



National Library  
of Canada

Acquisitions and  
Bibliographic Services Branch

335 Wellington Street  
Ottawa, Ontario  
K1A 0N4

Bibliothèque nationale  
du Canada

Direction des acquisitions et  
des services bibliographiques

395, rue Wellington  
Ottawa (Ontario)  
K1A 0N4

*Your file    Votre référence*

*Our file    Notre référence*

## NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

## AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

Canada

Severe Developmental Disorders:  
Social Support and Maternal Adaptation

by

Norma Kennedy Wadden

Submitted in partial fulfillment of the requirements for the degree of  
Doctor of Philosophy

at

Dalhousie University  
Halifax, Nova Scotia  
March, 1994

© Copyright by Norma Kennedy Wadden, 1994



National Library  
of Canada

Acquisitions and  
Bibliographic Services Branch

395 Wellington Street  
Ottawa, Ontario  
K1A 0N4

Bibliothèque nationale  
du Canada

Direction des acquisitions et  
des services bibliographiques

395 rue Wellington  
Ottawa (Ontario)  
K1A 0N4

Your file    *Votre référence*

Our file    *Notre référence*

**The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.**

**L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.**

**The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.**

**L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.**

ISBN 0-315-93842-0

**Canada**

Name Norma Fuzette Kennedy Warden

Dissertation Abstracts International is arranged by broad, general subject categories. Please select the one subject which most nearly describes the content of your dissertation. Enter the corresponding four digit code in the spaces provided.

Psychology

SUBJECT TERM

0622

SUBJECT CODE

U·M·I

Subject Categories

Severe Developmental Disorders - Social Support and Internal Adaptation

## THE HUMANITIES AND SOCIAL SCIENCES

### COMMUNICATIONS AND THE ARTS

Architecture 0729  
Art History 0377  
Cinema 0900  
Dance 0378  
Fine Arts 0357  
Information Science 0723  
Journalism 0391  
Library Science 0399  
Mass Communications 0708  
Music 0413  
Speech Communication 0459  
Theater 0465

### EDUCATION

General 0515  
Administration 0514  
Adult and Continuing 0516  
Agricultural 0517  
Art 0273  
Bilingual and Multicultural 0282  
Business 0688  
Community College 0275  
Curriculum and Instruction 0272  
Early Childhood 0518  
Elementary 0524  
Finance 0277  
Guidance and Counseling 0519  
Health 0680  
Higher 0745  
History of 0520  
Home Economics 0278  
Industrial 0521  
Language and Literature 0279  
Mathematics 0280  
Music 0522  
Philosophy of 0798  
Physical 0523

Psychology 0525  
Reading 0535  
Religious 0527  
Sciences 0714  
Secondary 0533  
Social Sciences 0534  
Sociology of 0340  
Special 0529  
Teacher Training 0530  
Technology 0710  
Tests and Measurements 0288  
Vocational 0747

### LANGUAGE, LITERATURE AND LINGUISTICS

Language 0679  
General 0289  
Ancient 0290  
Linguistics 0291  
Modern  
Literature 0401  
General 0294  
Classical 0295  
Comparative 0297  
Medieval 0298  
Modern 0316  
African 0591  
American 0305  
Asian 0352  
Canadian (English) 0355  
Canadian (French) 0593  
English 0311  
Germanic 0312  
Latin American 0315  
Middle Eastern 0313  
Romance 0314  
Slavic and East European

### PHILOSOPHY, RELIGION AND THEOLOGY

Philosophy 0422  
Religion  
General 0318  
Biblical Studies 0321  
Clergy 0319  
History of 0320  
Philosophy of 0322  
Theology 0469

### SOCIAL SCIENCES

American Studies 0323  
Anthropology 0324  
Archaeology 0326  
Cultural 0327  
Physical  
Business Administration  
General 0310  
Accounting 0272  
Banking 0770  
Management 0454  
Marketing 0338  
Canadian Studies 0385  
Economics  
General 0501  
Agricultural 0503  
Commerce Business 0505  
Finance 0508  
History 0509  
Labor 0510  
Theory 0511  
Folklore 0358  
Geography 0366  
Gerontology 0351  
History  
General 0578

Ancient 0579  
Medieval 0581  
Modern 0582  
Black 0328  
African 0331  
Asia, Australia and Oceania 0337  
Canadian 0334  
European 0335  
Latin American 0336  
Middle Eastern 0333  
United States 0337  
History of Science 0585  
Law 0398  
Political Science  
General 0615  
International Law and Relations 0616  
Public Administration 0617  
Recreation 0814  
Social Work 0452  
Sociology  
General 0526  
Criminology and Penology 0627  
Demography 0938  
Ethnic and Racial Studies 0631  
Individual and Family Studies 0628  
Industrial and Labor Relations 0629  
Public and Social Welfare 0630  
Social Structure and Development 0700  
Theory and Methods 0344  
Transportation 0709  
Urban and Regional Planning 0999  
Women's Studies 0453

## THE SCIENCES AND ENGINEERING

### BIOLOGICAL SCIENCES

Agriculture 0473  
General 0285  
Agronomy  
Animal Culture and Nutrition 0475  
Animal Pathology 0476  
Food Science and Technology 0359  
Forestry and Wildlife 0478  
Plant Culture 0479  
Plant Pathology 0480  
Plant Physiology 0817  
Range Management 0777  
Wood Technology 0746

Biology 0306  
General 0287  
Anatomy 0308  
Biostatistics 0309  
Botany 0379  
Cell 0329  
Ecology 0353  
Entomology 0369  
Genetics 0793  
Limnology 0410  
Microbiology 0307  
Molecular 0317  
Neuroscience 0416  
Oceanography 0433  
Physiology 0821  
Radiation 0778  
Veterinary Science 0472  
Zoology  
Biophysics  
General 0786  
Medical 0760

### EARTH SCIENCES

Biogeochemistry 0425  
Geochemistry 0996

Geodesy 0370  
Geology 0372  
Geophysics 0373  
Hydrology 0388  
Mineralogy 0411  
Paleobotany 0345  
Paleoecology 0426  
Paleontology 0418  
Paleozoology 0985  
Palynology 0427  
Physical Geography 0368  
Physical Oceanography 0415

### HEALTH AND ENVIRONMENTAL SCIENCES

Environmental Sciences 0768  
Health Sciences  
General 0346  
Audiology 0300  
Chemotherapy 0992  
Dentistry 0567  
Education 0350  
Hospital Management 0769  
Human Development 0758  
Immunology 0982  
Medicine and Surgery 0564  
Mental Health 0347  
Nursing 0569  
Nutrition 0570  
Obstetrics and Gynecology 0380  
Occupational Health and Therapy 0354  
Ophthalmology 0381  
Pathology 0571  
Pharmacology 0419  
Pharmacy 0572  
Physical Therapy 0382  
Public Health 0573  
Radiology 0574  
Recreation 0575

Speech Pathology 0460  
Toxicology 0383  
Home Economics 0386

### PHYSICAL SCIENCES

Pure Sciences  
Chemistry  
General 0485  
Agricultural 0749  
Analytical 0486  
Biochemistry 0487  
Inorganic 0488  
Nuclear 0738  
Organic 0490  
Pharmaceutical 0491  
Physical 0494  
Polymer 0495  
Radiation 0754  
Mathematics 0405  
Physics  
General 0605  
Acoustics 0986  
Astronomy and Astrophysics 0606  
Atmospheric Science 0608  
Atomic 0748  
Electronics and Electricity 0607  
Elementary Particles and High Energy 0798  
Fluid and Plasma 0759  
Molecular 0609  
Nuclear 0610  
Optics 0752  
Radiation 0756  
Solid State 0611  
Statistics 0463  
Applied Sciences  
Applied Mechanics 0346  
Computer Science 0984

Engineering  
General 0537  
Aerospace 0538  
Agricultural 0539  
Automotive 0540  
Biomedical 0541  
Chemical 0542  
Civil 0543  
Electronics and Electrical 0544  
Heat and Thermodynamics 0348  
Hydraulic 0545  
Industrial 0546  
Marine 0547  
Materials Science 0794  
Mechanical 0548  
Metallurgy 0743  
Mining 0551  
Nuclear 0552  
Packaging 0549  
Petroleum 0765  
Sanitary and Municipal System Science 0790  
Geotechnology 0428  
Operations Research 0796  
Plastics Technology 0795  
Textile Technology 0994

### PSYCHOLOGY

General 0621  
Behavioral 0384  
Clinical 0622  
Developmental 0620  
Experimental 0623  
Industrial 0624  
Personality 0625  
Physiological 0989  
Psychobiology 0349  
Psychometrics 0632  
Social 0451



## Dedication

This thesis is dedicated to my husband, Terry, for his patience, and to my son, Shannon, who helped me keep this process in perspective.

I would also like to dedicate this thesis to my mother, Mary Kennedy, for her faith in me, and to the memory of my father, Norman Kennedy.

## Table of Contents

Table of Contents	v
List of Tables and Figures	vii
Abstract	ix
Acknowledgements	x
Introduction to the Problem	1
The Autistic Syndrome	3
Description of the Disorder	3
Autism as an Inherent Stressor	5
Needs of Autistic Individuals and Their Families	6
Stress	8
Stimulus Model	8
Response Model	9
Transactional Model	10
Moderators	12
Social Support	14
The Buffering Hypothesis of Social Support	14
Structure	17
Quality of Supportive Relationships	18
Function	19
Support and Needs	22
Source of Support	24
Present Research	26
Method	30
Sample Characteristics	30
Response Rates	31
Measures	32
Procedure	34
Data Analyses of the Buffering Model	35
Results	38
Analyses of the Buffering Model	38
Mental Health and Stress	41
Perceptions of Social Support	43
Number of Support Sources and Needs	46
Most Important Needs	50
Discussion	52
Evidence of Buffering Effects	54
Meeting Needs Through Social Support	57
Maternal Group Differences	59
Group Differences in Mental Health	60
Group Differences in Level of Stress	61
Group Differences in Satisfaction With Support	64

Group Differences in How Well Support Meets Needs	65
Group Differences and Stress-Buffering Effects	68
Description of Needs Identified by Mothers	69
Future Research	72
Conclusions	73
Appendices	75
Appendix C: Social Support Interview Protocol	80
Appendix D: Questionnaire on Resources and Stress	109
Appendix E: Mental Health Inventory	119
Appendix F: Background Information	131
Appendix G: Letters of Introduction	133
Appendix H: Telephone Contact	137
Appendix I: Theoretical Variable	140
References	155

## List of Tables and Figures

Table	Page
1. Types of Social Support	21
2. Correlational Coefficients of Measures of Stress and Social Support on Mental Health Scores	38
3. Stepwise Regressions of Measures of Stress, Social Support, and the Theoretical Variable on Mental Health Scores	40
4. Reports of Stress and Mental Health in Mothers of Autistic, Learning-Impaired and Normally Developing Children	42
5. Maternal Evaluations of Satisfaction With Support	44
6. Maternal Evaluations of How Well Support Meets Needs	45
7. Means and Standard Deviations for the Number of Sources of Support by Group	47
8. Number of Needs Reported by Mothers of Autistic, Learning-Impaired and Normally Developing Individuals	49
9. Percentage of Mothers in Each Group Identifying Each of These Needs as One of Five Most Important and Either Met or Unmet	51
A-1. Descriptive Characteristics of Sample	77
B-1. Diagnostic Information for the Autistic and Learning-Impaired Groups	79
J-1. Correlation Coefficients Between Measures of Stress, Social Support, and Mental Health	143
J-2. Stepwise Regressions of Stress and Social Support on Mental Health	144
K-1. Means and Standard Deviations for Evaluations of Satisfaction with Support Type by Group	146
K-2. Means and Standard Deviations for Evaluations of Satisfaction With Support Source by Group	147
K-3. Means and Standard Deviations for Maternal Evaluations of Satisfaction With Support Type by Support Source	148
K-4. Means and Standard Deviations for Evaluations of Satisfaction With Support Type by Group and Support Source	149
L-1. Means and Standard Deviations for Maternal Evaluations of the Extent to Which Support Source Meets Needs	151
L-2. Means and Standard Deviations for Evaluations of the Extent to Which Support Source Meets Needs by Group	152



L-3.	Means and Standard Deviations for Maternal Evaluations of the Extent to Which Support Type Meets Needs by Support Source	153
L-4.	Means and Standard Deviations for Evaluations of the Extent to Which Support Type Meets Needs by Group and Source Support	154
 Figure		
1.	The Buffering Model of Social Support	15

## Abstract

Autism is a severe lifelong disorder characterized by impaired social, communicative, and behavioural development. Mothers caring for individuals with autism have been shown to be more stressed than mothers of children with other developmental disorders. Research has indicated that social support buffers the effects of stress on mental health. However, whether a buffering effect is found appears to depend on how support and stress are conceptualized and measured. Moreover, the extent to which social support benefits health may depend on how well the type of support meets the needs of the stressed individual. The purpose of the present thesis was twofold. First, the relationship between several dimensions of social support and mental health was examined in caregivers faced with a specific chronic stressor. The second objective was to investigate group differences in each of three main areas of interest (i.e., stress, social support, and mental health). Mothers of 25 autistic, 24 learning-impaired, and 25 normally developing children served as participants. All mothers evaluated (a) satisfaction with support, and (b) the extent to which support meets needs, for each of three types of support - instrumental, informational, emotional support - from informal and formal sources. The Questionnaire on Resources and Stress was used as a measure of stress. Mental health was defined in terms of the Mental Health Inventory. Evidence for stress-buffering effects on mental health emerged with the extent to which both emotional and instrumental support meets needs, and perceived satisfaction with emotional support. Group differences indicated that mothers of autistic and learning-impaired children experience poorer mental health than mothers of normally developing children. Mothers of autistic children reported more stress than mothers of learning-impaired children, who were more stressed than the norm. In terms of social support, mothers of autistic children reported that instrumental support was less effective at meeting their and their child's needs than mothers of normally developing children. Evaluations of how well instrumental support meets needs made by mothers of learning-impaired children fell mid-way between those of the previous two groups. Mothers of autistic and learning-impaired children reported that informational support meets their needs less well than the norm. The extent to which emotional support meets needs did not differentiate the three groups of mothers. The present findings extend previous research in the area of stress, social support, and mental health. Specifically, these findings underscore the importance of conceptualizing social support in the context of the needs of stressed individuals. The present data also enhance our understanding of how best to serve families caring for severely impaired individuals, with the needs of individuals given important consideration.

## Acknowledgements

I would like to extend my most sincere thanks and appreciation to the following individuals, all of whom have contributed in their own way to my perception that graduate school can be a rewarding and pleasant experience.

To Dr. Susan Bryson, my mentor, advisor, and friend. I would not have done this any other way.

To Drs. John Barresi and Robert Rodger, each of whom, at various times, acted as my in-house advisor and therapist.

To Dr. Richard Brown for being an efficient comprehensive chair and for including me in his lab when I really needed a home base.

To Isabel Smith for her encouragement and friendship.

To Mary MacConnachie, who rescued me from ASCII files and tedium.

To Kelly Frame for being a great research assistant.

To Bea, Suzanne, Carolyn, and Nancy, who keep things running smoothly on a daily basis.

To the Psychology Department at the Victoria General Hospital, who provided me with a sense of belonging.

To all the mothers, who made this study possible, and an enjoyable and enlightening experience for me.

And finally, to my family, who consistently provide me with instrumental, informational, and emotional support.

## **Introduction to the Problem**

With the move away from institutionalization and toward integration or normalization, more and more handicapped individuals are living within the community and being cared for by their families. Deinstitutionalization has meant that services previously provided within institutions must now be provided through outside professional and community services. However, the move toward normalization has not necessarily resulted in the provision of relevant community services, especially those designed specifically to meet the needs of handicapped individuals (Gallagher, Beckman, & Cross, 1983; Mesibov, 1990). With the onset of adolescence in autistic people, community resources appear particularly inadequate, and parents tend to lose hope (DeMyer & Goldberg, 1983).

Schopler and Mesibov (1984) have suggested that parents of children whose handicap is more obvious (e.g., blindness, cerebral palsy) have less difficulty obtaining social and political support than parents of autistic children. The data indicate that autistic individuals are typically excluded from generic services, or services are discontinued because the staff do not have the expertise to deal with the problems associated with autism (Van Bourgondien & Elgar, 1990). Yet, to realize the goal of normalization, services must be provided within the community (Schopler, Mesibov, Shigley, & Bashford, 1984). Without a more formal social support system (e.g., professionals, community agencies), the task of caring for a severely handicapped individual remains the responsibility of the family. In particular, it is typically mothers who are responsible for caring for handicapped children (Bristol, Gallagher, & Schopler, 1988; Konstantareas & Homatidis, 1989; Holmes & Carr, 1991).

It is well-documented that mothers of autistic children experience considerable stress (Holroyd & McArthur, 1976; Wolf, Noh, Fisman, & Speechley, 1989; also see Morgan, 1988). Over time, mothers who care for an autistic child can become burnt-out, anxious, and depressed (see Marcus, 1984; Morgan, 1988). One variable that has been shown to alleviate the effects of stress on health is social support (for a review see Cohen & Wills, 1985).

Both satisfaction with, and the adequacy of, support have been found to buffer the effects of stress on health (see Cohen & Wills, 1985). In addition, the extent to which support benefits health may depend upon how well the kind of support received meets the needs of the stressed individual (Cohen & Wills, 1985; Cutrona, 1990; Cutrona & Russell, 1990; Trivette, Deal, & Dunst, 1986). In the case of autism, certain needs (e.g., behaviour management, recreational activities for the impaired person) relate directly to the autistic individual. Other needs such as access to alternate caregivers relate more directly to the primary caregiver and/or the family as a whole.

Much of the research on social support has been criticized on the grounds that support tends to be ill-defined and is conceptualized oversimplistically (Coyne & DeLongis, 1986; Thoits, 1982). The use of aggregate support and stress scores makes it impossible to determine what dimensions of support are important to health when an individual is faced with a particular stressor. As well, research has focused primarily on informal sources of support (e.g., family, friends). However, when faced with a chronic stressor, informal support systems may burn-out and support through formal sources may become necessary (Billings & Moos, 1985a; Blythe, 1983).

The present thesis attempted to better understand the relationship between stress, social support, and psychological health. To this end, the role of social support in alleviating the effects of stress in mothers of autistic and other developmentally delayed individuals was systematically investigated. The study focused on maternal satisfaction with several types of support (instrumental, informational, and emotional) provided by both informal and formal sources. As well, of particular interest was maternal perceptions of the extent to which the type of support received meets needs.

### **The Autistic Syndrome**

#### **Description of the Disorder**

Autism is a severe, chronic developmental disorder beginning early in life. The syndrome is characterized by a triad of impairments consisting of (1) abnormal social development, (2) deviant communication, and (3) repetitive, stereotyped, or ritualistic behaviour (Denkla, 1986; Wing, 1981, 1982). The majority of autistic individuals (approximately 75%) are also mentally handicapped (Bryson, Clark, & Smith, 1988; Lotter, 1966; Wing & Gould, 1979). Autism occurs with a prevalence as high as 16 per 10,000, and is four times more common in males (Bryson et al., 1988; Sugiyama & Abe, 1989). In the majority of cases, there is no known aetiology. Prognosis is generally poor, and there is at present no specific treatment or prevention (Lotter, 1974; Wolf & Goldberg, 1986).

People with autism are fundamentally different in how they relate to others. Autistic children rarely initiate or respond to social overtures, and they do not form reciprocal relationships with others (Hobson, 1986; Richer, 1976; Rutter & Schopler, 1987; Wing & Gould, 1979). Their play is

nonimaginative and noninteractive, and they lack peer friendships (Rutter, 1977; Wing, 1981).

Approximately one third of autistic people do not speak (Bryson et al., 1988; Lotter, 1966). When present, language tends to be atonal, repetitive, echolalic, and/or marked by pronominal reversal (Rutter, 1977; Rutter & Schopler, 1987). Non-verbal communication such as gesturing is impaired as well (Boucher & Lewis, 1989; Rutter, 1977; Rutter & Schopler, 1987). Some have argued that the basic communicative deficit in autism is one of pragmatics, or the use of language for social purposes (Baron-Cohen, 1988; Rutter & Schopler, 1987; Tager-Flusberg, 1986).

Finally, autistic individuals engage in repetitive, stereotyped, and ritualistic behaviours. Body movements include finger flicking, rocking, or spinning (Bryson, in press; Rutter, 1977). Some engage in repetitive, self-injurious behaviour (e.g., head banging, biting). Typically, there is a strong attachment to and/or inappropriate use of objects. An insistence on sameness, as manifested by a rigid adherence to specific routines, as well as a preoccupation with colours, numbers, or patterns, may also be present (Rutter, 1977; Rutter & Schopler, 1987).

In summary, autism is a severe, life-long disorder, occurring with a prevalence as high as 16 per 10,000. Autistic individuals are profoundly deficient in how they relate to others, and they engage in repetitive behaviours. Regardless of IQ, all autistic children manifest deviant development in virtually all areas of functioning, which persists into adolescence and adulthood. Indeed, it is the pervasiveness of the deficits (i.e., failure to acquire virtually all adaptive skills) which distinguishes autism most from other developmental disabilities (Jacobson & Ackerman, 1990;



Rodigue, Morgan, & Geffkin, 1991). As the children mature, behaviour problems such as aggression and inappropriate sexual behaviours may become an issue (Bristol, 1979; Gray, 1993). Others become easier to manage and show some improvement, notably in their social awareness, but nonetheless remain severely impaired relative to normal (Mesibov, 1983). In most cases, long-term care and supervision are required (Gray, 1993).

### Autism as an Inherent Stressor

Mothers of autistic children have been found to experience more stress than mothers of children with Down syndrome (Holroyd & McArthur, 1976; Wolf et al., 1989). Sources of stress identified by parents of autistic children include the social and language deficits associated with autism, the cognitive impairment, the ambiguity of the handicap, dependency, and the age of the autistic individual (Bebko, Konstantareas, & Springer, 1987; Bristol, 1979, 1984; Bristol & Schopler, 1983, 1984; Holroyd & McArthur, 1976; Koegel et al., 1992). As well, severe self-abusive behaviour, hyper-irritability, behaviour problems, physical disability, and the difficult personality characteristics found in autism have all been shown to be related to increased parental stress (Bristol, 1979, 1984; Holroyd & McArthur, 1976; Konstantareas & Homatidis, 1989).

The consequences of caring for an individual with severe social, communicative, and behavioural deficits can have profound effects on individual family members and the family as a whole (Bristol, 1984; Bristol et al., 1988; DeMyer & Goldberg, 1983; Morgan, 1988). One area of family life that parents have consistently reported as important, but negatively affected by the symptoms of autism, is family recreation and leisure (Bristol, 1984; DeMyer & Goldberg, 1983; Gray, 1993). While participation in recreational activities has

been found to be related to more familial acceptance of an autistic child, these families are less likely to participate in social and recreational activities than families with normally developing children (Bristol, 1984). As Bristol (1984) points out, it is not clear whether families with autistic children chose to participate in fewer activities, whether they were overwhelmed, with little energy left for recreation, or whether outside activities excluded the child. Other areas of family life that have been adversely affected by the autistic disorder include family finances, interpersonal relationships (sibling, marital, familial, and friendship), and the personal development of individual family members (Bristol, 1984; DeMyer & Goldberg, 1983).

#### Needs of Autistic Individuals and their Families

Certain needs associated with autism have been identified as directly relevant to the autistic individual. These include better behaviour management recommendations, recreational activities for the handicapped individual, good residential treatment centres, speech therapy, and medical and dental care that will accommodate the autistic person (Bristol & Schopler, 1983; DeMyer & Goldberg, 1983; Holroyd & McArthur, 1976; Janicki & Jacobson, 1983; Janicki, Lubin, & Friedman, 1983). In addition, autistic individuals need access to relevant educational opportunities and vocational training (Bristol, 1984; Bristol & Schopler, 1983; DeMyer & Goldberg, 1983; Holroyd & McArthur, 1976; Janicki & Jacobson, 1983). Educational programmes should include physical and sex education, daily/independent living skills, vocational rehabilitation, and summer programmes (Bristol & Schopler, 1983; DeMyer & Goldberg, 1983; Janicki & Jacobson, 1983).

Other needs relate more directly to those caring for someone with autism. One need that is consistently reported as important, but not

addressed, is access to childcare and/or respite care (Bristol & Schopler, 1983, 1984; DeMyer & Goldberg, 1983; Janicki & Jacobson, 1983; Janicki et al., 1983). In the absence of such services family recreation and leisure are extremely difficult (Bristol, 1984; DeMyer & Goldberg, 1983). Parents are faced with either taking the child with them, or staying at home, which may be the less stressful option. For example, irritating or destructive autistic behaviours can make eating in restaurants, shopping, and entertaining friends very unpleasant (DeMyer & Goldberg, 1983; Gray, 1993; Marcus, 1977). Substitute caregivers could provide mothers with a much needed break, and enable families to have some social life. Alternate caregivers might also enable mothers to be employed outside the home, which in turn would enhance family finances. Unfortunately, it seems difficult to find others who are willing and/or capable of caring for an autistic individual (DeMyer & Goldberg, 1983; Van Bourgondien & Elgar, 1990). In addition to childcare and respite, parental needs include access to professional counselling and advice, and acceptance and support from family, friends, and the community (DeMyer & Goldberg, 1983; Gray, 1993).

### Summary

Autism is a lifelong developmental disorder, characterized by severe deficits across virtually all areas of functioning. Clearly, caring for an individual with autism can have a profound impact on family members, especially the mother. Research has shown that mothers are more responsible for the care of handicapped children and adults than fathers (Bristol et al., 1988; Konstantareas & Homatidis, 1988, 1989; Holmes & Carr, 1991; Milgram & Atzil, 1987, 1988). Research has shown also that the number of additional caregiving demands made by a handicapped child is highly

related to maternal stress (Beckman, 1983). Mothers of autistic children experience more stress than mothers of Down syndrome children (Holroyd & McArthur, 1976; Wolf et al., 1989). Over time, the constant care of raising an autistic child can result in maternal fatigue, burn-out, anxiety, and depressive symptomatology (Bristol & Schopler, 1983; DeMyer, 1979; DeMyer & Goldberg, 1983; Marcus, 1984; Morgan, 1988). This may not be surprising since stress is known to have an effect on both physical and mental health (see Hobfoll, 1989; Lazarus & Folkman, 1984; Taylor, 1986).

### Stress

Despite the popularity of the term, our theoretical understanding of stress remains limited (Hobfoll, 1989, Lazarus & Folkman, 1984). Three models of stress - stimulus, response, and transactional - have been particularly important to theory development and research in this area (Hobfoll, 1989; Lazarus & Folkman, 1984).

#### Stimulus Model

The stimulus model of stress highlights the role of the stressor, or the source of the stress reaction. A stimulus is considered to be a stressor when it typically results in a stress reaction (Hobfoll, 1989; Moos & Swindle, 1990). Stressors may be acute and time-limited (e.g., awaiting surgery); ongoing events initiated by major events such as job loss or bereavement; chronic and occurring intermittently (e.g., a regimen of painful treatments); or chronic and ongoing such as chronic illness (Elliott & Eisdorfer, 1982). Life events that are stressful are likely to be more ambiguous, undesirable, uncontrollable (nothing can prevent it or lessen its consequences), and have longer-lasting consequences (Cutrona, 1990; Cutrona & Russell, 1990; Monroe, Imhoff, Wise, & Harris, 1983). This 'normative' view of stressors assumes that some

environmental events are inherently stressful and that stress is not simply in the eye of the beholder.

One of the objections directed against the stimulus model of stress is that the stimulus is only one part of stress and it alone cannot be considered stress (Hobfoll, 1989; Lazarus, 1990; Lazarus & Folkman, 1984; Moos & Swindle, 1990). A second criticism against this model results from the use of life events inventories as a measure of stress (Lazarus, 1990; Pearlin, 1989). Much of the research on this model has been derived from the work on the magnitude of change required to adjust to major life events (Holmes & Rahe, 1967; Masuda & Holmes, 1967). But focusing only on major life events may ignore the circumstances under which the events occur, the consequences of the events, and/or the daily conditions under which people live (Lazarus, 1990; Pearlin, 1989; Moos & Swindle, 1990). An additional problem with the use of a combination of an array of life events is that it limits our understanding of the effects of specific stressors on health.

Finally, the stimulus model has been criticized for ignoring the role of the individual and the meaning of the event (Lazarus, 1990). Lazarus and Folkman (1984) argue that consideration must be given to the meaning people attach to events, which renders stress a relationship between the person and the environment. However, despite the importance of meaning, it bears emphasizing that some events, namely caring for a severely handicapped individual, are considered inherently stressful (e.g., Lazarus & Folkman, 1984).

### Response Model

A second approach, the response model of stress, focuses on the physiological response to a stressor. When faced with a stressor an

individual becomes mobilized for action via the adrenal glands which, in turn, activate the sympathetic nervous system, resulting in increased blood pressure, heart rate, pulse rate, skin conductivity, and respiration (Selye, 1974; Taylor, 1986). The same physiological response is believed to occur regardless of the stressor confronting the individual.

The response approach to stress has been criticized on several grounds. First, limiting stress to the physiological response ignores the psychological response to a stressor (Lazarus & Folkman, 1984; Taylor, 1986). Second, by defining stress in terms of the response, the stressor can only be identified retrospectively (i.e., following the outcome; Hobfoll, 1989; Lazarus & Folkman, 1984). Finally, criticism has been directed against the notion that the response is nonspecific to the stressor (Hobfoll, 1989; Taylor, 1986). It has been shown that the response to a stressor is a function of a number of variables, including personality characteristics (Husani, Neff, Newbrough, & Moore, 1982; Pearlin, Liberman, Menaghan, & Mullen, 1981) and the nature of the stressor (Monroe et al., 1983; see Paterson & Neufeld, 1987).

### Transactional Model

A more recent model of stress is the transactional model, which emphasizes the role of cognitive appraisal and coping. Lazarus and Folkman (1984) have defined psychological stress as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 19). A new or changing event is initially appraised as stressful (primary appraisal), followed by an evaluation of one's ability to cope (secondary appraisal; Lazarus & Folkman, 1984). Lazarus and Folkman (1984) suggest that primary

and secondary appraisal interact with each other in shaping the intensity of the stress reaction.

Among the criticisms launched against the transactional model are definitional problems, with stress defined as both a postappraisal state and a process (Lazarus, 1990; see Moos & Swindle, 1990). On the one hand, Lazarus (1990) argues that stress depends on an appraisal of harm, threat, or challenge, and as such is a postappraisal state. On the other, Lazarus (1990) argues that stress is a process, a continually changing relationship between person and environment" (Lazarus, 1990, p. 4). But, as Hobfoll (1989) points out, when everything is process, there is no basis upon which to make predictions or develop taxonomies.

Equally problematic is that the transactional model places too much emphasis on the individual, and not enough on inherently stressful events (Brown, 1990; Hobfoll, 1989; Moos & Swindle, 1990). Lazarus and Folkman (1984) do acknowledge that such 'extreme' events as caring for the chronically ill "result in stress for nearly everyone" (p. 19). Nevertheless, they argue that stress cannot be defined solely at the level of extreme environmental conditions, which may lead to the acceptance of simplistic models of stress. In their view, consideration must also be given to the more 'garden-variety' stressors, those which are perceived as stressful by some but not others (Lazarus & Folkman, 1984). Alternately, any single model of stress may not be able to account for both major, inherently stressful events and more minor stressors (Quitter, Glueckauf, & Jackson, 1990).

### Summary

Stress has been conceptualized in terms of the stimulus or stressor, the response, a postappraisal state, and/or a process. Attempts to account for both

major stressors and the more 'garden-variety' type in a general model of stress places too much emphasis on the individual, and not enough on the importance of inherently stressful events (Hobfoll, 1989; Moos & Swindle, 1990). The use of life-events inventories, which yield an overall stress score across an array of events, tells us little about specific events which are inherently stressful. Watson (1990) argues that stress research has to highlight environmental conditions, with the focus on specific stressors, rather than on a variety of life events. One such specific stressor would be caring for a severely handicapped individual.

### Moderators

Despite the limitations of life-events inventories, a consistent relationship has been found between stressful life events and health (see Dohrenwend & Dohrenwend, 1981). However, this relationship has typically been small, with correlations around .2 and .3 (see Rabkin & Struening, 1976). This has prompted researchers to look for variables that reduce the effects of stress on health (Dohrenwend, Dohrenwend, Dodson, & Shrout, 1984; McFarlane, Norman, Streiner, & Roy, 1983; Monroe et al., 1983; Thoits, 1982). Moderators which have been shown to have beneficial effects on health include personal resources (e.g., personal competency, mastery), coping, and social support (Billings, Cronkite, & Moos, 1983; Billings & Moos, 1985b; Dean & Ensel, 1982; Holahan & Moos, 1985; Husani et al., 1982; Pearlin et al., 1981; see also Billings & Moos, 1985a, Dohrenwend, 1978; Khrono, 1990; McCubbin & McCubbin, 1987).

While moderators have been shown to be related to health outcome in stressed individuals (e.g., Billings & Moos, 1985b; Husani et al., 1982), the precise nature of that relationship has yet to be understood. It remains



possible that moderators such as coping and social support may be related to each other. For example, coping has been defined as seeking information or support (e.g., Billings & Moos, 1985b; Fondacaro & Moos, 1989). But help-seeking may depend upon the availability of support, or one's past history of obtaining support from a significant other (Gottlieb, 1989). Thus, any health-related model of stress which includes both coping and support as moderators must clearly differentiate the two.

Perhaps before the moderator variables can be understood within an integrated model of stress, the moderators themselves need to be looked at more systematically. Moderators such as coping and social support are multidimensional concepts, yet are often defined and measured globally (e.g., Bristol, 1987; Wolf et al., 1989). A more fine-grained analysis of the variables themselves might tell us more about the mechanisms involved in the relationship between a single moderator and health, especially when faced with a specific stressor.

One moderator that has generated considerable interest regarding its role in maintaining physical and mental health is social support (Billings & Moos, 1985a, 1985b; Cobb, 1976; Dohrenwend et al., 1984; Gottlieb, 1987a; Pearlin, 1989; Thoits, 1982). Social support has been shown to be more strongly related to health outcome than coping (Billings & Moos, 1985b; Holahan & Moos, 1985). Moreover, problems in social systems that impact directly on a person's life may be relatively impervious to an individual's efforts to change them. This does not reflect a person's inability to cope, but rather a failure on the part of the system (Pearlin & Schooler, 1978).

## **Social Support**

Social support refers to the availability and use of support or resources provided to an individual by other individuals, groups, or organizations when dealing with problems (Cohen & Syme, 1985; Lin, Simeone, Ensel, & Kuo, 1979; Pearlin et al., 1981). Social support can be provided through informal or formal sources. Informal sources of support are significant others (family, friends, co-workers, neighbours, or others who are in a similar situation) who do not require the exchange of money or formal organization (Bristol, 1987; Thoits, 1986). Formal sources of support are organized groups or agencies, or those to whom a fee is paid, and include community supports and professional services which offer social, psychological, physical, or financial assistance (Bristol & Schopler, 1983; McCubbin et al., 1980). To date, research on social support has been conducted almost entirely on informal support systems (see Cohen & Wills, 1985, for a review of informal social support), or has failed to differentiate between informal and formal social support (e.g., Fiore, Coppel, Becker, & Cox, 1986; Konstantareas & Homatidis, 1989; Pagel, Erdly, & Becker, 1987).

### **The Buffering Hypothesis of Social Support**

A model that has been proposed to explain the relationship between stress, social support, and health is the buffering hypothesis. According to this model, social support provides a buffer, or protection, against the effects of stress (Alloway & Bebbington, 1987; Cobb, 1976; Cohen & Wills, 1985; Dooley, 1985; Gottlieb, 1987b; Taylor, Falke, Shoptaw, & Lichtman, 1986; Wheaton, 1985). The buffering hypothesis predicts that stress and social support interact such that stressed individuals with more support will experience fewer stress-related symptoms than those with less support.

Support should have little effect on outcome under conditions of low stress (see Figure 1; Cohen & Wills, 1985).

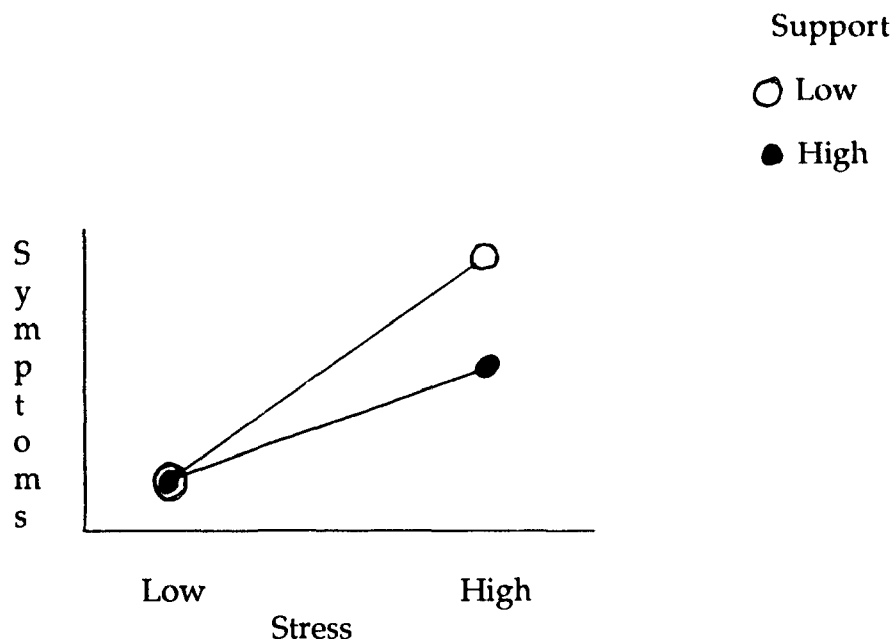


Figure 1. The buffering model of social support.

Some researchers have found support for the buffering hypothesis of informal support systems (e.g., Arling, 1987; Billings & Moos, 1985b; Cummins, 1988; Husani et al., 1982; Krause, 1986, 1987; Monroe et al., 1983; Nelson, 1990), while others have not (e.g., Dean & Ensel, 1982; Turner, 1981; Williams, Ware, & Donald, 1981; see also Cohen & Wills, 1985). Whether the buffering hypothesis is confirmed appears to be a function of how stress and/or social support are measured.

With respect to stress, concerns have been raised about the use of life-events inventories in studies investigating the buffering model of social support (Monroe & Steiner, 1986; Thoits, 1982). Life-events inventories

contain items that involve a gain (e.g., marriage) or loss (e.g., death of a spouse) of a supportive relationship. Moreover, negative life events such as exit events may bias the results in favour of a buffering effect (Monroe & Steiner, 1986; Thoits, 1982). For example, undesirable events, as opposed to neutral or desirable events, tend to be related to psychological distress (Dohrenwend et al., 1984; Vinokur & Selzer, 1975). If low social support scores are a product of undesirable events such as exit events, stressed individuals experiencing undesirable events should have less social support and poorer mental health than individuals whose stress scores reflect desirable events (Thoits, 1982). If high support scores are a product of desirable events, especially those involving a gain of a supportive relationship, stressed individuals experiencing positive events should have more support and less psychological distress. Thus, Thoits (1982) argues that buffering effects may occur as a result of the association between the type of events included in life-events inventories and the evaluation of the level of social support. On the other hand, Cohen and Wills (1985) concluded that a buffering effect was found when measures of support and stress were uncorrelated, but not when they were related.

Whether a buffering effect is found also appears to depend upon how social support is conceptualized, and thus measured (Cohen and Wills, 1985). In general, social support has been conceptualized in two ways. The first involves the structural aspects of social relationships; the second focuses on the nature of the social interactions, including the function that support serves (Bruhn & Philips, 1984; Cohen & Syme, 1985; D'Augelli, 1983; House & Kahn, 1985; McLeroy, DeVillis, DeVillis, Kaplin, & Toole, 1984; Thoits, 1986). Stress-buffering effects appear to be found when functional measures of social

support are used, but not when structural measures are employed (Cohen & Wills, 1985).

### Structure

When social support is conceptualized in terms of structure, the focus is on the more quantitative aspects of support, notably the number of social relationships and the degree of integration of the relationships within a social network (Barnett & Gotlib, 1988; Cohen & Syme, 1985). The term social network is used to denote the composition of structure of the relationship among a group of people or for an individual (Folkman & Lazarus, 1984; McLeroy et al., 1984). The assumption here is that integration in a social network provides an individual with feedback from others, which will influence a person's self-identity and behaviour (Cohen & Syme, 1985). This in turn may lead to reduced stress and better health.

Structural characteristics include (1) size (number of contacts), (2) frequency of contact, (3) dimensionality (number of functions served by a relationship), (4) reciprocity (mutual giving and receiving of support), and (5) density (extent to which network members have contact with each other independent of the support receiver; D'Augelli, 1983; Hall & Wellman, 1985; McLeroy et al., 1984; Mitchell & Trickett, 1980). Differences in structural characteristics such as network size and frequency of contact have been found between various populations and normal control groups, including parents of handicapped children (Kazak, 1987; Kazak & Marvin, 1984; Kazak & Wilcox, 1984).

However, a large social network does not necessarily mean that social support will be provided. Members of larger networks may fail to provide support when there are others who are also available to do so (Shumaker &

Brownell, 1984). As well, focusing solely on structure typically ignores the quality of the support received. The mere presence of social contacts does not ensure that the interactions with those contacts are perceived as supportive (Arling, 1987; Cohen & Syme, 1985). Cohen and Wills (1985) suggest that in those studies where 'structural' measures did show buffering effects, the measures may have been tapping more qualitative aspects of support. It appears to be the latter, not network characteristics, which buffer the effects of stress (Billings & Moos, 1985b; Husani et al., 1982; see also Cohen & Wills, 1985). In any event, assessing structural characteristics does not enhance our understanding of the underlying mechanisms through which social support influences health (Sarason, Sarason, & Pierce, 1990; Wortman & Conway, 1985).

#### Quality of Supportive Relationships

The more qualitative aspect of social support refers to the nature of the supportive interactions. Work in this area has focused on evaluations of the quality of the support received and the function support serves.

Investigations of the quality of social support have included perceptions of the adequacy of, and satisfaction with, social relationships (Bruhn & Philips, 1984; D'Augelli, 1983). Increased satisfaction with social support has been shown to be related to better mental health in mothers of children with Spina Bifida, caregivers of Alzheimers patients, and mothers following childbirth (Barakat & Linney, 1992; Fiore et al., 1986; O'Hara, 1986; Pagel et al., 1987). Moreover, positive perceptions of support satisfaction and support adequacy have been found to buffer the effects of stress on health (Henderson, 1981; Henderson, Byrne, Duncan-Jones, Scott, & Adcock, 1980; Husani et al., 1982; Nelson, 1990; see also Cohen & Wills, 1985; Fry, 1989).

One of the major criticisms directed at the research on social support has been that many studies fail to provide adequate conceptual definitions of support (for a review, see Thoits, 1982; Winemiller, Mitchell, Sutliff, & Cline, 1993). To date, much of this research has assessed global perceptions of support (e.g., Hobfoll & Lerman, 1989; Kissman, 1989; Lin et al., 1979; Pagel et al., 1987), while the multidimensionality of social support systems has been largely overlooked (Coyne & DeLongis, 1986; Cutrona & Russell, 1990; Dunkel-Schetter & Bennett, 1990; Thoits, 1982; Winemiller et al., 1993). Yet, evidence suggests that the beneficial effects of social support on health may depend on the particular function the support serves, how well support meets needs, and who provides the support (Bristol, 1987; Bristol et al., 1988; Cohen & Hoberman, 1983; Cutrona, 1990; Dunkel-Schetter, 1984).

### Function

Three types of social support based on function - emotional, informational, and instrumental - have consistently been described in the literature (Cohen & McKay, 1984; Cohen & Wills, 1985; Heller, Swindle, & Dusenbury, 1986; Krause, 1986, 1987; Sarason et al., 1990; Thoits, 1986; Wills, 1985). Emotional support is the provision of a sense of belonging, and of being cared for, loved, and esteemed (Cohen & McKay, 1984; Cohen & Wills, 1985; House & Kahn, 1985; McLeroy et al., 1984; Thoits, 1986). Emotional support has been judged to be helpful by cancer patients (Dunkel-Schetter, 1984), shown to be related to better parental adaptation (Bristol et al., 1988), and found to buffer the effects of stress on health (Cohen & Hoberman, 1983; Krause, 1987; Husani et al., 1982). Perceptions of less satisfaction with emotional support have also been found to predict depressive symptomatology in caregivers of Alzheimers patients (Fiore et al., 1986).

Emotional support is also referred to as esteem support, expressive support, socioemotional support, close support, and confidant support.

Informational support, also known as appraisal support, is the provision of information such as advice, knowledge, guidance, or personal feedback (Cohen & McKay, 1984; Cohen & Wills, 1985; House & Kahn, 1985; McLeroy et al., 1984; Thoits, 1986; Wills, 1985). Informational support has been evaluated as helpful by cancer patients (Dunkel-Schetter, 1984), and has been shown to buffer the effects of stress on health (Cohen & Hoberman, 1983; Krause, 1986, 1987). Whereas less satisfaction with emotional support predicted depression in caregivers of individuals with Alzheimers, less satisfaction with informational support predicted overall psychological functioning (Fiore et al., 1986). Thus, the relationship between support satisfaction and different aspects of mental health such as depression and overall psychological functioning may be influenced by the type of support (e.g., emotional or informational; Fiore et al., 1986).

Instrumental support is the delivery of material aid or services, such as money, labour, or time (Cohen & Wills, 1985; House & Kahn, 1985; McLeroy et al., 1984; Thoits, 1986). The adequacy of instrumental support has been found to distinguish between mothers experiencing postpartum depression and nondepressed mothers (O'Hara, 1986). Instrumental support has also been shown to buffer the effects of stress (Arling, 1987; Krause, 1986, 1987; Paykel, Emms, Fletcher, & Rassaby, 1980). It is also referred to as material or tangible support.

Others have made further distinctions within these three categories of social support (see Table 1). However, for the most part, they appear to have



been derived from one of the above three types (e.g., separating emotional support into esteem and emotional support).

**Table 1**  
**Types of Social Support**

---

Cobb 1976	Emotional (care, love) Esteem (value, esteem) Belonging to a network of mutual communication and obligation
Cohen & Wills 1985	Informational (aid in defining, understanding, and coping with problems) Instrumental (material goods, services) Social companionship (sharing recreational and social activities)
Cutrona 1990	Emotional (comfort, caring) Informational (advice, guidance) Tangible aid (services, resources) Esteem (increasing competency, self-esteem) Social integration/Network support (sharing common interests, concerns)
D'Augelli 1983	Emotional Access to information and contacts Task-oriented assistance Maintain social identity
Gottlieb 1985	Emotional (care, confidant) Esteem (value, self-confidence) Advice and guidance Tangible (goods, services) Socializing and companionship
House 1981	Emotional (esteem, trust, concern, listening) Informational (advice, information, suggestion) Appraisal (affirmation, feedback, social comparison) Instrumental (goods, services)

**Table (cont'd)**


---

McLeroy et al. 1985	Affective (care, love) Information (information, advice, knowledge) Instrumental (material aid, services) Social identity (maintain positive identity) Social contacts (contacts, social roles)
Mitchell & Trickett 1980	Emotional Access to information and contacts Communication of expectations, evaluation, and sharing a world view Task-oriented assistance
Wills 1985	Esteem (esteem, confidant) Informational (information, advice, guidance) Instrumental (goods, services) Social companionship (share activities) Motivational (encouragement, reassurance) Status (member of formal social relationship)

---

### Support and Needs

Although support is increasingly being conceptualized in terms of its function, to date, social support, like stress, has been examined somewhat simplistically and unsystematically (Cutrona & Russell, 1990; Dunkel-Schetter & Bennett, 1990; Thoits, 1982; Winemiller et al., 1993). Researchers have tended to use aggregate indices of support, as well as overall scores from an array of stressful life events (e.g., Bristol, 1987; Konstantares & Homatidis, 1989; Hobfoll & Lerman, 1989; Nelson, 1990; Sherbourne & Hayes, 1990). As a result, our knowledge about what types of support are most beneficial to health, especially when faced with a specific stressor, is limited (Cutrona & Russell, 1990).

The latter is of particular concern since the extent to which social support benefits health may depend upon how well the type of support meets the needs of the stressed individual (Cohen & McKay, 1984; Cohen & Wills, 1985; Cutrona, 1990; Cutrona & Russell, 1990; Trivette et al., 1986). Needs would be determined by the nature of the stressor. Evidence suggests that health is enhanced when the type of support received matches the needs of the stressed individual (Arling, 1987; Paykel et al., 1980; Wethington & Kessler, 1986; see also Cutrona & Russell, 1990). Some events (e.g., financial strain, transition to parenthood) may require a specific match between the stressor and a single type of support for a better outcome (Cutrona & Russell, 1990). For example, women experiencing postpartum depression have been found to receive less instrumental support (e.g., help with household tasks, childcare) from their spouses than nondepressed women (O'Hara, 1986; Paykel et al., 1980). Other events (e.g., bereavement) appear to need more than one type of support to enhance health. Cohen and Wills (1985) concluded that emotional and informational support may be important for a broad range of stressful events, while instrumental support may be effective in buffering stress only when a more specific match exists between the stressor and support.

The point is that support appears to enhance health when the type of support meets the needs of the stressed individual, with needs being determined by the nature of the stressor. Despite the wide recognition that needs should be considered, there is a paucity of research examining social support in relation to the needs associated with specific stressors. Thus, the question of whether mental health is enhanced when support addresses the needs of a particular stressor has yet to be examined. In the case of autism, it

would appear that several types of support would be required to meet the particular (and multiple) needs of the primary caregiver, the mother.

#### Source of Support

As previously mentioned, most of the existing research on social support has focused on informal social support, or has failed to differentiate between informal and formal support (e.g., Fiore et al., 1986; Konstantareas & Homatidis, 1989; Pagel et al., 1987). For example, Konstantareas and Homatidis (1989) found that parents of autistic children reported more aggravation with support from various sources (e.g., family, friends, workplace, schools, doctors) than parents of normal children. However, separate ratings of support were not given for informal and formal sources, and it is therefore unclear whether one source was more or less aggravating than the other.

The few studies that have distinguished between informal and formal social support indicate that the source of the support merits consideration. For example, while cancer patients rated emotional and instrumental support as equally helpful when received from family, friends, or medical personnel, informational support was helpful from medical staff, but unhelpful from family or friends (Dunkel-Schetter, 1984). Mothers of preterm infants who experienced less stress reported more helpful support from formal sources in the preceding three month period, but not from informal sources (Becrman, Pokorni, Maza, & Balzer-Martin, 1986). On the other hand, support from informal sources, but not formal sources, predicted quality of parenting and marital adjustment for mothers of young developmentally disabled children (Bristol, 1987). However, in Bristol's (1987) study, the mothers were

interviewed at a time when their exposure to formal support services was minimal.

The lack of research on formal social support may reflect the view that social support involves a mutual exchange of resources between individuals (Cobb, 1976; Gottlieb, 1987b; Shumaker & Brownell, 1984). Generally, reciprocity is absent in relationships with professionals. The shortage of research may also reflect the view that, in times of stress, most people turn to their informal, rather than formal, support system first (Bristol & Schopler, 1983; D'Augelli, 1983; Gottlieb, 1985). However, under conditions of chronic stress, individuals may need supports that extend beyond an informal support network. Informal sources of support may not, for example, have the expertise required to deal with a chronic stressor (Gottlieb, 1987a; Hobfoll & Lerman, 1989; Shumaker & Brownell, 1984). Research has shown that the provision of such professional services as information and training to parents of autistic children enhances the child's level of functioning, prevents unnecessary institutionalization, and reduces maternal stress (Marcus, Lansing, Andrews, & Schopler, 1978; see also Bristol & Scholper, 1983).

As well, when coping with a chronic stressor, an informal support system may become burnt-out and break down (Billings & Moos, 1985a; Blythe, 1983; Dunkel-Schetter & Bennett, 1990; Gottlieb, 1985). Informal sources may feel frustrated and helpless, and discontinue supportive behaviors when repeated attempts to help fail (Dunkel-Schetter & Bennett, 1990). Informal sources of support may also have difficulty providing effective support because of their own emotional reactions to the stressor (Dunkel-Schetter & Bennett, 1990; Gottlieb, 1989; Lehman, Ellard, &

Wortman, 1986; Wortman & Lehman, 1985). In any event, when faced with a chronic stressor such as caring for a severely impaired family member, a more formal support system involving professional or institutional sources of support may be necessary to address certain aspects of the stressor.

### Summary

Although a relationship clearly exists between stress, social support, and health (e.g., Billings & Moos, 1985b; Husani et al., 1982), several problems remain. Social support is a multidimensional construct, yet this has largely been ignored in empirical studies (Coyne & DeLongis, 1986; Thoits, 1982). The use of aggregate stress and support scores tells us very little about the nature of the relationship between support, stress, and health. Moreover, the beneficial effects of support on health may depend on how well the type of support received meets the needs of the stressed individual (Cohen & Wills, 1985; Cutrona, 1990; Cutrona & Russell, 1990; Sarason et al., 1990; Trivette et al., 1986). Clearly, it seems important to examine support in terms of the needs associated with specific stressors. As long as social support continues to be conceptualized globally or simplistically, our understanding of the role of support when faced, for example, with the stress of caring for a severely handicapped individual, will be limited. Without a better analysis, how certain variables are, or should be, inter-related remains to be understood.

### **Present Research**

This thesis tested the buffering hypothesis by examining the effects of social support on health in the context of a specific chronic stressor, namely caring for a handicapped older child or adolescent. The purpose of the study was twofold. First, the relationship between several dimensions of social support and psychological health was investigated in mothers faced with a

specific chronic stressor. The present study extended previous research on support by distinguishing between (1) instrumental, informational, and emotional support, and (2) informal and formal sources of support. Most importantly, support was examined in the context of the needs of stressed individuals. The second objective was to provide data relevant to service delivery to handicapped individuals and their families. It is hoped that this research will advance our understanding of how best to serve the families of severely and pervasively impaired individuals by identifying supports which might predict better adjustment in primary caregivers (i.e., mothers).

Mothers of autistic, learning-impaired, and normally developing older children, adolescents, and young adults were interviewed using a semi-structured interview protocol. It has been argued that in-depth interviews be conducted when investigating social support (Coyne & DeLongis, 1986). Since general support measures do not typically contain behaviours relevant to the needs associated with a specific stressor, measures of support should be specific to the stressor (Dunkel-Schetter and Bennett, 1990). In the case of autism, the assessment of support should include supportive behaviours that relate to the needs associated with the autistic syndrome. Indeed, it would seem important to measure support by using an interview protocol that includes an assessment of these needs and how well they are met by different types of social support.

In the present study, mothers first identified the needs related to the care of their son/daughter. They were then asked about the kinds of support, namely instrumental, informational, and emotional, they received from various sources. Mothers (1) rated their satisfaction with each type of support received from both informal and formal sources, and (2) indicated the extent

to which the different types of support from each source meets their needs. Stress, defined in terms of the problems or degree of difficulty associated with caring for a handicapped son/daughter, was assessed using the Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members (QRS; Holroyd, 1974). The Mental Health Inventory (MHI; Davies, Sherbourne, Peterson, & Ware, 1988; Veit & Ware, 1983) measured maternal mental health. Thus, the variables of interest in their study were (1) social support, (2) the stress associated with the care of a handicapped family member, and (3) maternal mental health.

Several hypotheses were investigated. First, it was predicted that social support would buffer the effects of stress associated with caring for a handicapped child. Specifically, stressed individuals who were more satisfied with the support they receive would experience better mental health than those who were less satisfied with support. This prediction was based on previous research which found stress-buffering effects using functional or qualitative measures of social support (e.g., Husani et al., 1982; Krause, 1987; see also Cohen & Wills, 1985). A related prediction was that stressed individuals would experience better mental health when support was perceived as meeting their needs (cf, Cohen & Wills, 1985; Cutrona, 1990; Cutrona & Russell, 1990).

Based on previous research (Holroyd & McArthur, 1976; Wolf et al., 1989), it was further hypothesized that mothers caring for autistic children would experience more stress than mothers caring for learning-impaired or normally developing children. A question of particular interest was whether



perceived support also differentiated the three groups. Finally, the relative importance of the source of support and the type of support received by each group of mothers were explored.

## **Method**

### **Sample Characteristics**

The mothers of 25 autistic children, adolescents, and young adults participated in the study. The autistic group consisted of 22 boys/young men and 3 girls/young women ranging in age from 8.92 years to 25.42 years ( $M = 15.64$ ;  $SD = 3.19$ ; see Table A-1 for a description of the sample). Twenty-three (92%) of the cases were identified in an epidemiological study of autism conducted in Nova Scotia (Bryson et al., 1988). All 25 cases met the DSM III-R criteria for autism (APA, 1987), as well as the more stringent criteria outlined by Denckla (1986) and operationalized by Bryson et al. (1988). Each autistic individual presented with (1) severe social impairments, (2) deviant communication, and (3) repetitive behaviours. In addition to autism, six individuals had seizures and one was diagnosed with Down syndrome (see Table B-1).

The mothers of 17 boys/young men and seven girls/young women with nonautistic, learning impairments served as a control group (see Table B-1). The children ranged in age from 10.58 to 20.67 years ( $M = 15.56$ ;  $SD = 2.63$ ). Twenty-two of the 24 mothers (92%) had participated in the Bryson et al. (1988) study. Participation of the remaining two mothers was solicited through the school system. The learning-impaired group were matched to the autistic group on developmental level (chronological age and nonverbal IQ) and geographic location (see Table A-1 for a description of the sample). The learning-impaired group provided a control for developmental level of the autistic group.

Twenty-five mothers of normally developing children, adolescents, and young adults served as a normal control group. The normal group consisted of 22 boys/young men and 3 girls/young women ranging in age

from 9.67 years to 20.0 years ( $M = 15.66$ ;  $SD = 2.28$ ; see Table A-1). Nineteen of the mothers (76%) had previously participated in the Bryson et al. (1988) study. The remaining six were solicited through acquaintances, but were not known by the primary investigator. The normal control group was matched to the autistic group on chronological age and geographic location, and provided a normal baseline against which to evaluate the variables of interest. The group of mothers of normal children should also add variability to the measures of stress, support, and mental health. Cohen and Wills (1985) recommend that, both from a conceptual and statistical perspective, the buffering model requires a sample with a broad range of stress, support, and symptomatology.

The mothers in all three groups were comparable in maternal age and family income (see Table A-1). All children were living at home. As well, care was taken to assure that there were no other disabled children in each of the families.

### Response Rates

The response rate for 34 mothers of autistic children was 79%. Four individuals (12%) were unable to participate because of time constraints ( $n=2$ ), illness ( $n=1$ ), or the recent death of a spouse ( $n=1$ ). Three children (9%) had recently been admitted to a training centre. Of the remaining 27 who were interviewed, two were later dropped from the study. One woman was unable to read the questionnaires on her own and had difficulty understanding the questions when they were read to her. In the second case, the interview and questionnaires were administered under extremely chaotic conditions, with constant interruptions, thereby questioning the validity of the data.

The response rate for 30 mothers of learning-impaired children was 80%. Five (17%) refused to participate because of time constraints (n=1), illness (n=1), or lack of interest (n=3). The child of one individual (3%) had recently been admitted to a training centre.

The response rate for 31 mothers of normally developing children was 84%. Five (16%) refused to participate (3 because of time constraints; 2 were not interested). The data from one mother was not included in the study because she was caring for a developmentally disabled child, as well as the target adolescent. No other data were rejected in either of the control groups.

### Measures

Support: Using a semi-structured interview format, mothers were asked about their needs and the support they received (see Appendix C). First, mothers were asked to identify individuals (family, friends, professionals, agencies) they and their son/daughter are currently involved with. Next, for each of three types of support (instrumental, informational, emotional), mothers were asked (1) about their needs and those of their son/daughter, (2) to identify who provides them with support, and (3) to describe what each source did. Mothers then rated (1) how satisfied they were with the support they receive, and (2) how well the support they receive meets their needs (see Appendix C). Separate evaluations of each type of support were obtained for informal and formal sources. Finally, where time permitted, mothers were asked to identify their five most important needs, to identify the support required for unmet needs, and why it is important for those particular needs to be met.

Informal sources of support included family, friends, relatives, neighbours, and other parents. Formal sources of support included

professionals, organized groups, community agencies, or others who are paid for their services (but not necessarily directly by their respondent).

Instrumental support was defined as the direct delivery of services or material aid such as money, time, or labour. Informational support was defined as the provision of information, advice, guidance, or feedback from others. Emotional support included having someone who listened, and who made the respondent or her son/daughter feel accepted, cared for, and valued. Support satisfaction and how well support meets needs were assessed using 10-point scales ranging from 0 to 10, with 0 being not at all satisfied/well and 10 being extremely satisfied/well (see Appendix C).

Stress: The Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members (QRS; Holroyd, 1974) is a 285-item true/false questionnaire designed to assess the stress of caring for a handicapped family member (Holroyd, 1987, 1988; see Appendix D). Examples of items include "\_\_\_\_\_ has some unusual habits which draw attention", "Taking \_\_\_\_\_ on a vacation spoils pleasure for the whole family", and "\_\_\_\_\_ can get around the neighbourhood quite easily". Ten items which form a subscale tapping the absence of social support were excluded from all analyses to reduce the possibility of confounding the support and stress (QRS) measures.

The QRS is simple to administer and requires a Grade 6 reading level. Kuder-Richardson reliability coefficient (internal consistency) has been reported to be .96 over all 285 items (Holroyd, 1987). Criterion validity studies of the QRS have shown that the questionnaire discriminates between groups that would be expected to differ in their level of stress (Holroyd, 1987, 1988). The QRS has differentiated between families of handicapped children such as

autistic and Down syndrome (Holroyd & Guthrie, 1986; Holroyd & McArthur, 1976; see also Holroyd, 1987, 1988) and between families with handicapped and normally developing children (Friedrich & Friedrich, 1981; Holroyd & Guthrie, 1986). Although several short forms of the QRS have been shown to be useful for screening purposes, the long form (the 285-item scale) is recommended for research purposes (Holroyd, 1987; Holroyd & Guthrie, 1986).

Psychological Health: The Mental Health Inventory (MHI; Davies et al., 1988; Veit & Ware, 1983) assessed psychological functioning. The MHI is a 38-item self-report measure of mental health, developed for use in a general population (see Appendix E). For each item, the respondent indicates which of several responses comes closest to the way she has been feeling over the past month. For example, to the question "During the past month, how often did you feel that you had nothing to look forward to?", the responses are as follows: Always, Very often, Fairly often, Sometimes, Almost never, Never.

Internal consistency reliability using Cronbach's Alpha coefficient has been reported to be .96 for the MHI (Davies et al., 1988; Veit & Ware, 1983). The MHI appears to be relatively stable over time, with a one-year stability coefficient of .64 (Davies et al., 1988; Veit & Ware, 1983).

Background Variables: Information was sought about the son's/daughter's age, the respondent's age and marital status, the number of children living in the family, and family income (see Appendix F).

### Procedure

Fifty-two of the 74 mothers (70%) were first sent a letter of introduction explaining the purpose of the study (see Appendix G). Direct contact was

then made by telephone, at which time participation was solicited (see Appendix H). For the remaining 30%, initial contact was made directly over the telephone. A 2 1/2 hour appointment was arranged at the respondent's convenience and in a location of her choice, usually in her home.

First, all participants were fully briefed on the purpose of the study and what would be asked of them. They were then asked to sign a consent form (see Appendix C). All participants were interviewed about the needs they and their child had and the support they receive. Following the interview, background information was requested, and the QRS and MHI were administered. Finally, when time permitted, mothers were asked to identify and elaborate on their five most important needs. All interviews were conducted by the primary investigator. All but two interviews were audiotaped; two respondents reported that they would be too distracted by the audiotape.

All information was treated as strictly confidential. No identifying information appeared on any of the research material, which was coded by number. Sources of support were recorded in terms of their relationship to the respondents (e.g., spouse) or in terms of their professional capacity (e.g., teacher). A master list of names is being stored in a locked cabinet in a secure room at Dalhousie University, as are the audiotapes. This information is available only to the investigator, her supervisor, and research assistant unless written permission has been obtained.

#### Data Analyses of the Buffering Model

Several researchers have argued that variables should be designed to capture the particular form of the effect predicted (Finney, Mitchell, Cronkite, & Moos, 1984; Smith & Saski, 1979; Southwood, 1978). To this end, the

buffering effect of support on stress was investigated directly using a theoretical measure of buffered stress. The buffering theory specifically states that the effects of stress on mental health should be attenuated in those with high, as opposed to low, social support. Support should not influence outcome for those who are relatively unstressed.

For the purposes of the present thesis, the following theoretical variable was developed to more precisely capture this predicted relationship:

$$\text{Theoretical Variable} = (QRS - c) (d - \text{support})$$

where  $c$  represents the minimum level of stress experienced by the sample and  $d$  represents the maximum level of support. This theoretical variable considers both the lowest level of stress and the highest level of support reported by this sample. Under conditions of low stress, both high or low support yield a theoretical variable that will be small. Under conditions of high stress and low support, the theoretical variable will be large. Under conditions of high stress and high support, the theoretical variable will be small relative to that when stress is high but support is low (see Appendix I for a further illustration of how this theoretical variable buffers stress).

The measure of buffered stress proposed here does have some arbitrary features. For example, the variances of the QRS and support scores have been left unmodified in the formula. Also a simple product has been used rather than some transformed combination designed to optimize the variable's correlation with mental health. Nevertheless, the theoretical variable does address the buffering of stress simply and directly.

In the present study, several stepwise multiple regression analyses were conducted. Because the number of independent variables is relatively large ( $n=13$ , plus the theoretical variables), the number of regressions were



reduced by collapsing social support across the source of support, but not the type of support. This created six social support measures based on type of support (three satisfaction scores; three scores representing the extent to which each type of support meets needs).

First, Pearson product-moment correlation coefficients were computed to examine the relationship between the measures of stress and support with mental health. Second, stepwise regression analyses were conducted to identify which measures (i.e., stress, social support, and the theoretical variable reflecting the buffering of support on stress) best predict mental health. Regressions which partialled out the effects of background variables (respondents age, child's age, number of children living at home, and income) did not affect the results appreciably. Thus, all analyses reported exclude these background variables. Group differences in mental health, stress, and perceived support were examined using mixed repeated measures ANOVAs.

## Results

### Analyses of the Buffering Model

Correlational Analyses. As shown in Table 2, all variables were significantly related to the MHI. The QRS was negatively correlated with reports of mental health. Measures of support (both satisfaction with support and how well support meets needs) were positively related to scores on the MHI. Thus, high stress is related to poorer mental health, while supportive relationships are associated with better mental health (see Table J-1 for intercorrelations between measures of stress, social support, and mental health).

**Table 2**  
**Correlation Coefficients of Measures of Stress and Social Support on Mental Health Scores**

Variables	R	R <sup>2</sup>
<b>STRESS</b>		
QRS	-.5286***	.2794
<b>SUPPORT SATISFACTION</b>		
INST	.2880*	.0830
INFO	.3339**	.1115
EMO	.4226***	.1786
<b>SUPPORT MEETS NEEDS</b>		
INST	.4893***	.2394
INFO	.4028***	.1622
EMO	.6031***	.3637

Note. N = 74. \*\*\*  $p < .001$ ; \*\*  $p < .01$ ; \*  $p < .05$ . QRS = Questionnaire on Resources and Stress; INST = Instrumental support; INFO = Informational support; EMO = Emotional support.

Stepwise Regression Analyses of Stress, Social Support, and the Theoretical Variables on Mental Health. First, the MHI was regressed on the combined effect of measures of stress and social support (see Table J-2). In brief, the QRS alone was a good predictor of mental health scores. As well, evaluations of the satisfaction with emotional support and the extent to which (1) instrumental and (2) emotional support meets needs added to the predictive value of the QRS.

Another set of stepwise regressions was computed to determine the single best predictors of mental health. In these analyses, the MHI was regressed on measures of stress alone, support alone, and the theoretical variables reflecting the relationship between each type of support and stress.

As shown in Table 3, three of the six theoretical variables were the single best predictors of scores on the MHI. These were the relationship between the QRS and perceptions of (1) satisfaction with emotional support, (2) the extent to which instrumental support meets needs, and (3) the extent to which emotional support meets needs. In the other three regressions, the QRS was the single best predictor of MHI scores.

Several aspects of the data bear emphasizing. First, for the theoretical variables reflecting the relationship between stress and satisfaction with support, evidence for stress-buffering effects on mental health was found only with emotional support. When needs were considered, the theoretical variables for the relationship between stress and the extent to which emotional support meets needs was a particularly strong predictor of mental health scores. In addition, the theoretical variable for the relationship between stress and instrumental support which meets needs also emerged as a significant predictor of scores on the MHI. Finally, there was no evidence

**Table 3**  
**Stepwise Regressions of Measures of Stress, Social Support, and the**  
**Theoretical Variables on Mental Health Scores**

Variables	Beta	F
<b>SATISFACTION WITH SUPPORT</b>		
QRS	-.5286	27.92***
INST	.1245	1.38
TH-INST	-.0839	.35
QRS	-.5286	27.92***
INFO	.1841	3.13
TH-INFO	-.2381	2.94
TH-EMO	-.5514	31.46***
QRS	-.2712	3.73
EMO	-.0246	.02
<b>SUPPORT MEETS NEEDS</b>		
TH-INST	-.5433	30.15***
QRS	-.2464	1.87
INST	.1006	.29
QRS	-.5286	27.92***
INFO	.1658	1.97
TH-INFO	-.2118	1.21
TH-EMO	-.6533	53.61***
QRS	-.1003	.57
EMO	.1485	.67

Note. \*\*\*  $p < .001$ ; QRS = Questionnaire on Resources and Stress; INST = Instrumental support; INFO = Informational support; EMO = Emotional support, TH-INST = Theoretical variable for QRS and INST; TH-INFO = Theoretical variable for QRS and INFO; TH-EMO = Theoretical variable for QRS and EMO.

that the theoretical variable for the relationship between stress and either perceived satisfaction with informational support or the extent to which informational support was perceived to meet needs had a buffering effect.

In summary, the QRS alone was clearly a good predictor of scores on the MHI, with individuals who were more stressed experiencing poorer mental health than those who were less stressed. While the QRS alone predicted MHI scores, whenever social support had an impact, it appeared through buffering, with the theoretical variable alone. Even in the one case where emotional support meets needs alone was more strongly related than the QRS to the MHI ( $R^2 = .36$  versus  $.28$ , respectively; see Table 2), the theoretical variable ( $R^2 = .43$ ) is superior to either variable alone, with no residual. Indeed, the strongest predictor of mental health scores was the theoretical variable for the stress-buffering effect of the extent to which emotional support meets needs. The theoretical variable for the relationship between the QRS and perceptions of how well instrumental support meets needs, but not perceived satisfaction with instrumental support, also predicted MHI scores. Thus, emotional support which is perceived to be more satisfying, instrumental support which meets needs, and, in particular, emotional support which meets needs buffered the effects of stress (as measured by the QRS) on mental health (i.e., MHI scores).

#### Analyses of Group Differences

Oneway ANOVAs were computed on the (1) QRS and (2) MHI, with Group (Autistic, Learning-Impaired, Normal) as the independent variable. Two 3 (Group) X 3 (Support Type) X 2 (Support Source) mixed repeated measures ANOVAs examined group differences in evaluations of (1) satisfaction with support, and (2) how well support meets needs. The within

subjects variables were Support Type (Instrumental, Informational, Emotional) and Support Source (Informal, Formal). Finally, oneway ANOVAs were conducted on (1) the number of sources of support and (2) the number of needs. The Rodger procedure (1974, 1975) was used to evaluate the overall  $F$  and the post-hoc contrasts. Critical  $F$  values were as follows:  $F[.05]; 1, 71 = 4.00$ ;  $F[.05]; 2, 71 = 2.486$ ;  $F[.05]; 2, 142 = 2.437$ ;  $F[.05]; 4, 142 = 1.581$ .

### Mental Health and Stress

There was a significant Group difference in scores on the MHI,  $F(2, 71) = 3.03$  (see Table 4). Mothers of autistic children did not differ from mothers of learning-impaired children in their reports of mental health,  $F(2, 71) = 0.096$ . Taken together, the two groups of mothers reported poorer mental health than mothers of normally developing children,  $F(2, 71) = 2.92$ .

**Table 4**  
**Reports of Stress and Mental Health in Mothers of Autistic, Learning-Impaired and Normally Developing Children**

	n	M	SD	F
<b>MHI</b>				
Autistic	25	173.76	21.61	3.03*
Learning-Impaired	24	176.46	27.19	
Normal	25	187.92	14.17	
<b>QRS</b>				
Autistic	25	68.24	23.92	36.93*
Learning-Impaired	24	50.83	19.08	
Normal	25	24.08	8.52	

Note: \* $> F[.05]; 2, 71 = 2.486$ . QRS = Questionnaire on Resources and Stress; MHI = Mental Health Inventory.

Table 4 also shows a significant Group difference on the QRS,  $F(2, 71) = 36.93$ . As predicted, mothers of the autistic group reported more stress than mothers of the learning-impaired group,  $F(2, 71) = 5.54$ . Mothers of the learning-impaired group reported more stress than mothers of normally developing children,  $F(2, 71) = 13.09$ . Thus, mothers of autistic and learning-impaired children reported poorer mental health than mothers of normally developing children. As well, mothers of autistic children reported experiencing more stress than either control group, while mothers of learning-impaired children were more stressed than the norm.

#### Perceptions of Social Support

Satisfaction with Social Support. The mixed design ANOVA yielded significant main effects of (1) Group,  $F(2, 71) = 4.49$ , (2) Support Type,  $F(2, 142) = 12.81$ , and (3) Support Source,  $F(1, 71) = 13.68$ , on satisfaction with social support (see Table 5). The interactions between Group, Type, and/or Source did not reach significance (see Tables K-1 to K-4).

Post hoc analyses indicated that the mothers of autistic children were less satisfied with the support they received than mothers of learning-impaired children,  $F(2, 71) = 2.98$ , who did not differ from the norm,  $F(2, 71) = 0.03$  (see Table 5). For all mothers, perceived satisfaction with support also depended on the type of support. Mothers were more satisfied with emotional support than with instrumental support,  $F(2, 71) = 5.22$ . There was no difference between how satisfied mothers were with instrumental and informational support,  $F(2, 71) = 1.55$ . Mothers also reported that they were more satisfied with the support they received from informal than from

**Table 5**  
**Maternal Evaluations of Satisfaction with Support**

	<i>n</i>	<i>M</i>	<i>SD</i>	<i>F</i>
<b>Group</b>				
Autistic	25	7.51	1.41	4.49**
Learning-Impaired	24	8.36	1.39	
Normal	25	8.45	.76	
<b>Type of Support</b>				
Instrumental	74	8.03	1.56	12.81***
Informational	74	7.79	1.60	
Emotional	74	8.48	1.16	
<b>Source of Support</b>				
Informal	74	8.42	1.26	13.68*
Formal	74	7.78	1.66	

Note. \* $> F[.05]; 1, 71 = 4.00$ ; \*\* $> F[.05]; 2, 71 = 2.486$ ; \*\*\* $> F[.05]; 2, 142 = 2.437$ .

formal sources (see Table 5).

How Well Support Meets Needs. The mixed ANOVAS conducted on the ratings of support meeting needs yielded a significant main effect of Group,  $F(2, 71) = 6.06$ , and Type,  $F(2, 142) = 37.62$ , as well as a significant Group X Type interaction,  $F(4, 142) = 2.91$ . All other interactions did not reach significance (see Tables L-1 to L-4). Nor was there a main effect of Source,  $F(1, 71) = 2.41$ .

Neither the mothers of autistic children nor the mothers of learning-impaired children differed from the norm on how well emotional support meets their needs,  $F(2, 71) = 1.33$  and .70, respectively (see Table 6). However,



**Table 6**  
**Maternal Evaluations of How Well Support Meets Needs**

	<u>Type of Support</u>					
	Instrumental		Informational		Emotional	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Autistic	5.84	2.11	5.30	1.91	7.56	1.70
Learning-Impaired	6.88	2.28	5.81	3.01	7.77	2.23
Normal	7.84	1.32	7.44	1.38	8.34	0.89
<i>F</i> =	6.64*		6.45*		1.42	

Note. \* $> F[.05]; 2, 71 = 2.486$ .

significant differences emerged between groups on the extent to which instrumental and informational support meets needs. Compared to mothers of normally developing children, mothers of autistic children reported that instrumental support was less effective at meeting their needs,  $F(2, 71) = 6.64$  (see Table 6). Evaluations of how well instrumental support meets needs made by the mothers of learning-impaired children fell mid-way between those of the mothers of the previous two groups,  $F(2, 71) = 0.003$ . In terms of informational support, mothers of autistic and learning-impaired children did not differ in the extent to which informational support was perceived to meet needs,  $F(2, 71) = 0.33$ . Taken together, the two groups combined reported that informational support meets their needs less well than mothers of normally developing children,  $F(2, 71) = 6.09$ .

### Summary of Group Differences

Mothers of autistic children reported more stress than mothers of learning-impaired children, who were more stressed than the norm. Mothers of autistic children did not differ from those of learning-impaired children in their reports of mental health, but together both groups reported poorer mental health than the normal control group. With respect to social support, mothers of the autistic group, but not mothers of the learning-impaired group, reported being less satisfied with support than the normal control group. All mothers reported more satisfaction with emotional, than either instrumental or informational, support. As well, support from informal sources was perceived as more satisfying than that from formal sources. The extent to which emotional support meets needs did not distinguish the three groups of mothers. Compared to mothers of normally developing children, mothers of the autistic group indicated that instrumental support is less effective at meeting their needs. For mothers of learning-impaired children, instrumental support was perceived as less effective at meeting their needs than those of the norm, but more effective than those of the autistic group. Mothers of both impaired groups indicated that informational support, meets their needs less well than the norm.

### Number of Support Sources and Needs

Support Sources. Oneway ANOVAs were conducted to determine whether the groups differed in the number of informal and formal sources of each type of support. The only group differences found were for reports of the total number of (1) informal sources of informational support,  $F(2, 71) = 8.84$ , and (2) formal sources of emotional support,  $F(2, 71) = 2.71$  (see Table 7).

**Table 7**  
**Means and Standard Deviations for the Number of Sources of Support By Group**

	<u>Group</u>			<i>F</i>
	Autistic	Learning-Impaired	Normal	
<b>Instrumental</b>				
Informal	3.88 (1.54)	4.12 (1.54)	4.44 (1.29)	0.93
Formal	5.88 (1.96)	6.25 (2.33)	5.40 (1.61)	1.13
<b>Informational</b>				
Informal	2.92 (1.29)	2.87 (1.62)	4.36 (1.32)	8.84*
Formal	3.36 (1.25)	3.33 (1.97)	3.44 (1.08)	0.03
<b>Emotional</b>				
Informal	5.12 (1.56)	4.54 (1.94)	5.44 (1.32)	2.10
Formal	4.20 (1.55)	3.54 (1.59)	3.28 (1.13)	2.71*

Note. \* $>F[.05]$ ; 2. 71 = 2.486.

Mothers of autistic and learning-impaired children did not differ in the number of informal sources of informational support,  $F(2, 71) = 0.006$ . Taken together, the two groups of mothers reported fewer informal sources of informational support than mothers of normally developing children,  $F(2, 71) = 8.84$ . Mothers of autistic children reported more formal sources of emotional support than the norm,  $F(2, 71) = 2.55$ . On this measure, mothers

of learning-impaired children fell mid-way between mothers of autistic children and the norm,  $F(2, 71) = 0.15$ . No other group differences were found (see Table 7).

Total Number of Needs. As shown in Table 8, the groups differed in the total number of instrumental and informational needs they reported,  $F(2, 71) = 6.62$  and  $6.12$  respectively, but not in the total number of emotional needs,  $F(2, 71) = .05$ . Mothers of autistic and learning-impaired individuals did not differ in the total number of reported instrumental needs,  $F(2, 71) = 0.73$ , although both together reported more instrumental needs than mothers of normally developing children,  $F(2, 71) = 5.84$ . Mothers of autistic children reported more informational needs than mothers of learning-impaired children,  $F(2, 71) = 2.69$ , who did not differ from the norm,  $F(2, 71) = 0.57$  (see Table 8).

Table 8 also shows there were significant group differences in the percentages of unmet instrumental, informational, and emotional needs. Mothers of autistic children reported a higher percentage of unmet instrumental needs than mothers of learning-impaired children,  $F(2, 71) = 3.97$ , who reported more than the norm,  $F(2, 71) = 3.68$ . Mothers of autistic children did not differ from mothers of learning-impaired children in the percentage of unmet informational or emotional needs,  $F(2, 71) = 0.08$  and  $0.04$ , respectively. Both groups together reported a higher percentage of unmet informational and emotional needs,  $F(2, 71) = 8.61$  and  $3.65$ , respectively, than mothers of normally developing children.

**Table 8**  
**Number of Needs Reported by Mothers of Austistic, Learning-Impaired, and Normally Developing Individuals**

	<i>M</i>	<i>SD</i>	<i>F</i>
<hr/>			
<b>Total Number</b>			
<b>Instrumental</b>			
Autistic	14.44	3.54	6.62*
Learning-Impaired	13.25	3.83	
Normal	10.96	2.89	
<b>Informational</b>			
Autistic	6.92	2.63	6.12*
Learning-Impaired	5.33	2.68	
Normal	4.60	1.78	
<b>Emotional</b>			
Autistic	8.36	2.90	.05
Learning-Impaired	8.54	1.56	
Normal	8.36	2.21	
<hr/>			
<b>% Unmet</b>			
<b>Instrumental</b>			
Autistic	53.63	24.31	15.57*
Learning-Impaired	35.81	23.45	
Normal	18.63	18.36	
<b>Informational</b>			
Autistic	74.41	29.76	8.69*
Learning-Impaired	71.03	35.72	
Normal	38.72	34.36	
<b>Emotional</b>			
Autistic	25.21	26.84	4.12*
Learning-Impaired	18.77	28.49	
Normal	5.94	15.14	

Note. \* $> F[.05]; 2, 71 = 2.486$ .

To summarize, with only two exceptions (sources of informal informational support and formal emotional support), the groups of mothers did not differ in the total number of sources of each type of support. However, they did differ in the total number of needs reported. Mothers of autistic and learning-impaired children reported more instrumental needs, but not emotional needs, than mothers of normally developing children. Mothers of autistic children reported more informational needs than mothers of learning-impaired children, who did not differ from the norm. In terms of the percentages of unmet needs, mothers of autistic children reported a higher percentage of unmet instrumental needs than mothers of learning-impaired children, who reported a higher percentage than the norm. Mothers of both impaired groups reported a higher percentage of unmet informational and emotional needs than did mothers of normally developing children.

#### Most Important Needs

Table 9 shows the five most important needs identified by mothers in this study. Unmet instrumental needs identified as important by mothers of autistic children/adolescents included a need for social opportunities, recreational activities, summer programmes, speech therapy, and behaviour management for their child, as well as acceptance of their child by others, and respite care. Mothers of learning-impaired children indicated that information about consultation or referral services, job opportunities for their child, and recreational activities, as well as job-related skill training, were important, but currently unmet, needs. For mothers of normally developing adolescents, information about their child's education and job opportunities for their child were important, but unmet, needs.

**Table 9**  
**Percentage of Mothers in Each Group Identifying Each of These Needs as One of Five Most Important and Either Unmet or Met**

	Autistic (n=23)		Learning-Impaired (n=16)		Normal (n=19)	
	Unmet	Met	Unmet	Met	Unmet	Met
<u>Instrumental Needs</u>						
Academic Skills	4	17	12	38	5	63
Daily Living Skills	9	4	6	6	5	-
Sex Education	9	4	-	6	-	5
Full Day School Programme	-	9	-	12	-	21
Summer Programme	17	4	-	-	-	-
Job-related Skill Training	4	9	19	-	10	10
Fun/Leisure Activities	17	9	19	19	10	16
Social Opportunities (Child)	26	9	12	12	4	32
Transportation for Child	-	-	-	-	-	5
Residential Centre	4	-	-	-	-	-
Respite Care	30	-	12	-	-	-
Other Caregivers	4	-	6	-	-	-
Help with Household Tasks	-	-	-	-	5	5
Financial Aid	13	-	12	-	5	-
Medical Care	-	-	-	25	-	26
Dental Care	4	-	-	-	-	10
Speech Therapy	26	-	12	-	-	-
Behaviour Management	17	-	-	6	10	-
Professional Counselling	13	-	-	-	-	-
<u>Informational Needs</u>						
Educational Skills	9	-	6	-	26	16
Job Opportunities (Child)	9	-	38	-	21	-
Activities (Child)	13	-	25	6	5	10
Social Opportunities (Child)	26	-	12	12	5	10
Sexual Behaviour	-	-	6	6	-	-
Behaviour Management	9	-	-	-	5	-
Communication Problems	-	-	6	-	-	-
Medical Problems	4	-	6	-	-	-
Residential Planning	13	-	19	-	-	-
Consultation Services	9	-	50	-	5	-
<u>Emotional Needs</u>						
Someone to talk to	4	9	-	-	-	10
People who listen/ take concerns seriously	4	4	6	6	-	47
People who are warm/ understanding to child	4	9	-	12	-	31
People concerned (child)	-	9	-	-	5	10
Acceptance of child	22	22	6	12	5	26
Acceptance as parent	-	4	-	-	-	-

## Discussion

The present study examined the relationship between stress, social support, and mental health. This was accomplished through an extensive structured interview of mothers caring for autistic, learning-impaired, and normally developing older children and adolescents. Stress, as measured by the QRS, was defined in terms of the specific problems associated with caring for impaired or handicapped individuals. Social support was defined with reference to three types of support - instrumental, informational, and emotional - from informal and formal sources. Unlike previous work in this area, not only did mothers rate their satisfaction with social support, they also evaluated how well the support they receive meets their and their child's needs. Mental health, as assessed by the MHI, was defined in terms of overall psychological functioning.

One purpose of this thesis was to examine the buffering effects of social support in individuals known to experience high levels of chronic stress. As recommended (e.g, Cohen & Wills, 1985; Cutrona & Russell, 1990), evidence for the buffering model was investigated using a measure of support which tapped the qualitative, as opposed to quantitative, aspects of social support. Support was conceptualized as a multidimensional construct, with the quality of support evaluated in terms of perceived satisfaction with the types of support received from different sources. Moreover, the present study considered the context within which support was received. A specific chronic stressor, as opposed to an array of stressful life events, was identified. Since support may be most effective when it meets needs (Cohen & MacKay, 1984; Cohen & Wills, 1985; Cutrona, 1990; Cutrona & Russell, 1990), the needs associated with that stressor, and the extent to which support was perceived to meet those needs was also considered. Finally, to ensure reasonable



variability on the measures of stress and support, respondents caring for autistic, learning-impaired, and normally developing children were interviewed. Thus, the present model was simple, emphasizing a single stressor and a fine-grained analysis of a single moderator (i.e., social support), as well as the relationship between the two. This is in contrast to other models which include a number of variables, each of which are often multidimensional, but assessed globally, in an integrated framework (e.g. see McCubbin & McCubbin, 1987).

A second, but equally important, purpose of this thesis was to investigate group differences in each of the three main areas of interest (i.e., stress, social support, and mental health). The consensus view is that primary caregivers of autistic individuals, especially those caring for adolescents, are a highly stressed and needy group (Bristol, 1979; Bristol & Schopler, 1983; Holroyd & McArthur, 1976; Morgan, 1988; Wolf et al., 1989). Group differences in caregivers' perceptions of how well the support they receive meets their needs and those of their child was of particular interest. Support which does not meet needs may not be particularly effective in serving families caring for handicapped children. Moreover, evidence suggests that families caring for children with autism receive less support, and may be less well-served by community resources, than those caring for children with less severe and/or better understood disabilities (Schopler & Mesibov, 1984; Van Bourgondien & Elgar, 1990).

Several hypotheses were examined in the present thesis. It was predicted that satisfaction with social support, and support which meets the needs of a specific stressor, would have stress-buffering effects. Stressed individuals who are more satisfied with the support they receive would experience better mental health than those who are less satisfied. As well,

stressed individuals who perceive that support meets their needs would report better mental health than those whose needs are less well met. It was also hypothesized that mothers of autistic children would report more stress than mothers caring for learning-impaired or normally developing children.

### **Evidence of Buffering Effects**

The results of the present study offer support for the claim that social support buffers the effects of stress on mental health. Evidence of buffering emerges on three of the six theoretical variables for the relationship between stress and social support; namely, satisfaction with emotional support, and the extent to which both instrumental and emotional support meets needs. The theoretical variable reflecting the stress-buffering effects of emotional support which meets needs appears to be a particularly strong predictor of mental health, accounting for 43% of the variance in maternal mental health scores. The theoretical variables reflecting the stress-buffering effects of (1) the extent to which instrumental support is perceived to meet needs, and (2) perceived satisfaction with emotional support each account for approximately 30% of the total variance in MHI scores. In each of these cases, the theoretical variable appears to account for more of the variance than either stress alone ( $R^2 = .28$ ) or social support alone (instrumental support meets needs,  $R^2 = .24$ ; satisfaction with emotional support,  $R^2 = .18$ ).

The findings in the present study are consistent with prior research which employed qualitative evaluations and/or functional measures of social support. For example, the quality of supportive relationships, including satisfaction with support, has been found to be important in buffering stress (e.g., Billings & Moos, 1985b; Holohan & Moos, 1985; Henderson, 1981; Nelson, 1990). Emotional support has been shown to alleviate the effects of various stressors (e.g., bereavement, crime and legal stressors, and financial

strain; Krause, 1986, 1987), as well as an array of life events (Cohen & Hoberman, 1983; Cummins, 1988; Henderson et al., 1980; Husani et al., 1982). Instrumental support appears especially beneficial to the health of stressed elderly individuals (Arling, 1987) and women who are stressed following childbirth (Paykel et al., 1980).

The present study extends previous work in this area by focusing on perceived satisfaction with the types of support mothers of autistic, learning-impaired, and normally developing children receive. It is satisfaction with emotional support, but not instrumental or informational support, which is associated with better mental health in these stressed caregivers. Mothers who report more stress and are more satisfied with the emotional support they receive experience better mental health than those who are stressed but less satisfied with emotional support.

The present findings indicate further that it is not simply a matter of being satisfied with support. What appears to be especially important to stress-buffering is whether support is perceived to meet the needs of stressed individuals. Specifically, both instrumental and emotional support which meets needs is associated with better mental health in stressed caregivers. Indeed, emotional support which meets the needs of these mothers appears to be especially important in alleviating the effects of the stress associated with caring for a handicapped child. Clearly, these findings offer support for the claim that social support which meets the needs associated with a particular stressor is especially beneficial to mental health (Cohen & Wills, 1985; Cutrona, 1990; Cutrona & Russell, 1990).

In addition, the present findings are consistent with the suggestion that, for some stressors, more than one type of support is required (Cohen & Wills, 1985; Cutrona & Russell, 1990). Cutrona and her colleagues have

proposed an optimal matching model of support, stress, and mental health. Under this model, the type of support which is beneficial to health is determined by dimensions of the stressor such as controllability and life domain (Cutrona, 1990; Cutrona & Russell, 1990). In a review of the empirical literature, Cutrona and Russell (1990) found support for a specificity model in some instances but not others. Findings that were inconsistent with what was predicted occurred when the stressor affected several life domains, as opposed to a single domain, and broader needs for social support were required for a positive outcome (Cutrona & Russell, 1990). Among other things, Cutrona and Russell (1990) recommended that further research include an assessment of the needs associated with specific stressors. Results from the present thesis suggest that both instrumental and emotional support which meets those needs are especially important to the mental health of stressed mothers.

At first glance, one might have expected informational support which meets needs to have stress-buffering effects. Others have found that informational support buffers the stress related to bereavement, chronic financial strain, and an array of life events (Cohen & Hoberman, 1983; Krause, 1986, 1987). Informational support is thought to enhance problem-solving (Cohen & Wills, 1985; Cutrona & Russell, 1990).

One possible explanation for the lack of stress-buffering effects for informational support may be the age of the children in question. Information, advice, and guidance concerning deficits, as well as diagnostic information, tend to be relevant for caregivers of younger children when attempting to understand the problem (DeMyer & Goldberg, 1983; Gray, 1993; Marcus, 1984). The children in the present sample were adolescents. Their mothers appeared to be well aware of the problems and what is needed to

improve the situation. To alleviate the effects of stress, it may no longer be a matter of simply obtaining information. What appears to be more relevant is direct assistance and emotional support which meets their needs and those of their child.

On the other hand, the present measure, which is an aggregate score of the extent to which informational support meets needs, may not be sensitive to the role of informational support in specific areas (e.g, education). Such finer-grained analysis is beyond the scope and purpose of this thesis.

### Meeting Needs Through Social Support

In his hierarchy of human needs, Maslow identified belongingness and love needs (affiliation, acceptance, and affection) as important basic human needs. Sarason et al. (1990) suggest that the communication of acceptance and love are fundamental ingredients in a supportive relationship. Indeed, many of the mothers in the present study identified the universality of the need to be understood and accepted by others. For their child, they saw acceptance as enhancing self-esteem and self-confidence, and their child's overall well-being. Perhaps, more poignantly, mothers of adolescents with special needs suggested that, through acceptance, others would get to know their child. By getting to know their child, others might become educated about special needs children, be less fearful of their child, and/or be less hurtful in their interactions with their child (e.g., name-calling). As one mother said "Everyone needs people who are warm and understanding, but this is especially important for someone with special needs ... to be accepted for who they are".

Emotional support which meets needs is important to the mental health of mothers experiencing the stress of caring for a handicapped child. Emotional support is assumed to decrease a sense of isolation and loneliness,

and to increase self-esteem (Cohen & Wills, 1985; Fry, 1989; Shumaker & Brownell, 1984). However, certain events such as major, on-going stressors may require more than emotional support or simply enhancing one's self-esteem (Heller et al., 1986; Thoits, 1986). Often, the stressor needs to be confronted and changed. Instrumental support involves changing or managing the stressor directly, which may resolve the problem or give the individual more time to engage in other pleasurable activities (Cohen & Wills, 1985; Fry, 1989; Thoits, 1986).

For the stressed caregivers in the present study, instrumental support which meets needs buffers the effects of stress on mental health. This finding attests to the importance of direct assistance and/or service delivery to the caregivers and their child. In other words, although it is important for others to be emotionally supportive of the caregiver and the adolescent, direct assistance which addresses needs, and consequently improves the situation, also appears critical for change to occur.

Instrumental support which directly addresses the needs of a severely disabled adolescent might reduce the child's level of impairment. In turn, this may make the caregiver's task easier in a variety of ways. For example, mothers in the present study indicate that speech therapy might enhance their child's ability to communicate with others; better behaviour management recommendations might reduce disruptive behaviours within the home and the school; education in daily living skills and job training might alleviate maternal concerns about the child's future and ability to live independently. Assistance from others might also provide the caregiver with extra time to pursue personal and social interests. Instrumental support which meets the needs of the caregiver and the child might enhance the quality of life for both individuals and, most likely, for the family as a whole.

In summary, the results of the present study offer support for the buffering hypothesis. More specifically, the extent to which both emotional and instrumental support meet needs and satisfaction with emotional support appear to be beneficial to mental health when faced with the specific stress of caring for a handicapped adolescent. Emotional support which meets needs seems a particularly strong predictor of a positive outcome in stressed individuals. Neither satisfaction with instrumental or informational support, nor the extent to which informational support meets needs, appear to be especially beneficial to the health of stressed caregivers of adolescent children. Although the measures of satisfaction with support and the extent to which it meets needs are not totally independent (see Table J-1), they do appear to be addressing different issues. This is also evident in the group differences, with perceptions of the extent to which the type of support meets needs, but not perceived satisfaction, differentiating the three groups of mothers.

To understand the relationship between social support, stress, and mental health, functional aspects of social support should be considered. Moreover, social support should be examined in the context of a particular stressor, and the needs associated with that stressor. It may be only then that decisions can be made about what supports are likely to be beneficial to the mental health of individuals faced with specific stressors such as caring for a handicapped child.

### **Maternal Group Differences**

The participants in the present study consisted of mothers who are the primary caregivers of three groups of children (autistic, learning-impaired, and normally developing). The children in each group are primarily male adolescents (mean age in each group is approximately 16). The vast majority

of the mothers have a partner, and report a family income over \$20,000, with 62% reporting an income of \$40,000 or more. The adolescents in the learning-impaired group have a variety of diagnoses, including reading disabilities, Down syndrome, and mental retardation of unknown aetiology. The learning-impaired group were matched to the autistic group on developmental level (chronological and nonverbal mental age). The normally developing group were matched to the autistic group on chronological age.

#### Group Differences in Mental Health

Mothers of autistic children did not differ from mothers of learning-impaired children in their reports of mental health. This finding is comparable to that reported elsewhere. For example, Wolf et al. (1989) found that mothers of autistic and Down syndrome children did not differ in their reports of depressive symptomatology. Nor did mothers of autistic and nonautistic, severely communication-impaired children (Bristol et al., 1988). In the present study, mothers of autistic and learning-impaired children do report poorer mental health than mothers of normally developing children. This finding is also consistent with that of Wolf et al., (1989), who found that the mothers of autistic children reported more depressive symptomatology than the norm.

It is important to note that, in general, mothers of autistic children, as well as those of learning-impaired children, appear to be experiencing good mental health. For example, in the Wolf et al., (1989) study mothers in the autistic group scored at the low end of the mildly depressed range ( $M = 10.3$  on the Beck Depression Inventory). In the present thesis, the mean scores for mothers caring for autistic ( $M = 174$ ;  $SD = 22$ ) and learning-impaired ( $M = 176$ ;  $SD = 27$ ) adolescents are consistent with those found for the normative



population (a community sample) derived from the Rand National Health Insurance Study ( $M = 178$ ;  $SD = 25$ ; Davies et al., 1988; Veit & Ware, 1983; Williams et al., 1981).

At first glance, it would appear that the mothers of normally developing children are experiencing much better mental health ( $M = 188$ ,  $SD = 14$ ) than the normative population. However, their mean score on the MHI was well within one standard deviation of that reported by the normative group. It also bears emphasizing that, compared to a normal control group drawn from the same geographic location, mothers caring for autistic and learning-impaired adolescents reported experiencing poorer mental health.

#### Group Differences in Level of Stress

As was hypothesized, mothers caring for autistic adolescents reported more stress than those in the learning-impaired group, who reported more stress than the mothers of the normal control group. These findings are consistent with previous research in which mothers of autistic children reported more stress than, for example, those of Down syndrome (Holroyd & McArthur, 1976; Wolf et al., 1989) or normally developing children (Konstantareas & Homatidis, 1988).

Autistic individuals manifest deviant development in virtually all areas of functioning. The deficits associated with autism are pervasive, severe, and chronic. The cognitive impairments and the social and language deficits which characterize autism have all been identified as sources of stress by parents (Bebko et al., 1987; Holroyd & McArthur, 1976; Koegel et al., 1992; Konstantareas & Homatidis, 1989). As children get older, aggression may become an issue, which was a concern expressed by several mothers in the current study.

The day-to-day care of an autistic individual is a daunting and stressful task. Research indicates that mothers are more involved than fathers in the care of an autistic child (Bristol et al., 1988; Konstantareas & Homatidis, 1988, 1989; Milgram & Atzil, 1987, 1988). Indeed, all mothers in the present study were identified as the primary caregivers within their households. This is not to suggest that fathers are not stressed, but it is the mothers who are primarily responsible for the daily care of a handicapped individual.

This said, mothers in all three groups in the present study appear to be reporting somewhat less stress than those in other studies which employed the QRS. For example, Bristol (1979) reported a mean QRS score of 94 ( $SD = 22$ ) for an older group of autistic children ( $M$  age = 13). In the present study, the mean total QRS score [including social support items, as in Bristol (1979); Friedrich and Friedrich (1981)] of 72 ( $SD = 24$ ) seems more in line with that of Bristol's younger group (QRS:  $M = 75$ ; age:  $M = 7$ ). Friedrich and Friedrich (1981) reported an average maternal QRS score of approximately 63 ( $SD = 29$ ) for their nonautistic handicapped group and 34 ( $SD = 12$ ) for their normal control group (mean age was approximately 10 years). Mothers of the learning-impaired and normally developing groups in the present study report an average total QRS score of 54 ( $SD = 20$ ) and 26 ( $SD = 9$ ), respectively. Thus, all scores in the current study, not just those for the autistic group, appear somewhat lower than those found in other studies.

One explanation for the somewhat lower levels of stress observed in the present study may be related to the child's developmental stage. Wikler (1986) proposed that there is a relationship between transitions in developmental stage of individuals with mental handicaps and family stress. The claim is that the onset of adolescence (between the ages of 11-15) and the onset of adulthood (between the ages of 22-25) in mentally handicapped

individuals are accompanied by increased familial stress. Wikler (1986) found that mothers of mentally handicapped children in transition reported more stress than mothers of those not in transition. As well, the average QRS score for mothers of nonautistic, mentally handicapped children in middle adolescence (ages 16-19) was approximately 55, which is comparable to the mean of 54 observed in the learning-impaired group in the present study.

One might expect then that mothers of middle adolescents who are not in a transitional stage of development (as in the present study; *M* age = 16) to report somewhat less stress than mothers of children in transition (e.g., Bristol's older group), or approaching adolescence (as in Friedrich and Friedrich's 1981 study). The findings reported here also suggest that the relationship between transitions in developmental stages and family stress may not be limited to families with mentally handicapped individuals. In the present study, mothers of normally developing adolescents not in transition also report a lower level of stress than that reported, for example, by Friedrich and Friedrich (1981) for their normal control group. Further research on stress and transitional stages needs to include families with normally developing children at various stages of development, as well as those caring for handicapped children.

Another possible explanation for the lower QRS scores in the present study compared to those of Bristol (1979) and Friedrich and Friedrich (1981) may be that autism, as well as other learning impairments, are better understood now than in the late seventies and early eighties. For example, the autistic syndrome is no longer attributed to 'refrigerator parents', especially as applied to mothers, as it was in the past. Increased understanding and the dissemination of knowledge may have had some influence on the attitudes of others toward the mothers and their child, as

well as enhancing maternal understanding of their child. In turn, these changes may reduce the overall stress experienced by mothers currently caring for handicapped adolescents, compared to those who did so 10 years ago. Differences in the QRS scores may also be due to geographic location.

This is not to suggest that the mothers of autistic and learning-impaired children are not under considerable stress. The findings in the present study, and those of others indicate otherwise. However, the idea that stress varies with developmental transitions does question the general assumption that older autistic children are more stressful than younger children. When considering the relationship between age of the child and maternal stress, one may need to be mindful of age in terms of transitions in developmental stage (e.g., the onset of adolescence versus middle adolescence), which may be more or less difficult.

#### Group Differences in Satisfaction With Support

Compared to mothers of learning-impaired and normally developing children, mothers of autistic children are less satisfied overall with the support they receive. This finding is consistent with prior research in which mothers of autistic children reported more aggravation with informal and formal community sources than fathers of autistic children, and fathers and mothers of normally developing children (Konstantareas & Homatidis, 1989).

It is important to note that, in the Konstantareas and Homatidis (1989) study, mothers of autistic children reported a minimal degree of aggravation. Likewise, mothers of autistic children in the present study are generally very satisfied with the support they receive. In other words, these mothers are neither aggravated with those they are dealing with, nor are they dissatisfied with what others are doing for them and their child. At least in terms of satisfaction with support, mothers caring for autistic adolescents appear to

have relatively few complaints about the quality of the support they are receiving.

In the present study, the type of support did not interact with source of support. In previous research with cancer patients, instrumental and emotional support were perceived as equally helpful from a variety of formal and informal sources (Dunkel-Schetter, 1984). Information and advice were viewed as helpful from health care professionals, but unhelpful from informal sources (e.g., family and friends). One might have expected that mothers of adolescents would be equally satisfied with emotional support from all sources, but perhaps more satisfied with instrumental and/or informational support from formal sources than informal sources. However, this does not appear to be the case. It may be that mothers caring for impaired adolescents appreciate any support that they and their child receive, regardless of the source of that support.

#### Group Differences in How Well Support Meets Needs

In the present thesis, the extent to which both instrumental and informational (versus emotional) support meets needs varied across the groups of mothers. Instrumental support differentiates mothers of the autistic group from mothers of normally developing children, while mothers of the learning-impaired group fall mid-way between the two. The extent to which informational support meets needs differentiates both impaired groups from the norm. The three groups of mothers do not differ in their reports of how well emotional support meets their needs. Thus, the extent to which social support meets needs depends on the type of support received and whether the adolescent is autistic, learning-impaired, or normally developing.

Mothers of autistic adolescents report that their needs are only moderately well met ( $M = 5.84$  on a 10-point scale) by the instrumental support they receive, whereas mothers of normally developing adolescents indicate that instrumental support is quite effective at meeting needs ( $M = 7.84$ ). That instrumental support is less effective at meeting the needs of the autistic group does not appear to be due to fewer sources of support. With only two exceptions, there are no group differences in the total number of informal and formal sources of each type of support. That the groups did not differ is consistent with a prior finding that parents of autistic and normally developing children did not differ in the number of sources of support (Konstantareas & Homatidis, 1989).

A more likely explanation is that mothers of autistic children have more instrumental needs, especially more unmet instrumental needs. In fact, in the present study, mothers of autistic children report more instrumental needs than mothers of normally developing children ( $M = 14.44$  and  $10.96$ , respectively). Moreover, they report a higher percentage of unmet instrumental needs than either control group. Whereas 19% and 36% of the total number of instrumental needs are unmet for mothers of normally developing and learning-impaired children, respectively, 54% are unmet for mothers of autistic children.

Mothers of learning-impaired children evaluated instrumental support as somewhat more effective at meeting needs ( $M = 6.88$ ) than mothers of the autistic group, but not as effective as the normal control group. These mothers also report a higher percentage of unmet instrumental needs than the normal control group, but a smaller percentage than mothers of autistic adolescents.

Mothers of autistic and learning-impaired children perceive that the informational support they receive meets their needs less well than mothers of normally developing children. Indeed, both impaired groups report that informational support is only moderately effective at meeting their needs. One possibility is that informational support is less effective because mothers in the impaired groups have a smaller informal support network for this type of support. One of the two group differences in the number of support sources is for informal informational support. Both mothers of autistic and learning-impaired children report receiving informational support from fewer informal sources than do mothers of normally developing children.

Another possible explanation, at least for mothers of autistic adolescents, is that they have a greater number of informational needs than mothers of normally developing children ( $M = 6.92$  and  $4.6$ , respectively, and  $5.33$  for the learning-impaired group). In addition, over 70% of the informational needs of mothers of both impaired groups are currently not being met by the informational support they receive. On average, mothers of normally developing children report that only 39% of these needs are not met by the informational support they receive.

With respect to emotional support, neither of the two impaired groups differ from the norm in the extent to which emotional support meets needs. In fact, all mothers indicate that emotional support is very effective at meeting their and their child's needs (the mean rating for each group is 7 or more). Although all three groups of mothers indicate an equal total number of emotional needs, mothers of autistic and learning-impaired children do report a higher percentage of unmet emotional needs than mothers of normally developing children. However, this percentage is fairly small ( $M =$

25% for the autistic and 19% for the learning-impaired groups, respectively), indicating that most needs are currently being met by emotional support.

The second group difference in total number of sources of support was found for formal emotional support. Mothers of autistic children report more formal sources of emotional support ( $M = 4.2$ ) than mothers of normally developing children ( $M = 3.28$ ). Mothers of learning-impaired children appear to have more sources ( $M = 3.54$ ) than the norm, but fewer than the autistic group. It could be that emotional support is effective at meeting the needs of mothers of autistic children because they have more formal sources of this type of support.

In summary, the present findings suggest that the mothers of autistic children are not dissatisfied with the manner in which family, friends, professionals, and other community organizations interact with, and support them, or their child. All groups report an equal number of emotional needs and that, at least in terms of emotional support, what others are doing is relatively effective at meeting these needs. With respect to understanding group differences in the extent to which instrumental and informational support meets needs, an important consideration appears to be the number of needs, especially unmet needs, not the number of sources of support, identified by each group of caregivers. However, one may need to be mindful that more sources of support may be required to meet the additional needs of handicapped individuals and their caregivers.

#### Group Differences and Stress-Buffering Effects

Emotional support is as effective at meeting the needs of mothers of autistic and learning-impaired adolescents as mothers of normally developing children. This finding is especially important since the extent to which emotional support meets needs is found to be beneficial to mental



health in stressed individuals. Mothers of autistic children report more stress than mothers of learning-impaired children, who report more stress than the normal control group. It may be that, in spite of the stress they are under, mothers of autistic and learning-impaired children are experiencing relatively good mental health because emotional support is perceived to meet their own and their child's needs. As well, their relative satisfaction with support may also provide some degree of buffering against the stress of caring for a severely handicapped child.

This is not to suggest that mothers of autistic and learning-impaired children could not be experiencing better mental health. In fact, however, relative to mothers of normally developing adolescents, these mothers report poorer mental health. The latter also report that the instrumental support they receive meets their needs less well than the norm. Since the extent to which instrumental support meets needs appears to have stress-buffering effects, perhaps, if instrumental support was more effective at meeting the needs of these mothers, they would not differ from the normal control group in their reports of mental health.

Mothers of both impaired groups report that informational support is less effective at meeting their needs than mothers of normally developing children. However, it appears that informational support has little stress-buffering effect on mental health, at least in mothers caring for handicapped individuals.

#### Description of Needs Identified by Mothers

Emotional support may be important to the mental health of stressed individuals, but in cases such as autism, mothers appear to need more than an emotionally supportive environment. More direct tangible assistance which addresses deficits may also be required so individuals with autism can

achieve some level of independent functioning, and they and their caregivers can experience enhanced quality of life.

Mothers of autistic children indicate the importance of support which directly addresses the communicative, social, and behavioural deficits found in autism. Speech therapy, social opportunities, fun and leisure activities, and behaviour management for their child are all identified as important, but relatively unmet needs for this group. Mothers suggest that, for some adolescents, speech therapy might correct articulation or tone problems. For others, it might enhance their ability to communicate their needs and wants. As well, mothers indicate that if their adolescent could communicate more effectively, others might understand them better as a person and be less inclined to avoid them. Social opportunities and fun and recreational activities would give autistic individuals a chance to be with others in a social context, as well as providing them with something to do. An appreciable number (30%) of mothers caring for autistic individuals also identify respite care as an important need, but one which is unmet. Respite, which responsibly cares for their child, was viewed as an opportunity for mothers to be with their significant other and go away for weekends and holidays. In addition, mothers indicate that respite would benefit their child by giving them an opportunity to be with people other than their mothers or family members.

The needs identified as important in the present study are consistent with those reported by others. For example, access to respite care, speech therapy, psychological services, and recreational activities, as well as community acceptance of the child, have all been identified as important, but mostly unmet, needs for autistic adolescents and adults, and their families (DeMyer & Goldberg, 1983; Janicki & Jacobson, 1983; Janicki et al., 1983;

Norbeck, Chafetz, Skodol-Wilson, & Weiss, 1991; Van Bourgondien & Elgar, 1990). Thus, the present findings do not appear to be specific to the geographic area of this study. What these caregivers are indicating as important and needed are similar to what others in different regions have also identified. It seems likely that the delivery of services needs to be prioritized in terms of people's needs. It may be that (a) services are currently unavailable, or (b) what is available must be re-evaluated because it does not appear to be meeting needs.

Needs of a more social and recreational nature are also important to mothers of learning-impaired and normally developing children. Unlike the autistic group, this need tends to be met for many of the mothers in the two control groups. The latter two groups also tend to emphasize the importance of needs of an educational nature more so than mothers in the autistic group. Although 26% of the normal control group report a need for information about their child's education, for the most part, educational needs are being met for all three groups of mothers. Information about job opportunities for their child is an important, but unmet, need for mothers of learning-impaired and normally developing children. Approximately 25% of the mothers in the two control groups, but none of the mothers of autistic children, consider medical care an important need, which is currently being met.

Half of the mothers of learning-impaired adolescents identified a need for consultation services as important, but unmet. Mothers of normally developing children report the need for others who (1) listen and take their concerns seriously, and (2) are warm, understanding, and accepting of their child, as both important and currently being met.

### **Future Research**

The findings of the present study offer several suggestions for the development of future research. One important consideration, as highlighted by this study, is the methodology employed to investigate the stress-buffering effects of social support. The continued conceptualization of stress and support in the absence of considering either the specificity of the stressor or the multidimensional nature of support will in all likelihood add little beyond what is already known about buffering effects. In fact, one might argue that it will only serve to further muddy already muddy waters. Thus, it will be important to continue to employ more specific measures of stress and social support.

Researchers will also need to go a step further. The results of this study suggest that support is important to caregivers to the extent that it is perceived to meet their own needs, as well as their child's needs. It will therefore be important for future studies to consider the needs associated with the stressor in question, and examine support in the context of those needs. It may only be then that results can be obtained which may enhance our understanding of what is especially beneficial to individuals under stress.

Several researchers have suggested that some attempted supportive behaviours may have a negative impact on the recipient (e.g., Fiore et al., 1986; Lehman et al., 1986; Pagel et al., 1987; Rook, 1990). The present thesis was designed to assess supportive relationships. Participants were asked to identify and describe what others did to support them and their child. Negative aspects of supportive relationships were not explored. In addition to identifying the factors that alleviate the effects of stress, it may be equally important to examine variables that are detrimental to those struggling to raise a severely impaired child.

Future research might also focus on needs, stress, and social support in the context of developmental transitions. Anecdotal evidence and prior research indicates that the needs and concerns of parents with mentally handicapped preschoolers differ from those who are caring for older individuals. Whether needs, stress, and effective support vary with developmental stage remains to be seen. It will also be important to include the families of normally developing individuals in such studies to determine what, if anything, is unique to families caring for impaired individuals. Such information might have important implications for how to better serve all families, including those with normally developing children.

The needs and support data for the three groups of mothers in the present study do suggest that the efficacy of services need to be evaluated. For example, despite the fact that schools employ speech therapists, one group, namely adolescents with autism, do not appear to be well-served by what is currently available. Other organizations that might consider programme evaluations include those offering social and recreational opportunities, and agencies that serve children with mental handicaps and their families.

### **Conclusions**

The present study extends previous research in the area of stress, social support, and mental health. First, a single stressor and the needs associated with that stressor were identified. Second, social support was conceptualized and measured as a multidimensional construct operating in the context of the needs of the caregiver and their child. Thus, in terms of the stress associated with caring for a handicapped child/adolescent, stress-buffering effects were found for perceived satisfaction with emotional support. When needs were considered, stress-buffering effects were found for the extent to which both emotional and instrumental support were perceived to meet needs. Indeed,

the extent to which emotional support meets needs was a particularly strong predictor of mental health in the stressed caregivers examined. These findings underscore the importance of considering support in the context of meeting the needs of the stressor.

The present findings also enhance our understanding of how best to serve families caring for a severely impaired individual. Specifically, it is the extent to which instrumental and informational support meets needs which differentiates mothers of autistic children from the norm. The extent to which informational support meets needs also distinguishes the learning-impaired group from the normal control group. Although mothers of both impaired groups report more instrumental needs than the norm, it is the mothers of the autistic group who report that the majority of these needs are not currently being met. Given the stress-buffering effects of instrumental support which meets needs, this type of support may be especially beneficial to the mental health of mothers caring for individuals with autism. Instrumental support which addresses needs such as speech therapy, behaviour management, social opportunities for the child, and respite for the caregiver could be particularly important to the autistic adolescent, their mothers, and their families.

## Appendices

## **Appendix A**

### **Sample Characteristics**



**Table A-1**  
**Descriptive Characteristics of Sample**

	Autistic (n=25)	Learning- Impaired (n=24)	Normal (n=25)	
Target's age:				<i>F</i> (2, 71)
Mean years	15.64	15.56	15.66	1.00
SD	3.19	2.63	2.28	
Respondent's age:				
Mean years	42.08	44.58	43.20	< 1
SD	4.74	8.68	4.32	
Number of children living at home:				
Mean	2.16	2.13	2.12	< 1
SD	.80	.95	1.09	
Nonverbal IQ:				<i>t</i> (47)
Mean	61.56	60.88	-----	.09
SD	27.18	25.57	-----	
Gender of Target:				$\chi^2(2)$
Male	22	17	22	3.30
Female	3	7	3	(ns)
<u>Respondent's</u>				
Marital Status:				$\chi^2(2)$
Alone	6	4	2	2.36
Married/Common law	19	20	23	(ns)
Family Income:				$\chi^2(4,$ N=74)
\$0-\$19,999	4	6	0	7.27
\$20,000-\$39,999	7	5	6	
\$40,000+	14	13	19	(ns)

Note. ns = Nonsignificant.

**Appendix B**  
**Diagnostic Information**

**Table B-1**  
**Diagnostic Information for the Autistic and Learning-Impaired Groups**

Diagnoses	n
<b>Autistic</b>	
Autism	18
with Seizures	6
with Down Syndrome	1
<b>Learning-Impaired</b>	
Reading Disability	3
Language Disorder	1
Borderline Intelligence	
with Language Disorder	1
with Seizures	2
Mental Retardation	2
with Epilepsy	1
with Cerebral Palsy	2
with Muscular Dystrophy	1
with a rare neuromuscular disorder	1
with Hydrocephaly and Seizures	2
Down Syndrome	6
William's Syndrome	1
Carpenter's Syndrome	1

## **Appendix C**

### **Social Support Interview Protocol**

## Semi-Structured Interview of Social Support and Needs

### **Introduction**

"As I mentioned during our phone conversation, I'm interested in the support services for families of individuals with special needs. Today, I'll ask you about the needs you and name of son/daughter have and the support you receive from others. I'll also ask you to complete two questionnaires. One deals with caring for a family member, while the other focuses on how you feel in general. Finally, I'll ask you for some background information, such as name of son/daughter's age. Do you have any questions?

Before we begin, I'd like you to have a look at this. It describes what the study is about. Please read it carefully and if you agree to participate please sign both copies on this line. Notice that you may withdraw your participation any time. Also, notice that you will not be identified by name on any of the measures. Because your name appears on this form, it will be kept separate from any of the information you give me today. One copy of the consent form is for you.

Let me begin by asking you about the people and professional agencies that you and name of son/daughter are involved with at this time.

A) Let's start with family, friends, relatives, and neighbours. Who do you and name of son/daughter see on a regular basis?

B) Could you tell me what professional or community agencies you or name of son/daughter are currently involved with? (Probes: Does name of son/daughter receive any special help in school? Resource? Special Education? Vocational training? Who does name of son/daughter see when he or she gets sick? Has a toothache? Does name of son/daughter see a speech therapist? Occupational therapist? Do you have any contact with psychologists/psychiatrists? What about a clinic? Local Hospital? I.W.K.? Does name of son/daughter go to the Y? Local recreation centre? Do you or name of son/daughter belong to a church? Can you think of any other professionals or agencies that you or name of son/daughter are involved with at this time?)"

Informed Consent

I agree to participate in a study examining the support individuals with special needs and their families receive. The study is being conducted by Norma Wadden of the Psychology Department, Dalhousie University. I understand that this study involves one session, during which I will be interviewed about our needs and the support we receive, and be asked to complete several questionnaires. I understand that the interview will be audiotaped and no one other than those directly involved in the research will have access to the tape without my written permission.

I understand that all information obtained in this study is strictly confidential and that my name or that of my son will not be identified in any presentation of the data.

I understand that I may withdraw from participation in the study at any time.

---

Caregiver's Name

---

Signature

---

Date

---

Witness

---

Date

## Social Support

"Now I'd like to talk to you about your needs and the support you receive. Support is what others do to help you care for name of son/daughter. Support can come from family and friends or from professionals and outside agencies. Support can also take various forms. Sometimes support is direct services or assistance such as financial aid, time, or labour such as help with household tasks or the care of name of son/daughter. Sometimes support is in the form of information such as advice or guidance. Finally, support can be emotional - the other person is a good listener and makes you feel accepted, cared for, and valued."

### Instrumental Support:

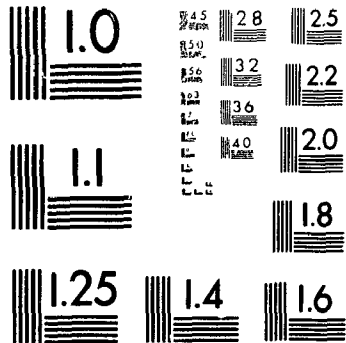
"Let's begin with what we call instrumental support and the needs that might be associated with it. Instrumental support is the delivery of services or material aid such as financial help or direct help with the care of name of son/daughter. Let's start by talking about what you or name of son/daughter need along these lines. I'm interested in what you or name of son/daughter need or do not need right now. For those needs you do have now, I'm interested in whether or not the needs are being met or not being met. For example, children need to be educated. For some, the school will meet this need. For others, the school, for whatever reason, will fail to meet educational needs. The point is that some needs you or name of son/daughter have at this time are probably being met, while other needs are not. I'm interested in both (go to needs list).

Let's start with educational needs. Does name of son/daughter need to be educated in academic skills such as reading or writing? Does name of son/daughter need to be educated in daily living skills such as grooming, mealtime behaviour, or using the telephone? What about physical education for name of son/daughter? Sex education? Does name of son/daughter need a full day school programme? A summer programme? (Go through each need on the list. For those that are needed, ask whether or not it is being met or unmet at this time.)

Are there any other needs that you have now that I have not mentioned? Again, include needs for direct help that are both met and unmet (if yes, get the respondent to name them)."

of/de

PM-1 3½"x4" PHOTOGRAPHIC MICROCOPY TARGET  
NBS 1010a ANSI/ISO #2 EQUIVALENT



## PRECISION<sup>SM</sup> RESOLUTION TARGETS



## Needs - Instrumental

	Not Needed	Needed and Met	Unmet
Educational:			
Academic skills (reading, writing)	_____	_____	_____
Daily living skills (for example, grooming; mealtime behaviour; using the telephone)	_____	_____	_____
Physical education for ____	_____	_____	_____
Sex education for ____	_____	_____	_____
Full day school programme for ____	_____	_____	_____
Summer programme for ____	_____	_____	_____
Job-related skill training	_____	_____	_____
Activities _____ can do for fun/recreation	_____	_____	_____
Opportunities for _____ to socialize with others	_____	_____	_____
Transportation for ____	_____	_____	_____
Residential centre (for example, group home)	_____	_____	_____
Respite care (service that looks after _____ designed to give you some relief):	_____	_____	_____
Nighttime	_____	_____	_____
Weekends	_____	_____	_____
Holidays/Vacation	_____	_____	_____

**Needs - Instrumental**

	Not Needed	Needed and Met	Unmet
Other caregivers (Sitters)	_____	_____	_____
Help with household tasks	_____	_____	_____
Financial aid	_____	_____	_____
Medical care for ____	_____	_____	_____
Dental care for ____	_____	_____	_____
Speech therapy for ____	_____	_____	_____
Behaviour management for ____	_____	_____	_____
Professional counselling:			
For ____	_____	_____	_____
For you or your family	_____	_____	_____
Other (Explain)	_____	_____	_____

### Instrumental Support:

A) "Now, let's talk about the instrumental support you or name of son/daughter receive. Remember that instrumental support is the direct delivery of services or aid. Examples include money, help around the house, help with the care of name of son/daughter or someone to look after name of son/daughter when you go out. Who provides you with direct services or assistance. Let's start with family, friends, relatives, neighbours, and other parents. Who among these gives you or name of son/daughter instrumental support? Now, let's take them one at a time. What does name of source do? Does name of source do anything else to support you or name of son/daughter along these lines? (Go through each source. If not mentioned, ask about the respondent's relationship with each source, e.g., spouse, sister?)"

If the respondent indicates that she does not receive instrumental support from any informal sources, specifically ask her about the individuals listed at the beginning of the interview. For example, what about name of source?

"I'd like you to think about the assistance that you do get from everyone you've just told me about. For the moment, ignore the fact that some of your needs may or may not be met. Consider only those things that you've just described that these people do for you or name of son/daughter. Please rate on this scale how satisfied you are overall with the instrumental support that you do receive from family, friends, relatives, neighbours, and/or other parents? Notice that the scale is from 0-10, with 0 being "not at all satisfied" and 10 being "extremely satisfied".

Now I'd like you to have a look at those needs, both met and unmet, that we talked about earlier (hands needs list to respondent). I'd like you to think about those needs that you or name of son/daughter have now which could reasonably be met by family, friends, etc. For example, some needs such as the need for speech therapy probably could not be met by a family member, unless of course that person was a speech therapist. Other needs such as help with household tasks probably could be met by a family member.

Now, consider only those needs for direct assistance and/or services that family, friends, relatives, neighbours, and/or other parents are in fact able to meet. On this scale from 0 to 10 I'd like you to rate how well the instrumental support you receive from family, friends, relatives, neighbours, and/or other parents actually meet the needs you have at this time." Remove needs list.





### **Instrumental Support:**

B) "Now let's talk about instrumental support from professionals, groups, community agencies, or others who are paid for their services, but not necessarily by you. Who among these gives you or name of son/daughter this type of support? What does name of source do? Is there anything else name of source does that supports you or name of son/daughter in this way?"

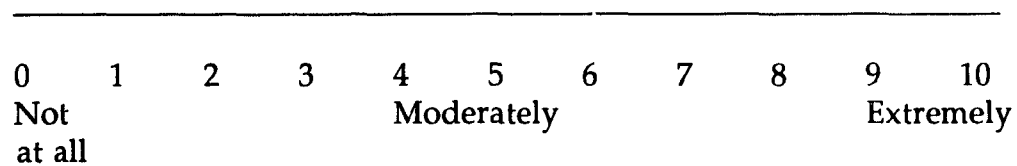
If the respondent fails to mention the professional capacity of the source, ask specifically who the source is (e.g., nurse, teacher). If the respondent indicates that she does not receive instrumental support from any formal sources, specifically ask her about the professionals and agencies listed at the beginning of the interview. For example, what about name of son's/daughter's teacher? Physician? Dentist? and so on.

"Now, think about the direct assistance and service you do receive from the sources you've just mentioned. Again, for the moment, ignore the fact that some of your needs may or may not be met. Consider only those things you've just described that these sources do for you or for name of son/daughter. Please rate on this scale how satisfied you are overall with the instrumental support that you do receive from professionals, groups, community agencies, and/or others who are paid for their service? Again, the scale is from 0-10, with 0 being "not at all satisfied" and 10 being "extremely satisfied".

Now, have another look at this list of met and unmet needs that you and name of son/daughter have at this time (hand respondent needs list). Consider only those needs for direct assistance and service that professionals, groups, community agencies, and/or others who are paid for their services are in fact able to meet. I'd like you to rate on this scale how well the instrumental support you receive from professionals, groups, community agencies, and/or others who are paid for their services actually meet the needs you have at this time."

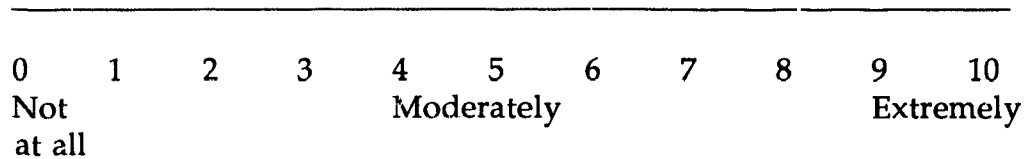
Remove needs list.

How satisfied are you overall with the instrumental support you do receive from professionals, groups, community agencies, and/or others who are paid for their services?



Consider only those needs for direct assistance and/or services that professionals, groups, community agencies, and/or others who are paid for their services are in fact able to meet.

How well does the instrumental support you receive from professionals, groups, community agencies, and/or others who are paid for their services actually meet the needs you have at this time?





### **Informational Support:**

"The next kind of support I'd like to talk to you about is informational support. Informational support is when you receive information, advice, guidance, or feedback from others. Let's start with the needs for information that you and name of son/daughter have at this time. Again, tell me whether or not it is a need. If it is a need, I'm interested in whether or not it is being met at this time (go to the needs list).

Let's start with name of son's /daughter's education. Do you need information, knowledge, guidance, advice, and/or feedback about name of son'/daughter's educational skills. What about information, advice or guidance about job opportunities for name of son/daughter? Do you need information about opportunities for name of son/daughter to interact socially with others? (Go through each need on the list. For those that are needed, ask whether or not it is being met or unmet at this time.)

At this time, do you have a need for information or advice about anything else which I have not mentioned here? Again, it could be a need for information that is currently being met, or it could be a need for information that is not being met (if yes, get the respondent to name them)."

### Needs - Informational

Information, knowledge, guidance, advice and/or feedback about any of the following:

	Not Needed	Needed and Met	Unmet
_____ educational skills	_____	_____	_____
Job opportunities for _____	_____	_____	_____
Activities that will keep _____ occupied	_____	_____	_____
Opportunities for _____ to interact socially with others	_____	_____	_____
_____ sexual behaviour	_____	_____	_____
Management of any difficult behaviours _____ may have	_____	_____	_____
_____ language/communication problems	_____	_____	_____
Development of medical problems for _____	_____	_____	_____
Long term residential planning for _____	_____	_____	_____
Other persons or services such as specialists or agencies that you or _____ could go to for help or consultation	_____	_____	_____
Other (Explain)	_____	_____	_____

### Informational Support:

A) Now, let's talk about the informational support you or name of son/daughter receive. Who among your family, friends, relatives, neighbours, and other parents gives you or name of son/daughter information, knowledge, advice, guidance, and/or feedback? What does name of source do? Does name of source do anything else to support you or name of son/daughter in this way? (Go through each source. If not mentioned, ask about the respondent's relationship with each source, e.g., sister.)"

If the respondent indicates that she does not receive informational support from any informal sources, specifically ask her about the individuals listed at the beginning of the interview. For example, what about name of source?

"Now, think about the information, advice, etc., that you do get from all the people you've just told me about. For the moment, ignore the fact that some of your needs may or may not be met. Consider only the information, advice, etc. that you actually do receive. Please rate on this scale from 0-10 how satisfied you are overall with the informational support you do receive from family, friends, relatives, neighbours, and/or other parents.

Now, I'd like you to have a look at this second list of met and unmet needs that you and name of son/daughter have at this time (hand respondent the needs list). Again, think about those needs for information, advice, etc. which could reasonably be met by family, friends, etc. For example, the need for information about communication or language problems probably could not be met by a family member unless that person was a speech therapist.

Now, consider only those needs for information, knowledge, guidance, advice, and/or feedback that family, friends, relatives, neighbours, and/or other parents are in fact able to meet. On this scale from 0-10 I'd like you to rate how well the informational support you receive from family, friends, etc. actually meet the needs you have at this time."

Remove needs list.

How satisfied are you overall with the informational support you do receive from family, friends, relatives, neighbours, and/or other parents?

0	1	2	3	4	5	6	7	8	9	10
Not at all				Moderately					Extremely	

Consider only those needs for information, knowledge, guidance, advice and/or feedback that family, friends, relatives, neighbours, and/or other parents are in fact able to meet.

How well does the informational support you receive from family, friends, relatives, neighbours, and/or other parents actually meet the needs you have at this time?

---

0	1	2	3	4	5	6	7	8	9	10
Not at all				Moderately				Extremely		

### **Informational Support:**

B) "Now let's talk about the informational support you or name of son/daughter receive from professionals, groups, community agencies, or others who are paid for their services, but not necessarily by you. Who gives you or name of son/daughter information, advice, guidance, or feedback? What does name of source do? Is there anything else name of source does to support you in this way?"

If the respondent fails to mention the professional capacity of the source, ask specifically who the source is (e.g., nurse, teacher). If the respondent indicates that she does not receive informational support from any formal sources, specifically ask her about the professionals and agencies she listed at the beginning of the interview. For example, what about name of son's/daughter's teacher? Physician? Dentist? and so on.

"Now think about the informational support you do receive from the sources you've just mentioned. For the moment, ignore the fact that some of your needs may or may not be met. Consider only the information, advice, etc. that you actually receive from these people or agencies. Please rate how satisfied you are overall with the informational support you do receive from professionals, groups, etc.

Now, have another look at this list of met and unmet needs that you and name of son/daughter have at this time (hand respondent needs list). Consider only those needs for information, knowledge, guidance, advice, and/or feedback that professionals, groups, community agencies, and/or others who are paid for their services are in fact able to meet. I'd like you to rate on this scale how well the informational support you receive from professionals, groups, etc. actually meet the needs you have at this time."

Remove needs list.

How satisfied are you overall with the informational support you do receive from professionals, groups, community agencies, and/or others who are paid for their services?

0	1	2	3	4	5	6	7	8	9	10
Not at all				Moderately					Extremely	

Consider only those needs for information, knowledge, guidance, advice, and/or feedback that professionals, groups, community agencies, and/or others who are paid for their services are in fact able to meet.

How well does the informational support you receive from professionals, groups, community agencies, and/or others who are paid for their services actually meet the needs you have at this time?

0	1	2	3	4	5	6	7	8	9	10
				Moderately			Extremely			
Not at all										



### **Emotional Support:**

"The final kind of support I'd like to talk to you about is emotional support. Emotional support is having someone who listens to you when you need someone to talk to and makes you feel that you are accepted and cared for. But first, let's have a look at some emotional needs that you and name of son/daughter may have. I'm interested in what you or name of son/daughter need or do not need at this time. For those needs that you or name of son/daughter have now, I'm interested in whether or not it is being met at this time (go to needs list).

Do you need someone to talk to when you are upset? Do you need people who listen and take your concerns seriously? Do you need people who are warm and understanding to name of son/daughter? To you? (Go through each need on the list. For those that are needed, ask whether or not it is being met or unmet at this time.)

Are there any other emotional needs that you or name of son/daughter have now that I have not mentioned? Again, include needs that are both met and unmet." (If yes, get respondent to name them).

**Needs - Emotional**

	Not Needed	Needed and Met	Unmet
Someone to talk to when you are upset	_____	_____	_____
People who listen and take your concerns seriously	_____	_____	_____
People who are warm and understanding:	_____	_____	_____
To _____	_____	_____	_____
To you	_____	_____	_____
People who express concern:	_____	_____	_____
About _____	_____	_____	_____
About you	_____	_____	_____
Acceptance of _____:	_____	_____	_____
by other individuals	_____	_____	_____
by the community as a whole	_____	_____	_____
Acceptance of you as a parent:	_____	_____	_____
by other individuals	_____	_____	_____
By the community as a whole	_____	_____	_____
Other (Explain)	_____	_____	_____

### **Emotional Support:**

A) "Let's talk about the emotional support you or name of son/daughter receive. Who amongst your family, friends, relatives, neighbours, and other parents listens to you and makes you or name of son/daughter feel accepted and cared for? What does name of source do? Does name of source do anything else to support you or name of son/daughter emotionally? (Go through each source. If not mentioned, ask about the respondent's relationship with each source, e.g., spouse, sister.)"

If the respondent indicates that she does not receive emotional support from any informal sources, specifically ask her about the individuals listed at the beginning of the interview. For example, what about name of source?

This time I'd like you to think about the emotional support that you do receive from all the people you've just mentioned. Ignore the fact that some of your needs may or may not be met. Consider only the things others do to support you or name of son/daughter emotionally. Please rate how satisfied you are overall with the emotional support you do receive from family, friends, etc.

Now, I'd like you to have a look at this final list of met and unmet needs that you or name of son/daughter have at this time (hand respondent needs list). Consider only those needs for others who listen, are accepting, and/or caring that family, friends, relatives, neighbours, and/or other parents are in fact able to meet. On this scale I'd like you to rate how well the emotional support you receive from family, friends, etc. actually meet the needs you have at this time."

Remove needs list.

How satisfied are you overall with the emotional support you do receive from family, friends, relatives, neighbours, and/or other parents?

0	1	2	3	4	5	6	7	8	9	10
Not at all				Moderately					Extremely	

Consider only those needs for others who listen, are accepting, and/or caring that family, friends, relatives, neighbours, and/or other parents are in fact able to meet.

How well does the emotional support you receive from family, friends, relatives, neighbours, and/or other parents actually meet the needs you have at this time?

0	1	2	3	4	5	6	7	8	9	10
Not at all				Moderately			Extremely			

### **Emotional Support:**

B) "Finally, could you tell me whether you receive emotional support from any professionals, groups, agencies, or others who are paid for their services, but not necessarily by you. Who among these listens to you and makes you and name of son/daughter feel accepted and cared for? What does name of source do? Does name of source do anything else to support you or name of son/daughter emotionally? (go through each source)."

If the respondent fails to mention the professional capacity of the source, ask specifically who the source is (e.g., nurse, teacher). If the respondent indicates that she does not receive emotional support from any formal sources, specifically ask her about the professionals and agencies she listed at the beginning of the interview. For example, what about name of son's/daughter's teacher? Physician? Dentist? and so on.

"Now think about the emotional support you do receive from the sources you've just mentioned. Ignore the fact that some of your needs may or may not be met at this time. Consider only the things that others actually do to support you or name of son/daughter emotionally. Please rate how satisfied you are overall with the emotional support you do receive from professionals, groups, etc.

Finally, have another look at this list of met and unmet needs that you and name of son/daughter have at this time (hand respondent needs list). Consider only those needs for others who listen, are accepting, and/or caring that professionals, groups, community agencies, and/or others who are paid a fee for their services are in fact able to meet. I'd like you to rate how well the emotional support you receive from professionals, groups, etc. actually meet the needs you have at this time."

Remove needs list.



Consider only those needs for others who listen, are accepting, and/or caring that professionals, groups, community agencies, and/or others who are paid for their services are in fact able to meet.

How well does the emotional support you receive from professionals, groups, community agencies, and/or others who are paid for their services actually meet the needs you have at this time?

0	1	2	3	4	5	6	7	8	9	10
				Moderately			Extremely			
Not at all										



### Most Important Needs

"We've been discussing those needs that you and name of son/daughter have now that are being met and those which are not being met. Now, let's take a final look at the needs that you and name of son/daughter have (hand the respondent all three needs list). Would you number the 5 most important needs that you or name of son/daughter have with number 1 being your most important need. Again, I'm interested in needs that are both met and unmet.

Now, I'd like to ask you more specifically about these needs that are important to you and name of son/daughter at this time. Can you tell me a bit more about these needs. Let's start with (go to most important need). Specifically, what do you need? Why is it important to you or name of son/daughter to have this need met?"

## **Appendix D**

### **Questionnaire on Resources and Stress For Families With Chronically Ill and Handicapped Members**

## **Questionnaire on Resources and Stress \***

### **Instructions**

The questionnaire deals with your feelings about a member of your family. There are many blanks on the questionnaire. Imagine the family member's name filled in on each blank. Give your honest feelings and opinions.

Please answer all of the questions even if they do not seem to apply. If it is difficult to decide if an item on the questionnaire is True or False, answer in terms of what you or your family feel or do most of the time.

The questions sometimes refer to an older or younger person, or someone who has problems that your family member does not have. Nevertheless, these questions still can be answered True or False.

For example: "We get special funds because of \_\_\_\_\_'s problem." If you are responding about a family member who does not have a problem, the answer would be False. There is no problem for which you would get special funds.

**DO NOT WRITE ON THE QUESTIONNAIRE.  
SIMPLY IMAGINE YOUR RELATIVE'S NAME IS ON THE BLANKS  
PROVIDED**

\* Research form, not to be used without author's permission.

Jean Holroyd  
Neuropsychiatric Institute  
Department of Psychiatry and Biobehavioral Sciences  
University of California, Los Angeles

Purchased from Clinical Psychology Publishing Co., Inc.  
4 Conant Square  
Brandon, Vermont 05733

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

33. \_\_\_\_'s problems or illness do not stand in the way of our family progress.
34. When others are around \_\_\_\_ I cannot relax; I am always on guard.
35. If \_\_\_\_ were more pleasant to be with, it would be easier to care for him/her.
36. Thinking about the future makes me sad.
37. Much of the time I think about \_\_\_\_ dying.
38. If I knew when \_\_\_\_ would die I wouldn't worry so much.
39. I don't worry too much about \_\_\_\_'s health.
40. Our family agrees on important matters.
41. Professionals (nurses etc.) in an institution would understand \_\_\_\_ better than I do.
42. When \_\_\_\_ is not well, I can't go out.
43. I am afraid by limiting \_\_\_\_'s activities he/she will not develop on his/her own.
44. Our family's income has dropped over the past 5 years.
45. The constant demands for care for \_\_\_\_ limit the growth and development of someone else in our family.
46. \_\_\_\_ feels that I am the only one who understands him/her.
47. In his/her own way \_\_\_\_ brings as much pleasure to our family as the other members.
48. I worry about what will happen to \_\_\_\_ when I can no longer take care of him/her.
49. I think in the future \_\_\_\_ will take up more and more of my time.
50. I am able to leave \_\_\_\_ alone in the house for an hour or more.
51. I fear the day when other members of the family leave home and I am left alone with \_\_\_\_.
52. It would be better for \_\_\_\_ if our house could be remodeled.
53. A counselor or teacher sees \_\_\_\_ at least once a month.
54. I get out of the house to do something interesting at least once a week.
55. I am very careful about asking \_\_\_\_ to do things which might be too hard for him/her.
56. The attitude of our family makes it impossible for \_\_\_\_ to live with us any longer.
57. I would rather be caring for \_\_\_\_ than doing some other kind of work.
58. \_\_\_\_ is limited in the kind of work he/she can do to make a living.
59. I have accepted the fact that \_\_\_\_ might have to live out his/her life in some special setting (i.e., hospital, institution, foster home).
60. I have given up things I really wanted in order to care for \_\_\_\_.
61. My family argues about how to care for \_\_\_\_.
62. \_\_\_\_ is able to fit into the family social group.
63. Some members of my family don't like the way I do things.
64. I would not want the family to go on vacation and leave \_\_\_\_ at home.
65. At times I fear \_\_\_\_ will not be able to function in society if he/she is out of our house.

66. It is difficult for me to stand back and watch \_\_\_\_\_'s condition get worse.
67. In the future our family's social life will suffer because of increased and financial pressure.
68. It doesn't make any difference to \_\_\_\_\_ if he/she is at home or in a hospital.
69. \_\_\_\_\_ knows the difference between strangers and friends.
70. I am afraid that other members of the family will be hurt because they are related to \_\_\_\_\_.
71. There is no way we can keep \_\_\_\_\_ in our house.
72. People should take care of their own.
73. One of us has had to pass up a chance for a job because \_\_\_\_\_ could not be removed from a clinic or special school, etc.
74. I would rather help \_\_\_\_\_ do something than have him/her fail and feel badly.
75. \_\_\_\_\_ has always lived with our family.
76. I cannot manage \_\_\_\_\_.
77. Sometimes I avoid taking \_\_\_\_\_ out in public.
78. \_\_\_\_\_ is on a special diet.
79. Many people simply don't understand what it is like to live with \_\_\_\_\_.
80. Every member of our family has had to do without things because of money spent on \_\_\_\_\_.
81. \_\_\_\_\_ can feed himself/herself.
82. I tend to do things for \_\_\_\_\_ that he/she can do himself/herself.
83. When we go on vacation, I'm not afraid to leave \_\_\_\_\_ for any length of time.
84. As the time passes I think it will take more and more to care for \_\_\_\_\_.
85. I belong to organizations which help with problems I have with \_\_\_\_\_.
86. There have been serious emotional problems for someone in our family.
87. Our relatives have been very helpful.
88. We have discussed what will happen when \_\_\_\_\_ dies.
89. It is easier for me to do something for \_\_\_\_\_ than to let him/her do it himself/herself and make a mess.
90. \_\_\_\_\_ is easy to manage most of the time.
91. I don't think that \_\_\_\_\_ depends too much on me or other members of the family.
92. It is not necessary for \_\_\_\_\_ to go up or down steps in our house.
93. I feel that I must protect \_\_\_\_\_ from the remarks of children.
94. We can afford to pay for the care \_\_\_\_\_ needs.
95. Just talking about problems with close friends make life easier.
96. I can never leave the house because of \_\_\_\_\_.
97. I am happy when I watch the development and achievements of \_\_\_\_\_.
98. It bothers me that \_\_\_\_\_ will always be this way.
99. No one in our family drinks alcohol too much.
100. The community is used to people like \_\_\_\_\_.
101. \_\_\_\_\_ uses special equipment because of his/her handicap.

102. \_\_\_\_\_ has a handicap which prevents him/her from improving.
103. \_\_\_\_\_ is sometimes too sexual.
104. \_\_\_\_\_ has a lot of pain.
105. I feel tense whenever I take \_\_\_\_\_ out in public.
106. \_\_\_\_\_ is easy to live with.
107. The doctor sees \_\_\_\_\_ at least once a year.
108. \_\_\_\_\_ eats his/her meals with other members of the family.
109. Wheelchairs or walkers have been used in our house.
110. An electricity failure would endanger \_\_\_\_\_'s life or health.
111. Caring for \_\_\_\_\_ has been a financial burden for our family.
112. \_\_\_\_\_ made a good income at one time.
113. Some friends are very helpful when it comes to \_\_\_\_\_.
114. I worry that \_\_\_\_\_ may sense that he/she does not have long to live.
115. \_\_\_\_\_ will not do something for himself/herself if he/she knows someone will do it for him/her.
116. I can go visit with friends whenever I want.
117. Members of the family show no interest in what happens to \_\_\_\_\_.
118. We enjoy \_\_\_\_\_ more and more as a person.
119. We have changed our house because of \_\_\_\_\_.
120. Taking \_\_\_\_\_ on a vacation spoils pleasure for the whole family.
121. The family does as many things now as we ever did.
122. \_\_\_\_\_ knows his/her own address.
123. \_\_\_\_\_ gets along very well with others.
124. \_\_\_\_\_ is aware of who he/she is (for example, male 14 years old).
125. \_\_\_\_\_ prevents any communication within our family.
126. Someone in our family turns against \_\_\_\_\_ when his/her friends are around.
127. Sometimes I need to get away from the house.
128. I get upset with the way my life is going.
129. Sometimes I feel very embarrassed because of \_\_\_\_\_.
130. Having to care for \_\_\_\_\_ has enriched our family life.
131. Neighbours want us to move because of \_\_\_\_\_.
132. I respect \_\_\_\_\_'s judgement about what he/she should be able to do.
133. \_\_\_\_\_ doesn't do as much as he/she should be able to do.
134. Our family has been on welfare.
135. We have discussed what will happen if \_\_\_\_\_ lives longer than we do.
136. \_\_\_\_\_ is truly accepted by the family.
137. A bed that raises and lowers has made things easier.
138. We take \_\_\_\_\_ along when we go out.
139. It makes me feel good to know I can take care of \_\_\_\_\_.
140. Others do for \_\_\_\_\_ what he/she could do for himself/herself.
141. Because of \_\_\_\_\_ our family has never enjoyed a meal.
142. I hate to see \_\_\_\_\_ try to do something and fail.
143. \_\_\_\_\_ is accepted by other members of the family.
144. I fear \_\_\_\_\_ might be hurt while playing games or sports.

145. It is difficult to communicate with \_\_\_\_\_ because he/she has difficulty understanding what is being said to him/her.
146. \_\_\_\_\_ spends time at a special day center or in special classes at school.
147. \_\_\_\_\_ is very anxious most of the time.
148. \_\_\_\_\_'s health is not getting worse.
149. There is no special government program to help \_\_\_\_\_.
150. I have no time to give the other members of the family.
151. Our family is quite religious.
152. In our family \_\_\_\_\_ takes an active part in family affairs.
153. There are many places where we can enjoy ourselves as a family when \_\_\_\_\_ comes along.
154. It is hard to think of enough things to keep \_\_\_\_\_ busy.
155. \_\_\_\_\_ is overprotected.
156. Our family income is more than average.
157. Some of our family do not bring friends into the home because of \_\_\_\_\_.
158. I try to get \_\_\_\_\_ to take care of himself/herself.
159. Caring for \_\_\_\_\_ gives one a feeling of worth.
160. We have discussed his/her death with \_\_\_\_\_.
161. \_\_\_\_\_ is able to take part in games or sports.
162. One of us has had to pass up the chance for a job because \_\_\_\_\_ could not be left without someone to watch him/her.
163. We think \_\_\_\_\_ will live longer in an institution.
164. \_\_\_\_\_ has too much time on his/her hands.
165. There is an organization for families who share our problems.
166. I am disappointed that \_\_\_\_\_ does not lead a normal life.
167. We spend up to 25 percent of our income on medical care (or care for \_\_\_\_\_).
168. Time drags for \_\_\_\_\_, especially free time.
169. I worry about how our family will adjust after \_\_\_\_\_ is no longer with us.
170. The part that worries me most about \_\_\_\_\_ going on his/her own is his/her ability to make a living.
171. \_\_\_\_\_ resents being treated as a handicapped person.
172. \_\_\_\_\_ can't pay attention very long.
173. I worry about what will be done with \_\_\_\_\_ when he/she gets older.
174. If \_\_\_\_\_ were healthier it would be easier to go away for a holiday.
175. Compared to others, we spend a lot of money on medical costs.
176. I get almost too tired to enjoy myself.
177. \_\_\_\_\_ has things to entertain him/her (TV, radio) in his/her room.
178. We owe a great deal of money.
179. \_\_\_\_\_ is depressed most of the time.
180. If I were healthier, it would be easier to care for \_\_\_\_\_.
181. Most persons in public places indicate they don't want \_\_\_\_\_ around.
182. \_\_\_\_\_ can get around the neighbourhood quite easily.
183. \_\_\_\_\_ wants more freedom than he/she has.



184. One of the things I appreciate about \_\_\_\_\_ is his/her confidence.
185. I don't mind when people look at \_\_\_\_\_.
186. Whenever I leave the house I am worried about what's going on at home.
187. In our family \_\_\_\_\_ plays as important a role as other members.
188. \_\_\_\_\_ will never be any brighter than now.
189. One of the things I appreciate about \_\_\_\_\_ is his/her ability to recognize his/her own limits.
190. I believe \_\_\_\_\_ should go places as often as others in the family.
191. I am not embarrassed when others question me about \_\_\_\_\_'s condition.
192. There is a lot of anger and resentment in our family.
193. If \_\_\_\_\_ could get around better we would do more as a family.
194. Our family has managed to save money or make investments.
195. We own or are buying our own home.
196. Information and encouragement are available to those who seek it.
197. We get special funds because of \_\_\_\_\_'s problem.
198. One of the things I enjoy about \_\_\_\_\_ is his/her sense of humor.
199. We have no luxuries.
200. I have enough time to myself.
201. \_\_\_\_\_ is able to go to the bathroom alone.
202. I am afraid \_\_\_\_\_ will not get the individual attention, affection, and care that he/she is used to if he/she goes somewhere else to live.
203. I have too much responsibility.
204. No member of the family pities \_\_\_\_\_ too much.
205. \_\_\_\_\_ cannot remember what he/she says from one moment to the next.
206. \_\_\_\_\_ is better off in our home than somewhere else.
207. \_\_\_\_\_ can describe himself/herself as a person.
208. Others in the family should help care for \_\_\_\_\_.
209. A nurse sometimes works in our home.
210. Relatives have done more harm than good when it comes to \_\_\_\_\_.
211. I am afraid that as \_\_\_\_\_ gets older it will be harder to manage him/her.
212. It is easy to keep \_\_\_\_\_ entertained.
213. It makes me feel worthwhile to help \_\_\_\_\_.
214. \_\_\_\_\_ wants to do things for himself/herself.
215. In the future \_\_\_\_\_ will be more able to help himself/herself.
216. \_\_\_\_\_ needs a walker or wheelchair.
217. I have become more understanding in my relationship with people as a result of \_\_\_\_\_.
218. The constant demands to care for \_\_\_\_\_ limit my growth and development.
219. \_\_\_\_\_ cannot get any better.
220. \_\_\_\_\_ is very tense in strange surroundings.
221. It is easy to communicate with \_\_\_\_\_.

222. I feel sad when I think of \_\_\_\_.
223. Our family should do more together.
224. I have had to give up a chance for a job because of \_\_\_\_.
225. \_\_\_\_ accepts himself/herself as a person.
226. Outside activities would be easier without \_\_\_\_.
227. Our relatives give us much help.
228. I enjoy church.
229. Caring for \_\_\_\_ puts a strain on me.
230. I often worry about what will happen to \_\_\_\_ when I no longer can take care of him/her.
231. \_\_\_\_ can use the bus to go wherever he/she wants.
232. People can't understand what \_\_\_\_ tries to say.
233. If it were not for \_\_\_\_ things would be better.
234. I feel that \_\_\_\_ would prefer a professional (nurse, daycare helper, etc.) to care for him/her rather than a member of our family.
235. Some members of the family resent \_\_\_\_.
236. Members of our family get to do the same kind of things other families do.
237. \_\_\_\_ embarrasses others in our family.
238. My happiness goes up and down with \_\_\_\_'s behavior.
239. \_\_\_\_ uses the phone frequently.
240. \_\_\_\_ has many things to keep him/her busy.
241. Sometimes the demands \_\_\_\_ makes drives me out of my mind.
242. I had high hopes for \_\_\_\_'s future.
243. \_\_\_\_ could do more for himself/herself.
244. My family understands the problems I have.
245. It is easy to do too much for \_\_\_\_.
246. \_\_\_\_ appreciates the interest others show in him/her.
247. It is easier for our family to do things with people we know than with strangers.
248. I am pleased when others see my care of \_\_\_\_ as important.
249. We can hardly make ends meet.
250. \_\_\_\_ rarely has nightmares.
251. I don't try to shelter \_\_\_\_ from life's difficulties.
252. Members of my family are able to discuss personal problems.
253. I often have the desire to protect \_\_\_\_.
254. I am as healthy as I ever was.
255. \_\_\_\_ does not dress right.
256. Most of \_\_\_\_'s care falls on me.
257. No one can ever understand what I go through.
258. We have household help (cleaning women, nurse, etc.).
259. It is fortunate how \_\_\_\_ has adjusted to life.
260. \_\_\_\_ accepts his/her handicap.
261. \_\_\_\_ has his/her own room.
262. \_\_\_\_ is very irritable.
263. We have lost most of our friends because of \_\_\_\_.

264. \_\_\_\_\_ has an attractive, clean appearance.
265. \_\_\_\_\_ can ride a bus.
266. \_\_\_\_\_ will always be a problem to us.
267. \_\_\_\_\_ is able to express his/her feelings to others.
268. It is easy for me to relax.
269. \_\_\_\_\_ has to use a bedpan or diaper.
270. I rarely feel blue.
271. We have good laundry facilities at home.
272. \_\_\_\_\_ can walk without help.
273. \_\_\_\_\_ needs help in the bathroom.
274. I have chances to carry on interests outside the home.
275. It bothers me to see \_\_\_\_\_ in pain.
276. Every cloud has a silver lining.
277. I like myself as a person.
278. I am worried much of the time.
279. \_\_\_\_\_ has a strongly defiant personality.
280. Because \_\_\_\_\_ uses special equipment and facilities, it is difficult to take him/her out.
281. One of the things I appreciate about \_\_\_\_\_ is his/her sensitivity to others.
282. Others have offered to share the load in caring for \_\_\_\_\_.
283. \_\_\_\_\_ likes to follow the same schedule all the time.
284. \_\_\_\_\_'s needs come first.
285. \_\_\_\_\_ attracts attention.

**Appendix E**  
**Mental Health Inventory**

## Mental Health Inventory

These questions are about how you feel, and how things have been with you within the past month.

For each question, please circle a number for the one answer that comes closest to the way you have been feeling.

1. How happy, satisfied, or pleased have you been with your personal life during the past month?

Circle one

Extremely happy, could not have been more satisfied or pleased .....	1
Very happy most of the time .....	2
Generally satisfied, pleased .....	3
Sometimes fairly satisfied, sometimes fairly unhappy .....	4
Generally dissatisfied, unhappy .....	5
Very dissatisfied, unhappy most of the time .....	6

2. How much of the time have you felt lonely during the past month?

Circle one

All of the time .....	1
Most of the time .....	2
A good bit of the time .....	3
Some of the time .....	4
A little of the time .....	5
None of the time .....	6

3. How often did you become nervous or jumpy when faced with excitement or unexpected situations during the past month?

Circle one

Always .....	1
Very often .....	2
Fairly often .....	3
Sometimes .....	4
Almost never .....	5
Never .....	6

4. During the past month, how much of the time have you felt that the future looks hopeful and promising:

	Circle one
All of the time . . . . .	1
Most of the time . . . . .	2
A good bit of the time . . . . .	3
Some of the time . . . . .	4
A little of the time . . . . .	5
None of the time . . . . .	6

5. How much of the time, during the past month, has your daily life been full of things that were interesting to you?

	Circle one
All of the time . . . . .	1
Most of the time . . . . .	2
A good bit of the time . . . . .	3
Some of the time . . . . .	4
A little of the time . . . . .	5
None of the time . . . . .	6

6. How much of the time, during the past month, did you feel relaxed and free of tension?

	Circle one
All of the time . . . . .	1
Most of the time . . . . .	2
A good bit of the time . . . . .	3
Some of the time . . . . .	4
A little of the time . . . . .	5
None of the time . . . . .	6

7. During the past month, how much of the time have you generally enjoyed the things you do?

	Circle one
All of the time . . . . .	1
Most of the time . . . . .	2
A good bit of the time . . . . .	3
Some of the time . . . . .	4
A little of the time . . . . .	5
None of the time . . . . .	6

8. During the past month, have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel or of your memory?

Circle one

No, not at all .....	1
Maybe a little .....	2
Yes, but not enough to be concerned or worried about it .....	3
Yes, and I have been a little concerned .....	4
Yes, and I am quite concerned .....	5
Yes, and I am very much concerned about it .....	6

9. Did you feel depressed during the past month?

Circle one

Yes, to the point that I did not care about anything for days at a time .....	1
Yes, very depressed almost every day .....	2
Yes, quite depressed several times .....	3
Yes, a little depressed now and then .....	4
No, never felt depressed at all .....	5

10. During the past month, how much of the time have you felt loved and wanted?

Circle one

All of the time .....	1
Most of the time .....	2
A good bit of the time .....	3
Some of the time .....	4
A little of the time .....	5
None of the time .....	6

11. How much of the time, during the past month, have you been a very nervous person?

Circle one

All of the time .....	1
Most of the time .....	2
A good bit of the time .....	3
Some of the time .....	4
A little of the time .....	5
None of the time .....	6

12. When you got up in the morning, this past month, about how often did you expect to have an interesting day?

Circle one

Always .....	1
Very often .....	2
Fairly often .....	3
Sometimes .....	4
Almost never .....	5
Never .....	6

13. During the past month, how much of the time have you felt tense or "high-strung"?

Circle one

All of the time .....	1
Most of the time .....	2
A good bit of the time .....	3
Some of the time .....	4
A little of the time .....	5
None of the time .....	6

14. During the past month, have you been in firm control of your behavior, thoughts, emotions, feelings?

Circle one

Yes, very definitely .....	1
Yes, for the most part .....	2
Yes, I guess so .....	3
No, not too well .....	4
No, and I am somewhat disturbed .....	5
No, and I am very disturbed .....	6

15. During the past month, how often did your hands shake when you tried to do something?

Circle one

Always .....	1
Very often .....	2
Fairly often .....	3
Sometimes .....	4
Almost never .....	5
Never .....	6



16. During the past month, how often did you feel that you had nothing to look forward to?

Circle one

Always .....	1
Very often .....	2
Fairly often .....	3
Sometimes .....	4
Almost never .....	5
Never .....	6

17. How much of the time, during the past month, have you felt calm and peaceful?

Circle one

All of the time .....	1
Most of the time .....	2
A good bit of the time .....	3
Some of the time .....	4
A little of the time .....	5
None of the time .....	6

18. How much of the time, during the past month, have you felt emotionally stable?

Circle one

All of the time .....	1
Most of the time .....	2
A good bit of the time .....	3
Some of the time .....	4
A little of the time .....	5
None of the time .....	6

19. How much of the time, during the past month, have you felt downhearted and blue?

Circle one

All of the time .....	1
Most of the time .....	2
A good bit of the time .....	3
Some of the time .....	4
A little of the time .....	5
None of the time .....	6

- 20 How often have you felt like crying, during the past month?

	Circle one
Always .....	1
Very often .....	2
Fairly often .....	3
Sometimes .....	4
Almost never .....	5
Never .....	6

21. During the past month, how often did you feel that others would be better off if you were dead?

	Circle one
Always ..	1
Very often .....	2
Fairly often .....	3
Sometimes .....	4
Almost never .....	5
Never .....	6

22. How much of the time, during the past month, were you able to relax without difficulty?

	Circle one
All of the time .....	1
Most of the time .....	2
A good bit of the time .....	3
Some of the time .....	4
A little of the time .....	5
None of the time .....	6

23. During the past month, how much of the time did you feel that your love relationships, loving and being loved, were full and complete?

	Circle one
All of the time .....	1
Most of the time .....	2
A good bit of the time .....	3
Some of the time .....	4
A little of the time .....	5
None of the time .....	6

24. How often during the past month, did you feel that nothing turned out for you the way you wanted it to?

Circle one

Always .....	1
Very often .....	2
Fairly often .....	3
Sometimes .....	4
Almost never .....	5
Never .....	6

25. How much have you been bothered by nervousness, or your "nerves", during the past month:

Circle one

Extremely so, the point where I could not take care of things .....	1
Very much bothered .....	2
Bothered quite a bit by nerves .....	3
Bothered some, enough to notice .....	4
Bothered just a little by nerves .....	5
Not bothered at all by this .....	6

26. During the past month, how much of the time has living been a wonderful adventure for you?

Circle one

All of the time .....	1
Most of the time .....	2
A good bit of the time .....	3
Some of the time .....	4
A little of the time .....	5
None of the time .....	6

27. How often, during the past month, have you felt so down in the dumps that nothing could cheer you up?

Circle one

Always .....	1
Very often .....	2
Fairly often .....	3
Sometimes .....	4
Almost never .....	5
Never .....	6

28. During the past month, did you ever think about taking your own life?

Circle one

Yes, very often ..... 1  
 Yes, fairly often ..... 2  
 Yes, a couple of times ..... 3  
 Yes, at one time ..... 4  
 No, never ..... 5

29. During the past month, how much of the time have you felt restless, fidgety, or impatient?

Circle one

All of the time ..... 1  
 Most of the time ..... 2  
 A good bit of the time ..... 3  
 Some of the time ..... 4  
 A little of the time ..... 5  
 None of the time ..... 6

30. During the past month, how much of the time have you been moody or brooded about things?

Circle one

All of the time ..... 1  
 Most of the time ..... 2  
 A good bit of the time ..... 3  
 Some of the time ..... 4  
 A little of the time ..... 5  
 None of the time ..... 6

31. How much of the time, during the past month, have you felt cheerful, light-hearted?

Circle one

All of the time ..... 1  
 Most of the time ..... 2  
 A good bit of the time ..... 3  
 Some of the time ..... 4  
 A little of the time ..... 5  
 None of the time ..... 6

32. During the past month, how often did you get rattled, upset, or flustered?

	Circle one
Always .....	1
Very often .....	2
Fairly often .....	3
Sometimes .....	4
Almost never .....	5
Never .....	6

33. During the past month, have you been anxious or worried?

	Circle one
Yes, extremely so, to the point of being sick or almost sick . . . .	1
Yes, very much so .....	2
Yes, quite a bit .....	3
Yes, some, enough to bother me .....	4
Yes, a little bit .....	5
No, not at all .....	6

34. During the past month, how much of the time were you a happy person?

	Circle one
All of the time .....	1
Most of the time .....	2
A good bit of the time .....	3
Some of the time .....	4
A little of the time .....	5
None of the time .....	6

35. How often during the past month did you find yourself having difficulty trying to calm down?

	Circle one
Always .....	1
Very often .....	2
Fairly often .....	3
Sometimes .....	4
Almost never .....	5
Never .....	6

36. During the past month, how much of the time have you been in low or very low spirits?

Circle one

- |                              |   |
|------------------------------|---|
| All of the time .....        | 1 |
| Most of the time .....       | 2 |
| A good bit of the time ..... | 3 |
| Some of the time .....       | 4 |
| A little of the time .....   | 5 |
| None of the time .....       | 6 |

37. How often, during the past month, have you been waking up feeling fresh and rested?

Circle one

- |                                    |   |
|------------------------------------|---|
| Always, every day .....            | 1 |
| Almost every day .....             | 2 |
| Most day .....                     | 3 |
| Some days, but usually not .....   | 4 |
| Hardly ever .....                  | 5 |
| Never wake up feeling rested ..... | 6 |

38. During the past month, have you been under or felt you were under any strain, stress, or pressure?

Circle one

- |   |   |
|---|---|
| Yes, almost more than I could stand or bear ..... | 1 |
| Yes, quite a bit of pressure .....                | 2 |
| Yes, some, more than usual .....                  | 3 |
| Yes, some, but about normal .....                 | 4 |
| Yes, a little bit .....                           | 5 |
| No, not at all .....                              | 6 |

THE **RAND** CORPORATION

June 10, 1991

Norma Wadden, M Sc  
Department of Psychology  
Halifax, Nova Scotia  
Canada B3H 4j1

Dear Ms Wadden

Enclosed is a RAND publication that contains the Mental Health Inventory - - both the long and short forms — as well as descriptions of the scoring rules. The inventory is in the public domain so special permission to use it is not required.

I hope all goes well with your research.

Sincerely,



Clairice T. Veit, Ph.D.

CTV:ss

Enclosure 1

## **Appendix F**

### **Background Information**



## Background Information

\_\_\_\_\_ age (yrs) \_\_\_\_\_

Date of birth (M/D/Y) \_\_\_\_\_

Your age (yrs) \_\_\_\_\_

Date of birth (M/D/Y/) \_\_\_\_\_

## Marital Status:

Single \_\_\_\_\_

Married \_\_\_\_\_

Commonlaw \_\_\_\_\_

Separated \_\_\_\_\_

Divorced \_\_\_\_\_

Widowed \_\_\_\_\_

Other \_\_\_\_\_

Number of people in household \_\_\_\_\_

Children	Age
_____	_____
_____	_____
_____	_____

Mother's highest level of education: Secondary \_\_\_\_\_

Post-secondary \_\_\_\_\_

Occupation \_\_\_\_\_

Father's highest level of education: Secondary \_\_\_\_\_

Post-secondary \_\_\_\_\_

Occupation \_\_\_\_\_

## Family Income:

\$0 - 9,999 \_\_\_\_\_

\$10,000 - 19,999 \_\_\_\_\_

\$20,000 - 29,999 \_\_\_\_\_

\$30,000 - 39,999 \_\_\_\_\_

\$40,000 - 49,999 \_\_\_\_\_

\$50,000+ \_\_\_\_\_

## **Appendix G**

### **Letters of Introduction**

**Letter of Introduction- Autistic Group**

Date

Dear Name of Respondent

My name is Norma Wadden and I am in the Department of Psychology at Dalhousie. You might recall that 5-6 years ago you and name of son/daughter participated in a study conducted by Drs. Susan Bryson and Barbara Clark. That study provided important information on individuals with learning problems within the province.

Dr. Bryson and I now want to extend that study by looking at the needs associated with the daily care of someone with special needs, and the support you and other mothers receive. We are interested in what others such as family, friends, professionals, and community agencies do to support you and name of son/daughter. We hope to gain a better understanding of the support services that are required by people with special needs and their families. Ultimately, we hope that this information will help in the delivery of better services for you and others like you in the province of Nova Scotia.

I am writing to ask if you would be willing to participate in such a study. I would like to meet with you for about 2 1/2 hours to discuss your needs and the support services you and your family currently receive. We would meet at your convenience, in your home or any location of your choice. At that time I will interview you and ask you to complete two questionnaires. One questionnaire deals with the problems of caring for a family member. The other focuses on your well-being. No identifying information will appear on any of the research material.

I hope that you find this project worthwhile and that you will consider participating in the study. I will contact you by phone within the next three weeks. At that time, please feel free to ask me any questions or raise any concerns that you may have about the study. I look forward to speaking with you in the very near future. Thank-you for your time.

Sincerely,

Norma Wadden, M.Sc.

**Letter of Introduction- Learning-Impaired Group**

Date

Dear Name of Respondent

My name is Norma Wadden and I am in the Department of Psychology at Dalhousie University. You might recall that 5-6 years ago you and name of son/daughter participated in a study conducted by Drs. Susan Bryson and Barbara Clark. That study provided important information on individuals with learning problems within the province.

Dr. Bryson and I now want to extend that study by looking at the needs associated with caring for someone with learning problems, and the support families receive. We hope to gain a better understanding of the support services that are required by individuals with special needs and their families. To accomplish this, some understanding of the needs and supports received by individuals with a variety of learning problems, and their families, is required. We are interested in what others such as family, friends, professionals, and community agencies do to support you and name of son/daughter. Ultimately, we hope that this information will help in the delivery of better services in the province of Nova Scotia.

I am writing to ask if you would be willing to participate in such a study. I would like to meet with you for about 2 1/2 hours to discuss your needs and the support services you and your family currently receive. We would meet at your convenience, in your home or any location of your choice. At that time I will interview you and ask you to complete two questionnaires. One questionnaire deals with caring for a family member, while the other focuses on your well-being. No identifying information will appear on any of the research material.

I hope that you find this project worthwhile and that you will consider participating in the study. I will contact you by phone within the next few weeks. At that time, please feel free to ask me any questions or raise any concerns that you may have about the study. I look forward to speaking with you in the very near future. Thank-you for your time.

Sincerely,

Norma Wadden, M.Sc.

**Letter of Introduction - Normal Control Group**

Date

Dear Name of Respondent

My name is Norma Wadden and I am in the Department of Psychology at Dalhousie University. You might recall that 5-6 years ago you and name of son/daughter participated in a study conducted by Drs. Susan Bryson and Barbara Clark. That study provided important information on individuals with learning problems within the province.

Dr. Bryson and I now want to extend that study by looking at the needs associated with caring for someone with special needs, and the support families receive. We hope to gain a better understanding of the support services that are required by individuals with special needs and their families. To accomplish this, some understanding of the needs and supports received by families of normally developing children is required. We are interested in what others such as family, friends, professionals, and community agencies do to support you and name of son/daughter. Ultimately, we hope that this information will help in the delivery of better services for those with special needs in the province of Nova Scotia.

I am writing to ask if you would be willing to participate in such a study. I would like to meet with you for about 2 1/2 hours to discuss your needs and the support services you and your family currently receive. We would meet at your convenience, in your home or any location of your choice. At that time I will interview you and ask you to complete two questionnaires. One questionnaire deals with caring for a family member, while the other focuses on your well-being. No identifying information will appear on any of the research material.

I hope that you find this project worthwhile and that you will consider participating in the study. I will contact you by phone within the next few weeks. At that time, please feel free to ask me any questions or raise any concerns that you may have about the study. I look forward to speaking with you in the very near future. Thank-you for your time.

Sincerely,

Norma Wadden, M.Sc.

**Appendix H**  
**Telephone Contact**

### Telephone Contact: Austistic and Learning-Impaired Groups

"Hello Ms. name of mother. My name is Norma Wadden. I'm a graduate student at Dalhousie University. A few weeks ago I sent you a letter describing a study about support services for families of individuals with special needs. This study is an extension of one that you participated in several years ago, conducted by Dr. Susan Bryson. Did you receive the letter? Is this a good time to talk or would you rather I call you back?

I'd like to take this opportunity to tell you a bit more about the study. But first let me ask you: Who would you say is the person primarily responsible for caring for name of son/daughter on a daily basis?

The study focuses on two things: (1) the needs that families of individuals with special needs have, and (2) the supports that you and your family receive. In order to develop better support services we must first get a sense of the supports you currently receive, and how it benefits you.

Let me tell you about what I will ask of you. I would like to interview you at your convenience. The interview will take about 2 1/2 hours, in any location of your choice. I will ask you specifically about your and name of son's daughter's needs, about who provides you with support, and what they do. I will also ask you to evaluate that support. I will ask you to complete two questionnaires. One deals with caring for a family member, while the other focuses on how you feel in general. Finally, I will ask you to provide some background information such as name of son/daughter age. All information will be treated as strictly confidential.

I hope that you find this project worthwhile. Do you have any questions, comments, or concerns? Would you be willing to participate?

If you have no objection, I would like to audiotape the interview so that the information can be coded by someone other than myself. Only myself and those directly involved in the study such as my supervisor will have access to the tapes without your written permission. And, as I mentioned, all information will be treated as strictly confidential. None of the research material will contain any identifying information, including your name."

### Telephone Contact: Normal Control Group

"Hello Ms. name of mother. My name is Norma Wadden. I'm a graduate student at Dalhousie University. A few weeks ago I sent you a letter describing a study about support services for families of individuals with special needs. This study is an extension of one that you participated in several years ago, conducted by Dr. Susan Bryson. Did you receive the letter? Is this a good time to talk or would you rather I call you back?

I'd like to take this opportunity to tell you a bit more about the study. But first let me ask you: Who would you say is the person primarily responsible for caring for name of son/daughter on a daily basis?

The study focuses on two things: (1) the needs that families of individuals with special needs have, and (2) the supports that these families receive. But to get a better understanding of the supports required by these families, we must get a sense of the supports required by families with normally developing children and adolescents.

Let me tell you about what I will ask of you. I would like to interview you at your convenience. The interview will take about 2 1/2 hours, in any location of your choice. I will ask you specifically about your and name of son's daughter's needs, about who provides you with support, and what they do. I will also ask you to evaluate that support. I will ask you to complete two questionnaires. One deals with caring for a family member, while the other focuses on how you feel in general. Finally, I will ask you to provide some background information such as name of son/daughter age. All information will be treated as strictly confidential.

I hope that you find this project worthwhile. Do you have any questions, comments, or concerns? Would you be willing to participate?

If you have no objection, I would like to audiotape the interview so that the information can be coded by someone other than myself. Only myself and those directly involved in the study such as my supervisor will have access to the tapes without your written permission. And, as I mentioned, all information will be treated as strictly confidential. None of the research material will contain any identifying information, including your name."



**Appendix I**  
**Theoretical Variable**

### Theoretical Variable

Under the buffering hypothesis, the theoretical variable should be relatively high under conditions of high stress and low support. It should be relatively small under conditions of low stress and either high or low support. When both stress and support are high the variable should also be small relative to when stress is high but support is low.

In the present data set,  $c = 12$  and  $d = 10$ . Under the following conditions, the theoretical variables computed by  $(\text{stress} - c)(d - \text{support})$  would be:

High stress:  $QRS = 114$   
 Low stress:  $QRS = 16$   
 High support:  $\text{Rating} = 8$   
 Low support:  $\text{Rating} = 2$

### Theoretical Variable

Low stress, high support:	$(16-12)(10-8) = 8$
Low stress, low support:	$(16-12)(10-2) = 32$
High stress, high support:	$(114-12)(10-8) = 204$
High stress, low support:	$(114-12)(10-2) = 816$

Thus, the theoretical variable  $(\text{stress} - c)(d - \text{support})$  directly reflects the particular interaction predicted when social support buffers the effect of stress on mental health.

## **Appendix J**

### **Correlation Coefficients and Stepwise Regressions**

**Table J-1**  
**Correlation Coefficients Between Measures of Stress, Social Support, and Mental Health**

	QRS	<u>SATISFACTION</u>			<u>SUPPORT MEETS NEEDS</u>		
		INST	INFO	EMO	INST	INFO	EMO
MHI	-.53	.29	.33	.42	.49	.40	.60
QRS		-.34	-.32	-.31	-.56	-.54	-.45
<b>SATISFACTION</b>							
INST			.67	.70	.62	.52	.60
INFO				.69	.57	.61	.67
EMO					.55	.47	.73
<b>SUPPORT MEETS NEEDS</b>							
INST						.67	.65
INFO							.65

Note.  $p < .05$  for all correlation coefficients. INST = Instrumental support; INFO = Informational support; EMO = Emotional support.

**Table J-2**  
**Stepwise Regressions of Stress and Social Support on Mental Health**

Variables	Beta	F
<b>SATISFACTION WITH SUPPORT</b>		
QRS	-.5286	27.92***
INST	.1245	1.38
QRS	-.5286	27.92***
INFO	.1841	3.13
QRS	-.4385	18.90***
EMO	.2829	7.87**
<b>SUPPORT MEETS NEEDS</b>		
QRS	-.3706	9.99**
INST	.2806	5.73*
QRS	-.5286	13.84***
INFO	.1658	1.97
EMO	.4575	21.30***
QRS	-.3213	10.50**

Note. \*\*\*  $p < .001$ ; \*\*  $p < .01$ ; \*  $p < .05$ . QRS = Questionnaire on Resources and Stress; INST = Instrumental support; INFO = Informational support; EMO = Emotional support.

## **Appendix K**

### **Satisfaction With Social Support**

**Table K-1**  
**Means and Standard Deviations for Evaluations of Satisfaction with Support**  
**Type by Group**

Group	<u>Support Type</u>					
	Instrumental		Informational		Emotional	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Autistic (n=25)	7.38	1.78	7.12	1.76	8.02	1.21
Learning-Impaired (n=24)	8.44	1.56	7.94	1.79	8.71	1.32
Normal (n=25)	8.30	1.12	8.32	0.90	8.72	0.78

$F(4, 142) = 0.99$

**Table K-2**  
**Means and Standard Deviations for Evaluations of Satisfaction With Support Source by Group**

Group	<u>Support Source</u>			
	Informal		Formal	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Autistic (n=25)	7.95	1.45	7.07	1.89
Learning-Impaired (n=24)	8.69	1.41	8.03	1.71
Normal (n=25)	8.63	0.70	8.27	1.11
$F(2, 71) = 0.78$				



**Table K-3**  
**Means and Standard Deviations for Maternal Evaluations of Satisfaction**  
**With Support Type by Support Source**

<u>Support Type</u>	<u>Support Source</u>			
	Informal		Formal	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Instrumental (n=74)	8.28	1.81	7.78	2.00
Informational (n=74)	8.28	1.68	7.30	2.23
Emotional (n=74)	8.69	1.26	8.27	1.50
$F(2, 142) = 2.28$				

**Table K-4**  
**Means and Standard Deviations for Evaluations of Satisfaction With Support**  
**Type by Group and Support Source**

<u>Group</u>	<u>Support Source</u>					
	<u>Informal</u>			<u>Formal</u>		
	INST	INFO	EMO	INST	INFO	EMO
Autistic (n=25)	7.72 (2.32)	7.72 (1.79)	8.40 (1.41)	7.04 (2.30)	6.52 (2.60)	7.64 (1.55)
Learning-Impaired (n=24)	8.75 (1.48)	8.46 (2.13)	8.88 (1.33)	8.12 (1.99)	7.42 (2.34)	8.54 (1.64)
Normal (n=25)	8.40 (1.38)	8.68 (0.75)	8.80 (1.00)	8.20 (1.50)	7.96 (1.40)	8.64 (1.11)

$F(4, 142) = 0.08$

Note. INST = Instrumental Support; INFO = Informational Support; EMO = Emotional Support

## **Appendix L**

### **The Extent to Which Support Meets Needs**

**Table L-1**  
**Means and Standard Deviations for Maternal Evaluations of the Extent to Which Support Source Meets Needs**

<u>Support Source</u>				
Informal		Formal		
<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
7.10	1.83	6.86	2.02	
$F(1, 71) = 2.41$				

**Table L-2**  
**Means and Standard Deviations for Evaluations of the Extent to Which**  
**Support Source Meets Needs by Group**

<u>Group</u>	<u>Support Source</u>			
	Informal		Formal	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Autistic (n=25)	6.16	1.56	6.31	2.03
Learning-Impaired (n=24)	7.15	2.29	6.49	2.45
Normal (n=25)	7.99	1.00	7.76	1.14
$F(2, 71) = 2.14$				

**Table L-3**  
**Means and Standard Deviations for Maternal Evaluations of the Extent to Which Support Type Meets Needs by Support Source**

<u>Support Type</u>	<u>Support Source</u>			
	<u>Informal</u>		<u>Formal</u>	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Instrumental (n=74)	6.88	2.36	6.82	2.46
Informational (n=74)	6.27	2.71	6.11	2.41
Emotional (n=74)	8.15	1.79	7.63	2.05
$F(2, 142) = 1.16$				

**Table L-4**  
**Means and Standard Deviations for Evaluations of the Extent to Which**  
**Support Type Meets Needs by Group and Support Source**

<u>Group</u>	<u>Support Source</u>					
	<u>Informal</u>			<u>Formal</u>		
	INST	INFO	EMO	INST	INFO	EMO
Autistic (n=25)	5.84 (2.44)	4.88 (2.13)	7.76 (1.72)	5.84 (2.79)	5.72 (2.21)	7.36 (2.04)
Learning-Impaired (n=24)	7.08 (2.41)	6.21 (3.44)	8.17 (2.43)	6.67 (2.66)	5.42 (2.92)	7.38 (2.67)
Normal (n=25)	7.72 (1.86)	7.72 (1.51)	8.52 (0.92)	7.96 (1.21)	7.16 (1.70)	8.16 (1.18)

$$F(4, 142) = 1.54$$

Note. INST = Instrumental Support; INFO = Informational Support; EMO = Emotional Support.

## References

- Alloway, R., & Bebbington, P. (1987). The buffer theory of social support - A review of the literature. *Psychological Medicine*, 17, 91-108.
- American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, D.C.: Author.
- Arling, G. (1987). Strain, social support, and distress in old age. *Journal of Gerontology*, 42, 107-117.
- Barakat, L.P. & Linney, J.A. (1992). Children with physical handicaps and their mothers: The inter-relation of social support, maternal adjustment, and child adjustment. *Journal of Pediatric Psychology*, 17, 725-739.
- Barnett, P.A., & Gotlib, I.H. (1988). Psychological functioning and depression: Distinguishing among antecedents, concomitants, and consequences. *Psychological Bulletin*, 104, 97-126.
- Baron-Cohen, S. (1988). Social and pragmatic deficits in autism: Cognitive or affective? *Journal of Autism and Developmental Disorders*, 18, 379-402.
- Bebko, J.M., Konstantareas, M.M., & Springer, J. (1987). Parent and professional evaluations of family stress associated with characteristics of autism. *Journal of Autism and Developmental Disorders*, 17, 565-576.
- Beckman, P.J. (1983). Influence of selected child characteristics on stress in families of handicapped infants. *American Journal of Mental Deficiency*, 88, 150-156.
- Beckman, P.J., Pokorni, J.L., Maza, E.A., & Balzer-Martin, L. (1986). A longitudinal study of stress and support in families of preterm and full-term infants. *Journal of the Division for Early Childhood*, 11, 2-9.
- Billings, A.G., Cronkite, R.C., & Moos, R.H. (1983). Social-environmental factors in unipolar depression: Comparisons of depressed patients and nondepressed controls. *Journal of Abnormal Psychology*, 92, 119-133.
- Billings, A.G., & Moos, R.H. (1985a). Psychosocial stressors, coping, and depression. In E.E. Beckman, & W.R. Leber (Eds.), *Handbook of depression: Treatment, assessment and research* (pp. 940-974). Homewood, IL: The Dorsey Press.
- Billings, A.G., & Moos, R.H. (1985b). Life stressors and social resources affect posttreatment outcomes among depressed patients. *Journal of Abnormal Psychology*, 94, 140-153.



- Blythe, B.J. (1983). Social support networks in health care and health promotion. In J.K. Whittaker & J. Garbarzino (Eds.), *Social support networks: Informal helping in the human services* (pp. 105-131). New York: Aldrine.
- Boucher, J., & Lewis, V. (1989). Memory impairments and communication in relatively able autistic children. *Journal of Child Psychology and Psychiatry*, 30, 99-122.
- Bristol, M.M. (1979). Maternal coping with autistic children: Adequacy of interpersonal support and effects of child's characteristics. *Dissertation Abstracts International*, (University Microfilms No. 7925890).
- Bristol, M.M. (1984). Family resources and successful adaptation to autistic children. In E. Schopler & G.B. Mesibov (Eds.), *The effects of autism on the family* (pp. 290-310). New York: Plenum Press.
- Bristol, M.M. (1987). Mothers of children with autism or communication disorders: Successful adaptation and the Double ABCX model. *Journal of Autism and Developmental Disorders*, 17, 469-486.
- Bristol, M.M., Gallagher, J.J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. *Developmental Psychology*, 24, 441-451.
- Bristol, M.M., & Schopler, E. (1983). Stress and coping in families of autistic adolescents. In E. Schopler & G.B. Mesibov (Eds.), *Autism in adolescents and adults* (pp. 251-278). New York: Plenum Press.
- Bristol, M.M., & Schopler, E. (1984). A developmental perspective on stress and coping in families of autistic children. In J. Blacher (Ed.), *Severely handicapped young children and their families: Research in review* (pp. 91-141). Orlando: Academic Press.
- Brown, G.W. (1990). What about the real world? Hassles and Richard Lazarus [Commentary]. *Psychological Inquiry*, 1, 19-22.
- Bruhn, J.G., & Phillip, B.U. (1984). Measuring social support: A synthesis of current approaches. *Journal of Behavioral Medicine*, 7, 151-169.
- Bryson, S.E. (in press). Autism and anomalous handedness. In S. Coren (Ed.), *Left-handedness: Behavioural implications and anomalies*. Elsevier Science Publishers B.V./North-Holland Book Series.

- Bryson, S.E., Clark, B.S., & Smith, I.M. (1988). First report of a Canadian epidemiological study of autistic syndromes. *Journal of Child Psychology and Psychiatry*, 29, 433-445.
- Carveth, W.B., & Gottlieb, B.H. (1979). The measurement of social support and its relation to stress. *Canadian Journal of Behavioural Science*, 11, 179-188.
- Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine*, 38, 300-314.
- Cohen, S., & Hoberman, H. (1983). Positive events and social supports as buffers of life change stress. *Journal of Applied Social Psychology*, 13, 99-125.
- Cohen, S., & McKay, G. (1984). Social support, stress, and the buffering hypothesis: A theoretical analysis. In A. Baum, J.E. Singer, & S.E. Taylor (Eds.), *Handbook of psychology and health: Vol. 4. Social psychological aspects of health* (pp. 253-267). Hillsdale, NJ: Laurence Erlbaum.
- Cohen, S., & Syme, S.L. (1985). Issues in the study and application of social support. In S. Cohen & S.L. Syme (Eds.), *Social support and health* (pp. 3-22). Orlando, FL: Academic Press.
- Cohen, S., & Wills, T.A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98, 310-357.
- Coyne, J.C., & DeLongis, A. (1986). Going beyond social support: The role of social relationships in adaptation. *Journal of Consulting and Clinical Psychology*, 54, 454-460.
- Cummins, R.C. (1986). Perceptions of social support, receipt of supportive behaviours, and locus of control as moderators of the effects of chronic stress. *American Journal of Community Psychology*, 16, 685-700.
- Cutrona, C.E. (1990). Stress and social support - In search of optimal matching. *Journal of Social and Clinical Psychology*, 9, 3-14.
- Cutrona, C.E., & Russell, D. (1990). Type of social support and specific stress: Toward a theory of optimal matching. In B.R. Sarason, I.G. Sarason, & G.R. Pierce (Eds.), *Social support: An interactional view* (pp. 319-366). New York: John Wiley & Sons.
- D'Augelli, A. (1983). Social support networks in mental health. In J.K. Whitaker & J. Garbazine (Eds.), *Social support networks: Informal helping in the human services* (pp. 71-106). New York: Aldrine.

- Davies, A.R., Sherbourne, C.D., Peterson, J.R., & Ware, J.E. Jr. (1988, April). *Scoring manual: Adult health status and patient satisfaction measures used in RAND's health insurance experiment* (N-2190-HHS). Santa Monica: The Rand Corporation.
- Dean, A., & Ensel, W.M. (1982). Modelling social support, life events, competence, and depression in the context of age and sex. *Journal of Community Psychology*, 10, 392-408.
- DeMyer, M.K. (1979). *Parents and children in autism*. Washington, DC: Winston.
- DeMyer, M.K. & Goldberg, P. (1983). Family needs of the autistic adolescent. In E. Schopler & G.B. Mesibov (Eds.), *Autism in adolescents and adults* (pp. 225-250). New York: Plenum Press.
- Denckla, M.B. (1986). Editorial: New diagnostic criteria for autism and related behavioral disorders - Guidelines for research protocol. *Journal of the American Academy of Child Psychiatry*, 25, 221-224.
- Dohrenwend, B.S. (1978). Social stress and community psychology. *American Journal of Community Psychology*, 6, 1-14.
- Dohrenwend, B.S., & Dohrenwend, B.P. (1981). *Stressful life events and their context*. New York: Rutgers University Press.
- Dohrenwend, B.S., Dohrenwend, B.P., Dodson, M., & Shrout, P.E. (1984). Symptoms, hassles, social supports, and life events: Problem of confounded measures. *Journal of Abnormal Psychology*, 93, 222-230.
- Dooley, D. (1985). Causal influence in the study of social support. In S. Cohen & S.L. Syme (Eds.), *Social support and health* (pp. 109-125). New York: Academic Press.
- Dunkel-Schetter, C. (1984). Social support and cancer: Findings based on patient interviews and their implications. *Journal of Social Issues*, 40, 77-98.
- Dunkel-Schetter, C., & Bennett, T.L. (1990). Differentiating the cognitive and behavioural aspects of social support. In B.R. Sarason, I.G. Sarason, & G.R. Pierce (Eds.), *Social support: An interactional view* (pp. 267-296). New York: John Wiley & Sons.
- Elliott, G.R., & Eisdorfer, C. (1982). *Stress and human health*. New York: Springer.

- Finney, J., Mitchell, R., Cronkite, R., & Moos, R. (1984). Methodological issues in estimating main and interactive effects: Examples from coping/social support and stress field. *Journal of Health and Social Behavior*, 25, 85-98.
- Fiore, J., Coppel, D.B., Becker, J., & Cox, G.B. (1986). Social support as a multifaceted concept: Examination of important dimensions for adjustment. *American Journal of Community Psychology*, 14, 93-111.
- Fondacaro, M.R., & Moos, R.H. (1989). Life stressors and coping: A longitudinal analysis among depressed and nondepressed adults. *Journal of Community Psychology*, 17, 330-340.
- Friedrich, W.N., & Friedrich, W.L. (1981). Psychological assets of parents of handicapped and nonhandicapped children. *American Journal of Mental Deficiency*, 87, 606-613.
- Fry, P.S. (1989). Mediators of stress in older adults: Conceptual and integrative frameworks. *Canadian Psychology*, 30, 636-649.
- Gallagher, J.J., Beckman, P.J., & Cross, A. (1983). Families of handicapped children: Sources of stress and its amelioration. *Exceptional Children*, 50, 10-19.
- Gottlieb, B.H. (1985). Assessing and strengthening the impact of social support on mental health. *Social Work*, 293-300.
- Gottlieb, B.H. (1987a). Marshalling social support for medical patients and their families. *Canadian Psychology*, 28, 201-217.
- Gottlieb, B.H. (1987b). Using social support to protect and promote health. *Journal of Primary Prevention*, 8, 49-70.
- Gottlieb, B.H. (1989, May). *The contingent nature of social support*. Paper presented at the second Iowa Conference on Personal Relationships. Iowa City, Iowa.
- Gray, D.E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health and Illness*, 15, 102-120.
- Hall, A., & Wellman, B. (1985). Social networks and social support. In S. Cohen & S.L. Syme (Eds.), *Social support and health* (pp. 23-41). Orlando, FL: Academic Press.

- Heller, K., Swindle, R.W. Jr., & Dusenbury, L. (1986). Component social support processes. Comments and integration. *Journal of Consulting and Clinical Psychology*, 54, 466-470.
- Henderson, S. (1981). Social relationships, adversity, and neurosis: An analysis of prospective observations. *British Journal of Psychiatry*, 138, 391-398.
- Henderson, S., Byrne, D.G., Duncan-Jones, P., Scott, R., & Adcock, S. (1980). Social relationships, adversity, and neurosis: A study of associations in a general population sample. *British Journal of Psychiatry*, 136, 354-538.
- Hobfoll, S.E. (1989). Conservation of resources: A new attempt at conceptualizing stress. *American Psychology*, 44, 513-525.
- Hobfoll, S.E., & Lerman, M. (1989). Predicting receipt of social support: A longitudinal study of parents' reactions to their children's illness. *Health Psychology*, 8, 61-77.
- Hobson, R.P. (1986). The autistic child's appraisal of expressions of emotion: A further study. *Journal of Child Psychology and Psychiatry*, 27, 671-680.
- Holahan, C.J., & Moos, R.H. (1985). Life stress and health: Personality, coping, and family support in stress resistance. *Journal of Personality and Social Psychology*, 49, 739-747.
- Holmes, N., & Carr, J. (1991). The pattern of care in families of adults with a mental handicap: A comparison between families of autistic adults and Down syndrome adults. *Journal of Autism and Developmental Disorder*, 21, 159-176.
- Holmes, T.H., & Rahe, R.H. (1967). The social readjustment rating scale. *Journal of Psychosomatic Research*, 11, 213-218.
- Holroyd, J. (1974). The Questionnaire on Resources and Stress: An instrument to measure response to a handicapped member. *Journal of Community Psychology*, 2, 92-94.
- Holroyd, J. (1987). *Questionnaire on resources and stress for families with chronically ill or handicapped members*. Brandon, VT: Clinical Psychology Publishing Co., Inc.
- Holroyd, J. (1988). A review of criterion validation research on the Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members. *Journal of Clinical Psychology*, 44, 335-354.

- Holroyd, J., & Guthrie, D. (1986). Family stress with chronic childhood illness: Cystic fibrosis, neuromuscular disease, and renal disease. *Journal of Clinical Psychology, 42*, 552-561.
- Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down's syndrome and childhood autism. *American Journal of Mental Deficiency, 80*, 431-436.
- House, J.S. (1981). *Work stress and social support*. Reading, MA: Addison-Wesley.
- House, J.S., & Kahn, R.L. (1985). Measures and concepts of social support. In S. Cohen & S.L. Syme (Eds.), *Social support and health* (pp. 83-108). New York: Academic Press.
- Husani, B.A., Neff, J.A., Newbrough, J.R., & Moore, M.C. (1982). The stress-buffering role of social support and personal competence among the rural married. *Journal of Community Psychology, 10*, 409-426.
- Jacobson, J.W., & Ackerman, L.J. (1990). Differences in adaptive functioning among people with autism or mental retardation. *Journal of Autism and Developmental Disorders, 20*, 205-219.
- Janicki, M.P., & Jacobson, J.W. (1983). Selected clinical features and service characteristics of autistic adults. *Psychological Reports, 52*, 387-390.
- Janicki, M.P., Lubin, R.A., & Friedman, E. (1983). Variations in characteristics and service needs of persons with autism. *Journal of Autism and Developmental Disorders, 13*, 73-85.
- Kazak, A.E. (1987). Families with disabled children: Stress and social networks in three samples. *Journal of Abnormal Child Psychology, 1*, 137-146.
- Kazak, A.E., & Marvin, R.S. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. *Family Relations, 33*, 67-77.
- Kazak, A.E., & Wilcox, B.L. (1984). The structure and function of social support networks in families with handicapped children. *American Journal of Community Psychology, 12*, 645-661.
- Kissman, K. (1989). Social support, parental belief systems, and well-being. *Youth and Society, 21*, 120-130.

- Khrone, H.W. (1990). Personality as a mediator between objective events and their subjective representation [Commentary]. *Psychological Inquiry*, 1, 26-29.
- Koegel, R.L., Schreibman, L., Loos, L.M., Dirlich-Wilhelm, Dunlap, G., Robbins, F.R., & Plien, A.J. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders*, 22, 205-216.
- Konstantareas, M.M., & Homatidis, S. (1988). Stress and differential parental involvement in families of autistic and learning disabled children. In E.D. Hibbs (Ed.), *Children and families: Studies in prevention and intervention* (pp. 321-336). Madison: International Universities Press.
- Konstantareas, M.M., & Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry*, 30, 459-470.
- Krause, N. (1986). Social support, stress, and well-being among older adults. *Journal of Gerontology*, 41, 512-519.
- Krause, N. (1987). Chronic financial strain, social support, and depressive symptoms among older adults. *Psychology and Aging*, 2, 185-192.
- Krohne, H.W. (1990). Personality as a mediator between objective events and their subjective representation [Commentary]. *Psychological Inquiry*, 1, 26-29.
- Lazarus, R.S. (1990). Theory-based stress measurement [Target article]. *Psychological Inquiry*, 1, 3-13.
- Lazarus, R.S., & DeLongis, A. (1983). Psychological stress and coping in aging. *American Psychologist*, 38, 245-254.
- Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lehman, D.R., Ellard, J.H., & Wortman, C. (1986). Social support for the bereaved: Recipients' and providers' perspectives on what is helpful. *Journal of Consulting and Clinical Psychology*, 54, 438-446.
- Lin, N., Simeone, R.S., Ensel, W.M., & Kuo, W. (1979). Social support, stressful life events, and illness: A model and an empirical test. *Journal of Health and Social Behavior*, 20, 108-119.

- Lotter, V. (1966). Epidemiology of autistic conditions in young children. I. Prevalance. *Social Psychiatry*, 1, 124-137.
- Lotter, V. (1974). Social adjustment and placement of autistic children in Middlesex: A follow-up study. *Journal of Autism and Childhood Schizophrenia*, 4, 11-32.
- Marcus, L.M. (1977). Patterns of coping in families of psychotic children. *American Journal of Orthopsychiatry*, 47, 388-399.
- Marcus, L.M. (1984). Coping with burnout. In E. Schopler & G.B. Mesibov (Eds.), *The effects of autism on the family* (pp. 311-326). New York: Plenum Press.
- Marcus, L., Lansing, M., Andrews, C., & Schopler, E. (1978). Improvement of teaching effectiveness in parents of autistic children. *Journal of the American Academy of Child Psychiatry*, 17, 625-639.
- Masuda, M., & Holmes, T.H. (1967). Magnitude estimations of social readjustments. *Journal of Psychosomatic Research*, 11, 219-225.
- McCubbin, M.A., & McCubbin, H.I. (1987). Family stress theory and assessment: The T-Double ABCX model of family adjustment and adaptation. In H.I. McCubbin & A.I. Thompson (Eds.), *Family assessment inventories for research and practice* (pp. 2-32). Madison, WI: The University of Wisconsin-Madison.
- McCubbin, H.I., Joy, C.B., Cauble, A.E., Comeau, J.K., Patterson, J.M., & Needle, R.H. (1980). Family stress and coping: A decade review. *Journal of Marriage and the Family*, 42, 855-871.
- McFarlane, A.H., Norman, G.R., Streiner, D.L., & Roy, R.G. (1983). The process of social stress: Stable, reciprocal and mediating relationships. *Journal of Health and Social Behaviour*, 24, 160-173.
- McLeroy, K.R., DeVellis, R., DeVellis, B., Kaplin, B., & Toole, J. (1984). Social support and physical recovery in a stroke population. *Journal of Social and Personal Relationships*, 1, 395-413.
- Mesibov, G.V. (1983). Current perspectives and issues in autism and adolescence. In E. Schopler & G.B. Mesibov (Eds.), *Autism in adolescents and adults* (pp. 37-53). New York: Plenum Press.
- Mesibov, G.B. (1990). Normalization and its relevance today. *Journal of Autism and Developmental Disorders*, 20, 379-390.



- Milgram, N.A., & Atzil, M. (1987). Consensus and conflict in parents of autistic children. *Psychological Report*, 61, 557-558.
- Milgram, N.A., & Atzil, M. (1988). Parenting stress in raising autistic children. *Journal of Autism and Developmental Disorders*, 18, 415-424.
- Mitchell, R.E., & Trickett, E.J. (1980). Task force report: Social networks as mediators of social support. An analysis of the effects and determinants of social networks. *Community Mental Health Journal*, 16, 27-44.
- Monroe, S.M., Imhoff, D.F., Wise, B., & Harris, J.E. (1983). Prediction of psychological symptoms under high-risk psychosocial circumstances: Life events, social support, and symptom specificity. *Journal of Abnormal Psychology*, 92, 338-350.
- Monroe, S.M., & Steiner, S.C. (1986). Social support and psychopathology: Interrelations with preexisting disorder, stress, and personality. *Journal of Abnormal Psychology*, 95, 29-39.
- Moos, R.H., & Swindle, R.W. Jr. (1990). Person-environment transactions and the stressor-appraisal-coping process [Commentary]. *Psychological Inquiry*, 1, 30-32.
- Morgan, S.B. (1988). The autistic child and family functioning: A developmental-family systems perspective. *Journal of Autism and Developmental Disorders*, 18, 263-280.
- Nelson, G. (1990). Women's life strains, social support, coping, and positive and negative affect: Cross-sectional and longitudinal tests of the two-factor theory of emotional well-being. *Journal of Community Psychology*, 18, 239-263.
- Norbeck, J.S., Chafetz, L., Skodol-Wilson, H., & Weiss, S.J. (1991). Social support needs of family caregivers of psychiatric patients from three age groups. *Nursing Research*, 40, 208-213.
- O'Hara, M.W. (1986). Social support, life events, and depression during pregnancy and the puerperium. *Archives of General Psychiatry*, 43, 569-573.
- Pagel, M.D., Erdly, W.W., & Becker, J. (1987). Social networks: We get by with (and in spite of) a little help from our friends. *Journal of Personality and Social Psychology*, 53, 793-804.

- Paykel, E.S., Emms, E.M., Fletcher, J., & Rassaby, E.S. (1980). Life events and social support in puerperal depression. *British Journal of Psychology*, 136, 339-346.
- Pearlin, L.I. (1989). The sociological study of stress. *Journal of Health and Social Behavior*, 30, 241-256.
- Pearlin, L.I., Menaghan, E.G., Lieberman, M.A., & Mullan, J.T. (1981). The stress process. *Journal of Health and Social Behavior*, 22, 337-356.
- Pearlin, L.I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior*, 19, 2-21.
- Quittner, A.L., Glueckauf, R.K., & Jackson, D.N. (1990). Chronic parenting stress: Moderating versus mediating effects of social support. *Journal of Personality and Social Psychology*, 59, 1266-1278.
- Rabkin, J., & Struening, E. (1976). Events, stress, and illness. *Science*, 194, 1013-1020.
- Richer, J. (1976). The social-avoidance behavior of autistic children. *Animal Behavior*, 24, 898-906.
- Rodger, R.S. (1974). Multiple contrasts, factors, error rate, and power. *British Journal of Mathematics and Statistical Psychology*, 27, 179-198.
- Rodger, R.S. (1975). The number of non-zero, post hoc contrasts from anova and error-rate I. *British Journal of Mathematics and Statistical Psychology*, 28, 71-78.
- Rodrigue, J.R., Morgan, S.B., & Geffkin, G.R. (1991). A comparative evaluation of adaptive behavior in children and adolescents with autism, Down syndrome, and normal development. *Journal of Autism and Developmental Disorders*, 21, 187-196.
- Rook, K. (1990). Parallels in the study of social support and social strain. *Journal of Social and Clinical Psychology*, 9, 118-132.
- Rutter, M. (1977). Infantile autism and other child psychoses. In M. Rutter & L. Herson (Eds.), *Child Psychiatry* (pp. 717-739). Oxford: Blackwell Scientific Publications.
- Rutter, M., & Schopler, E. (1987). Autism and pervasive developmental disorders: Concepts and diagnostic issues. *Journal of Autism and Developmental Disorders*, 17, 159-186.

- Sarason, B.R., Sarason, I.G., & Pierce, G.R. (1990). Traditional views of social support and their impact on assessment. In B.R. Sarason, I.G. Sarason, & G.R. Pierce (Eds.), *Social support: An interactional view* (pp. 9-25). New York: John Wiley & Sons.
- Schaefer, C., Coyne, J.C., & Lazarus, R.S. (1982). The health-related functions of social support. *Journal of Behavioral Medicine*, 4, 381-406.
- Schopler, E., & Mesibov, G.B. (1984). Professional attitudes toward parents: A forty-year progress report. In E. Schopler & G.B. Mesibov (Eds.), *The effects of autism on the family* (pp. 3-17). New York: Plenum Press.
- Schopler, E., Mesibov, G.B., Shigley, R.H., & Bashford, A. (1984). Helping autistic children through their parents: The TEACCH model. In E. Schopler & G.B. Mesibov (Eds.), *The effects of autism on the family* (pp. 65-81). New York: Plenum Press.
- Selye, H. (1974). *Stress without distress*. Philadelphia: Lippincott.
- Sherbourne, C.D., & Harp, R.D. (1990). Marital status, social support, and health transitions in chronic disease patients. *Journal of Health and Social Behavior*, 31, 328-343.
- Shumaker, S.A., & Brownell, A. (1984). Towards a theory of social support: Closing conceptual gaps. *Journal of Social Issues*, 40, 11-36.
- Smith, K.W., & Sasaki, M.S. (1979). Decreasing multicollinearity: A method for models with multiplicative functions. *Sociological Methods and Research*, 8, 35-56.
- Southwood, K.E. (1978). Substantive theory and statistical interactions: Five models. *American Journal of Sociology*, 83, 1154-1203.
- Sugiyama, T., & Abe, T. (1989). The prevalence of autism in Nagoya, Japan: A total population study. *Journal of Autism and Developmental Disorders*, 19, 87-98.
- Tager-Flusberg, H. (1986). The semantic deficit hypothesis of autistic children's language. *Australian Journal of Human Communication*, 14, 51-58.
- Taylor, S.E. (1986). Stress and the development of illness. In S.E. Taylor (Ed.), *Health psychology*, (pp. 145-175). New York: Random House.

- Taylor, S.E., Falke, R.L., Shoptaw, S.J., & Lichman, R.R. (1986). Social support, support groups, and the cancer patient. *Journal of Consulting and Clinical Psychology, 54*, 608-615.
- Thoits, P.A. (1982). Conceptual, methodological, and theoretical problems in studying social support as a buffer against life stress. *Journal of Health and Social Behavior, 23*, 145-159.
- Thoits, P.A. (1986). Social support as coping assistance. *Journal of Consulting and Clinical Psychology, 54*, 416-423.
- Trivette, C.M., Deal, A., & Dunst, C.J. (1986). Family needs, sources of support and professional roles: Critical elements of family systems assessment and intervention. *Diagnostic, 11*, 246-267.
- Turner, R.J. (1981). Social support as a contingency in psychological well-being. *Journal of Health and Social Psychology, 22*, 357-367.
- Van Bourgondien, M.E., & Elgar, S. (1990). The relationship between existing residential services and the needs of autistic adults. *Journal of Autism and Developmental Disorders, 20*, 299-308.
- Veit, C.T., & Ware, J.E. Jr. (1983). The structure of psychological distress and well-being in general populations. *Journal of Consulting and Clinical Psychology, 51*, 730-742.
- Vinokur, A., & Selzer, M.L. (1975). Desirable versus undesirable life events: Their relationship to stress and mental distress. *Journal of Personality and Social Psychology, 32*, 329-337.
- Watson, D. (1990). On the dispositional nature of stress measures: Stable and nonspecific influences on self-reported hassles [Commentary]. *Psychological Inquiry, 1*, 34-37.
- Wethington, E., & Kessler, R.C. (1986). Perceived support, received support, and adjustment to stressful life events. *Journal of Health and Social Behavior, 27*, 78-89.
- Wheaton, B. (1985). Models for the stress-buffering effects of coping resources. *Journal of Health and Social Psychology, 26*, 352-364.
- Wikler, L.M. (1986). Periodic stresses of families of older retarded children: An exploratory study. *American Journal of Mental Deficiency, 90*, 703-706.

- Williams, A.W., Ware, J.E. jr., & Donald, C.A. (1981). A model of mental health, life events, and social supports applicable to general populations. *Journal of Health and Social Psychology*, 22, 324-336.
- Wills, T.A. (1985). Supportive functions of interpersonal relationships. In S. Cohen & S.L. Syme (Eds.), *Social support and health* (pp. 61-82). Orlando, FL: Academic Press.
- Winemiller, D.R., Mitchell, M.E., Sutliff, J., & Cline, D.J. (1993). Measurement strategies in social support: A descriptive review of the literature. *Journal of Clinical Psychology*, 49, 638-648.
- Wing, L. (1981). Language, social, and cognitive impairments in autism and severe mental retardation. *Journal of Autism and Developmental Disorders*, 11, 31-44.
- Wing, L. (1982). Clinical description, diagnosis, and differential diagnosis. In J.K. Wing & L. Wing (Eds.), *Psychoses of uncertain origin* (pp. 191-197). Cambridge: Cambridge University Press.
- Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9, 11-29.
- Wolf, L., & Goldberg, B. (1986). Autistic children grow up: An eight to twenty-four year follow-up. *Canadian Journal of Psychiatry*, 31, 550-556.
- Wolf, L.C., Noh, S., Fisman, S.F., & Speechley, M. (1989). Brief report: Psychological effects of parenting stress on parents of autistic children. *Journal of Autism and Developmental Disorders*, 19, 157-166.
- Wortman, C.B., & Conway, T.L. (1985). The role of social support in adaptation and recovery from physical illness. In S. Cohen & S.L. Syme (Eds.), *Social support and health* (pp. 281-302). Orlando, FL: Academic Press.
- Wortman, C.B., & Lehman, D.R. (1985). Reactions to victims of life crisis: Support attempts that fail. In I.G. Sarason & B. R. Sarason (Eds.), *Social support: Theory, research, and applications* (pp. 463-489). Dordrecht, Netherlands: Martinus Nijhoff.
- Yirmiya, N., Kasari, C., Sigman, M., & Mundy, P. (1989). Facial expressions of affect in autistic, mentally retarded and normal children. *Journal of Child Psychology and Psychiatry*, 30, 725-735.