 11, (1976) 277-286.
- Intagliata, James. D; Wilder, Barry S., & Cooley, Frederick B. "Cost Comparison of Institutional & Community Based Alternatives for Mentally Retarded Persons" Mental Retardation 17: (June 1970) #3, 154-156.
- Itard, J. M. G. (1801, 1807b) The Wild Boy of Aveyron, Eng. trans. of two reports by G. & M. Humphrey, 1932, Appleton-Century-Crafts, New York, 1962.
- Jackson, Carrie Baptiste. "Family Life Satisfaction and Job Satisfaction as Predictors of Perceived Well-Being." Unpublished Ph.D. Dissertation, Michigan State University, 1979.
- Kanner, L. "Childhood Psychosis: Initial Studies and New Insights," Washington, D.C. V. H. Winston, 1973.
- Kanner, L. "Early Childhood Autism Revisited," Psychiatry Digest 29, 17. 1968.
- Kanner, Leo. "Parents Attitudes toward Mentally Retarded Children." American Journal of Mental Deficiency. LVII: (1953) 374-383.
- Kanner, L. "Problems of Nosology and Psychodynamics in Early Childhood Autism" American Journal of Ortho-Psychiatry 19. (1949) 416.
- Kanner, L. and Lesser, L. I. "Early Infantile Autism" Pediatric Clinics of North America 5, (1958) 711.
- Katz, Myer. "Agreement on Connotative Meaning in Marriage." Family Process, 4 (March) 1965, 64-74.
- Kerlinger, Fred M. and Pedhazur, Elazer, J. Multiple Regression in Behavioral Research. New York: Holt, Rinehart and Winston, Inc., 1973.

- Kohut, S. A. "The Abnormal Child: His Impact on the Family." Physical Therapy. 46 (1966) (2): 160-167.
- Koegel, Robt. "Generalization of Parent Training Results" Journal of Applied Behavior Analysis 11, (Spring '78) #1, 95-101.
- Koegel, R. and Schreibman, L. "The Role of Stimulus Variables in Teaching Autistic Children." in Lovaas, O. I. and Bucher, B. (eds.) Readings in Behavior Modification with Deviant Children. New York: Basic Books, 1977.
- Kolvin, I., Garside, R. and Kidd, J. "Studies in the Childhood Psychoses. IV. Parental Personality & Attitude & Childhood Psychoses." British Journal of Psychiatry. 118 (1971) 403-406.
- Kysar, J. E. "The Two Camps in Child Psychiatry: A Report from a Psychiatrist-Father of an Autistic & Retarded Child" American Journal of Psychiatry. 125 (1968) 103.
- Lennox, C. "Conceptual Reasoning in Parents of Autistic Children: A Function of Anxiety?" B.Sc. Thesis, University of Toronto. Substudy 73.3, Clark Institute Psychiatric Child & Adolescent Service, 1973.
- Lewis, Jerry M.; Beaners, W. Robert; Gossett, John T.; and Phillips, Virginia Auston. No Single Thread. New York: Brunner/Mazel, 1976.
- Liberman, A. "Economic Impact of Child Development Services on Families of Retarded Children" Mental Retardation 17 (June 1979) 158-9.
- Lichstein, Kenneth "The Ecological Assessment of an Autistic Child" U. Microfilms U. of Tennessee Microfiche CAT. #77-3657.
- Lotter, V. "Epidemiology of Autistic Conditions in Young Children: 2. Some Characteristics of the Parents & Children. Social Psychiatry (1976) 1 (4): 163.
- Lotter, Victor "Epidemiology of Autistic Conditions in Young Children" I. Prevalence." Social Psychiatry 1966. 1 #3, 124-137.
- Love, Harold Parental Attitudes Toward Exceptional Children, Springfield, Ill.: C. C. Thomas, 1970.
- Marcus, Lee., Lansing, Margurite, Andrews, Carol E.; and Schopler, Eric. "Improving the Teaching Effectiveness in Parents of Autistic Children." Journal of Child Psychiatry 17 (1978) #4. 625-639.
- Meyers, D. and Goldfarb, W. "Childhood Schizophrenia: Studies of Perplexity in Mothers of Schizophrenic Children." American Journal of Orthopsychiatry (1961) 31, 551-564.

- Mittler, P. J. (ed.) Aspects of Autism. London: British Psychological Society, 1968.
- Moore, B. L. and Bailey, J. S. "Social Punishment in the Modification of a Preschool Child's "Autistic-like" Behavior with a Mother as therapist." Journal Applied Behavior Analysis 6: (1973) 497-507.
- Netley, C. Lockyer, L. and Greenbaum, G. "Parental Characteristics in Relation to Diagnosis and Neurological Status in Childhood Psychosis." British Journal of Psychiatry 127 (1975) 440-444.
- Ney, P. G., Palvesky, A. E., and Markely, J. "Relative Effectiveness of Operant Conditioning and Play Therapy in Childhood Schizophrenia" American Journal of Autism & Childhood Schizophrenia 1 (1971): 337-349.
- Nie, N. H.; Hull, C. H.; Jenkins, J. G.; Steinbrenner, K.; and Brent, D. H. Statistical Package for the Social Sciences (2nd ed.) NY: McGraw-Hill, 1975.
- Olshansky, S. "Chronic Sorrow. A Response to Having a Mentally Defective Child." Social Case Work, 43 (1962): 190-194.
- Olson, David H., Sprinkle, Douglas H., Russell, Candyce S. "Circumplex Model of Marital and Family Systems: I. Cohesion and Adaptability Dimensions, Family Types, and Clinical Application." Family Process 18 (1979): 3-27.
- Paluszny, Maria J. Autism: A Practical Guide for Parents and Professionals. Syracuse, New York: Syracuse University Press, 1979.
- Park, Clara Clairborne. The Seige. Boston: Little, Brown, & Co., 1967.
- Parsons, T. "An Outline of Social Systems." In T. Parsons, E. Schils, K. D. Naegle, and J. R. Pitts (eds.) Theories of Society New York: The Free Press, 1961, 38-39.
- Pitfield, M. and Oppenheim, A. N. "Child Rearing Attitudes of Mothers of Psychotic Children." Journal of Child Psychology and Psychiatry, 5 (1964): 51.
- Polan, C. G. and Spencer, B. L. "A Check List of Symptoms of Autism of Early Life" West Virginia Medical Journal 55 (1959) 198-204.
- Prick, J. J. G. Infantile Autistic Behavior & Experience Rotterdam, Holland: Universitaire Press, 1971.

- Rank, B. "Adaptation of the Psycho-Analytic Technique for the Treatment of Young Children with Atypical Development," American Journal of Orthopsychiatry 19 (1959): 130.
- Reiss, Ira L. and Miller, Brent C. "Heterosexual Permissiveness: A Theoretical Analysis." In Wesley R. Burr, Rueben Hill, F. Ivan Nye and Ira L. Reiss. Contemporary Theories about the Family. Vol. I. New York: The Free Press, 1979 57-100.
- Rettig, Kathryn Dalbey. "Interpersonal Resource Exchanges as Predictors of Quality of Marriage and Family Life. Ph.D. dissertation, Michigan State University. 1980.
- Reynell, J. Reynell Developmental Language Scales. Slough: N.F.E.R. Publishing, 1969.
- Richer, John "Reacting to Autistic Children: The Danger of Trying Too Hard" British Journal of Psychiatry 127 (Dec. '75): 526-29.
- Richer, J. M. and Nicoll, S. "A Playroom for Autistic Children." British Journal of Mental Subnormality 17 (1971): 132-43.
- Rimland, Bernard Infantile Autism, NY: Appleton-Century-Crafts; '64.
- Rincover, Arnold; Koegel, Robert L., and Russo, Dennis, C. "Some Recent Behavioral Research on the Education of Autistic Children." Education & Treatment of Children 1 (1978): #4.
- Rhodes, Wm. C. and Sweeney, Dwight P. "Alternatives to Litigation: The Necessity for Parent Consultation." In A Final Institute Report: Special Education Services. Mich. Dept. of Education May 1977.
- Rochlin, Gregory Griefs and Discontents. Boston: Little, Brown and Co., 1965.
- Roth, Edna "A Psychodynamic Model of the Mother of the Autistic Child." Smith College Studies in Social Work: 42 (June 1972): 3, 175-202.
- Russell, Robert. An Act of Loving. New York: Vanguard Press, 1967.
- Rutter, M. "Clinical Assessment of Language Disorders in the Young Child" in M. Rutter & J. A. M. Martin (eds.) The Child with Delayed Speech. Clinics in Developmental Medicine No. 43. London: SIMP/Heineman, 1972.

- Rutter, Michael "Developmental Issues and Prognosis." In Michael Rutter and Eric Schopler (Eds.) Autism: A Reappraisal of Concepts and Treatment. New York: Plenum Press, 1978.
- Rutter, M. and Boutak, L. "Special Education Treatment of Autistic Children: A Comparative Study II. Follow-Up Findings & Implications for Services" Journal of Child Psychology & Psychiatry (14) (1973) 241-70.
- Rutter, Michael and Brown, George W. "The Reliability & Validity of Measures of Family Life & Relationships in Families Containing a Psychiatric Patient." Social Psychiatry 1 (1966) 1, 38-53.
- Rutter, M., Bartak, L. and Neuman, S. "Autism--A Central Disorder of Condition and Language?" in Rutter, M and Schopler, Eric (Eds.) Infantile Autism: Concepts, Characteristics and Treatment. London: Churchill, 1971.
- Rutter, M. "Psychotic Disorders in Early Childhood." In A. Coppen and A. Walk (Eds.) Recent Developments in Schizophrenia British Journal of Psychiatry Special Publication. Ashford, Kent: Headley Bros., 1967, 133-158.
- Satir, Virginia, Stachowiak, James and Taschman, Harvey A. Helping Families To Change. N.Y.: Jason Aronson, Inc. 1975.
- Schopler, Eric, Andrews, Carol E. and Strupp, Karen. "Do Autistic Children Come from Upper-Middle-Class Parents?" Journal of Autism & Developmental Disorders. 9 (1979): 2.
- Schopler, Eric, Rutter, Michael, and Chess, Stella. "Editorial: Change of Journal Scope and Focus." Journal of Autism and Developmental Disorders. 9 (March 1979): 1.
- Seligman, Milton "Strategies for Helping Parents of Exceptional Children". NY: The Free Press, 1979.
- "Siblings of Autistic Children." Journal of Autism and Developmental Disorders 9 (S '79) #3 287-98.
- Skelton, M. "Areas of Parental Concern about Retarded Children." Mental Retardation 10 (1972) 38-41.
- Smith, Margaret Joanne "The Development and Study of Competencies Needed by Teachers of Students with Autistic Characteristics." Unpublished Ph.D. dissertation, Michigan State University, 1979.



- Sontag, M. Suzanne, Burbolz, Margaret M., and Slocum, Ann C. Perceived Quality of Life of Oakland County Families. A Preliminary Report. East Lansing, Michigan: Michigan State University Agricultural Experiment Station, 1979.
- Speers, R. W. and Lansing, C. "Group Therapy in Childhood Psychoses." London: Oxford University Press, 1965.
- Spence, M. A. "Genetic Studies" In E. R. Ritvo (Ed.) Autism Disgnosis, Current Research and Management. NY: ~~Halstead/~~Wiley, 1976, 169-174.
- Spence, M. A. "Sex Ratios in Families of Autistic Children." American Journal of Mental Deficiency. 77 (Jan. '73) 405-407.
- Sprey, Jesse "Family Disorganization: Toward a Conceptual Clarification." Journal of Marriage and the Family. 28 (1966) (4) 398-406.
- Stark, Mary H. and Solnit, A. J. "Mourning and the Birth of a Defective Child." Psychoanalytic Study of the Child 16 (1961) 523-537.
- Steinglas, Peter. "The Home Observation Assessment Method (HOAM): Real-Time Naturalistic Observation of Families in Their Homes." Family Process, 18 (1979): 337-351.
- Stott, D. H. Studies of Troublesome Children. London: Tarristock Publications, Ltd., 1966.
- Stuecher, Uve Tommy: A Treatment Study of an Autistic Child. Arlington: VA:, the CEC 1972.
- Sullivan, Ruth Christ. "Siblings of Autistic Children." Journal of Autism and Developmental Disorders. 9 (1979): 287-297.
- Sullivan, Ruth Christ. "The Burn-Out Syndrome." Journal of Autism and Developmental Disorders 9 (1979): 1, 113-127.
- Tanguay, P. E.; Ritvo, E. R.; Forsythe, A. B.; Ornitz, E. M.; de la Pena, A.; and Ghahre-Mani, J. "The Recovery Cycle of the Averaged Auditory Evoked Response during sleep in Autistic Children.: Electroencephalography and Clinical Neurophysiology, 37 (1974) 173-174.
- Tavorimina, J. B.; Ball, N. J.; Dunn, R. L.; Luscomb, B.; and Taylor, J. R. "Psychosocial Effects of Raising a Physically Handicapped child on Parents." Unpublished Manuscript, 1977.

- Tavormina, J. B. and Walker, J. "Evaluation of Respite Care." Unpublished Manuscript. University of Virginia 1976.
- Thurston, J. R. "A Procedure for Evaluating Parental Attitudes Toward the Handicapped." American Journal of Mental Deficiency 59 (1964) 148-155.
- Thurston, John B. "Counseling the Parents of the Severely Handicapped." Exceptional Children 26 (March 1960) 251-354.
- Tinbergen, N. and E. A. "Social Interactions, In Normal and Autistic Children." The Animal in Its World - 40 Years of Exploratory Behavior of an Ethologist. London: Allen & Unwin, 1971.
- Torres, Leticia, Olivas "Age at Birth of the First Child and Indicators of Quality of Life." Unpublished M. A. Thesis, Michigan State University, 1979.
- Treffert, D. A. "Epidemiology of Infantile Autism." Archives General Psychiatry 23 (1970) 431.
- Tustin, F. Autism and Childhood Psychosis. NY: Arson, 1973.
- Ward, A. Childhood Autism & Structural Therapy. Chicago: Nelson Hall, 1976.
- Warren, Frank "A Society that is Going to Kill Your Children." in Turnbull, H. Rutherford III (Ed.) Parents Speak Out. Columbus, Ohio: Chas. E. Merrill Publishing Co., 1978.
- Wing, Lorna. Early Childhood Autism (2nd ed.) New York: Pergamon Press, 1976.
- Wing, L. "The Handicaps of Autistic Children - A Comparative Study." Journal of Child Psychology & Psychiatry 10 (1969), 1-40.
- Wing, Lorna and Wing, J. K. "The Elements of the Syndrome of Childhood Autism." In Mittler, P. J. (ed.) Aspects of Autism. London: British Psychological Society, 1968, 84-89.