

4-26-1996

Determinants of Resilience in Mothers of Children with Disabilities: An Exploratory Study

Anne Dussol Humes
Augsburg College

Follow this and additional works at: <https://idun.augsburg.edu/etd>



Part of the [Social Work Commons](#)

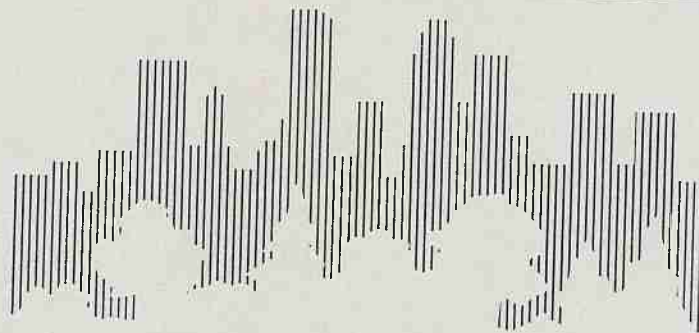
Recommended Citation

Humes, Anne Dussol, "Determinants of Resilience in Mothers of Children with Disabilities: An Exploratory Study" (1996). *Theses and Graduate Projects*. 208.

<https://idun.augsburg.edu/etd/208>

This Open Access Thesis is brought to you for free and open access by Idun. It has been accepted for inclusion in Theses and Graduate Projects by an authorized administrator of Idun. For more information, please contact bloomber@augsbu.edu.

AUGSBURG



C • O • L • L • E • G • E

**MASTERS IN SOCIAL WORK
THESIS**

Anne Dussol Humes

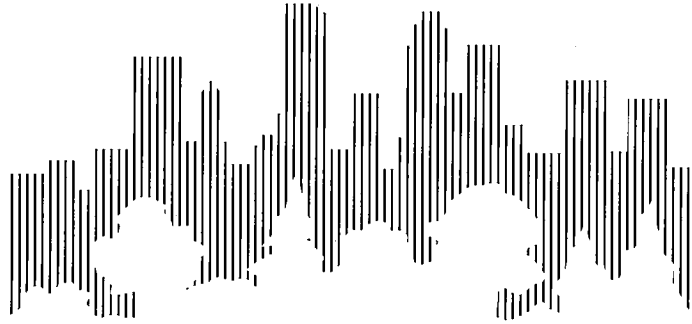
**Determinants of Resilience in
Mothers of Children with Disabilities:
An Exploratory Study**

1996

**MSW
Thesis**

Thesis
Humes

AUGSBURG



C • O • L • L • E • G • E

**MASTERS IN SOCIAL WORK
THESIS**

Anne Dussol Humes

**Determinants of Resilience in
Mothers of Children with Disabilities:
An Exploratory Study**

1996

Determinants of Resilience in
Mothers of Children with Disabilities:
An Exploratory Study

by

Anne Dussol Humes

A Thesis

Submitted to the Graduate Faculty
of Augsburg College
in Partial Fulfillment of the Requirement
for the Degree
Master of Social Work

Minneapolis, Minnesota

April, 1996

MASTER OF SOCIAL WORK
AUGSBURG COLLEGE
MINNEAPOLIS, MINNESOTA

CERTIFICATE OF APPROVAL

This is to certify that the Master's thesis of:

Anne Dussol Humes

has been approved by the Examining Committee for the thesis requirements for the Master of Social Work Degree.

Date of Oral Presentation: April 26, 1996

Thesis Committee:

Carol Kuechler
Carol Kuechler, MSSW, Ph.D.
Thesis Advisor

Joseph R. Clubb
Joseph Clubb, MSW
Thesis Reader

Sheila Maybanks
Sheila Maybanks, MSW, LICSW
Thesis Reader

Michael Schock
Michael Schock, MSW, Ph.D.
Thesis Reader

DEDICATION

This thesis is dedicated to the mothers of the Stillwater Parent Group whose resilience and love for their children provided the inspiration for this study.

ACKNOWLEDGEMENTS

I would like to thank Sally Swallen at Arc of Anoka and Ramsey Counties, Celeste denDaas and Chloette Haley at Arc Suburban, and Karen Sebesta at Arc of Hennepin County for their help with distributing the survey materials.

My gratitude also goes to my thesis readers: Sheila Maybanks, Joe Clubb, and Dr. Michael Schock for their valuable feedback and support.

I would never have made it through this process without the help of my thesis advisor, Dr. Carol Kuechler, whose encouragement and high expectations never wavered.

A final word of thanks goes to my family, Doug, Claire, and Laura, who've helped me remember the truly important things in life. I love you.

ABSTRACT OF THESIS

Determinants of Resilience in Mothers of Children
with Disabilities: An Exploratory Study

Anne Humes

April, 1996

This exploratory study examined the factors that contribute to the resilience of mothers of children with disabilities. Two measures of resources and support were administered to 16 mothers of children with disabilities who attended parent support groups offered by three agencies in the Twin Cities area. Findings indicated that social support, employment status, and number of children with disabilities are important to the understanding of resilience within this population. The small sample size and variability in scores suggest caution in the clinical application of the findings.

TABLE OF CONTENTS

	PAGE
List of Tables.....	vi
List of Figures.....	vii
Chapter I. Introduction	
Overview.....	1
Introduction.....	1
Historical Perspective.....	2
Purpose.....	4
Summary.....	4
Chapter II. Review of the Literature	
Overview.....	6
Theoretical Frameworks	
Resilience Theory.....	6
Social Support Theory.....	8
Issues Relevant to the Study of Resilience.....	9
Type of Disability.....	9
Social Support.....	11
Additional Variables.....	13
Summary.....	14
Research Question.....	14
Chapter III. Methodology	
Overview.....	16
Design.....	16
Concepts and Variables.....	17
Sample.....	19

Data Collection Instruments.....19

Administration of Data Collection Instruments.....22

Protection of Human Subjects.....23

Data Analysis.....23

Strengths and Limitations.....24

Summary.....25

Chapter IV. Findings

Overview.....27

Demographics of Respondents.....27

Characteristics of Children with Disabilities.....28

Findings.....31

Summary.....43

Chapter V. Discussion and Implications

Overview.....44

Discussion of Research Findings.....44

Strengths and Limitations.....49

Implications for Social Work Policy and Practice.....50

Suggestions for Future Research.....51

Summary.....53

References.....55

APPENDICES

Appendix A: Cover Letter to Participants.....60

Appendix B: Agency Consent Forms.....62

Appendix C: Data Collection Instruments.....66

Appendix D: State of MN Office of Ombudsman for Mental
Health and Mental Retardation Brochure.....76

LIST OF TABLES

TABLE	PAGE
1: QRS Scales in Three Domains.....	22
2: Gender and Age for Each Child with Disabilities.....	29
3: Type of Disability.....	30
4: Services Received in Each Family for Child(ren) with a Disability.....	31
5: Number of Responses for Each Resource Category by Helpful or Stressful.....	33
6: Type of Child Disability Compared to Mothers' QRS Patient Problems Domain Score, a Summation of Scales 1,2, & 8.....	35
7: Comparison of Married Mothers' QRS Respondent Attitudes Domain Score and Combined Eco-map Scores of Friends Spouse/Partner, and Extended Family Categories.....	37
8: \$35,000+ Annual Income Level Compared to QRS score on Financial Stress Scale and Eco-map Scores on Finances...38	38
9: Comparison of Non-employed Mothers' Total QRS and Total Eco-map Scores.....	39
10: Comparison of Employed Mothers' Total QRS and Total Eco-map Scores.....	40
11: Mothers Employment Status Compared to Age Range of the Children.....	41
12: Number of Children with Disabilities Compared to Average Total QRS and Average Total Eco-map Scores.....	41
13: Number of Children Living in the Home Compared to Average Total QRS and Average Total Eco-map Scores.....	42
14: Number of Services Received Compared to Average QRS and Eco-map Scores.....	43

LIST OF FIGURES

FIGURE	PAGE
1: Age Range of Respondents.....	28
2: Age Range of Children with Disabilities.....	29
3: Total Eco-map Score.....	34

Introduction

Overview

This chapter contains background information on the research project and discusses the purpose and significance of the study.

Introduction

Research has shown that the majority of the burden of care of children with disabilities is typically carried by the mother (Sloper & Turner, 1993; Wallander, Pitt, & Mellins, 1990), and that there are unique problems associated with having a child with a disability that often lead to high levels of stress (Scott & Sexton, 1989).

Several factors have been identified as causes of stress in this population including type of disability of the child, lack of social support, and financial status. Previous studies about this population have focused primarily on measures of distress rather than coping mechanisms and strengths (McCubbin & Huang, 1989). Consequently, mothers have been stereotyped as overly stressed and mentally unstable, and their children as great burdens on their lives.

The theoretical frameworks for the study, as described in chapter two, include resilience and social support theories. Resilience theory provides the backbone of the study with its focus on a strengths perspective. Social support theory offers a depth of understanding about the aspect of social support which is critical to the resilience of this population (Gill & Harris, 1991).

Historical Perspective

A brief review of the literature dating back as far as 1943 provides insight into the origins of the image of the unstable, overprotective mother of a child with disabilities that is still found in literature today.

Levy, in his classic 1943 book Maternal Over-Protection, states that:

intensification of maternal care initiated by conditions in the child of severe illness, accident, or deformity is a very common occurrence in everyday life. That mothers tend to favor the weaker, sicklier and generally more dependent child is an honored lay observation (p.25).

Levy goes on to say that he did not include mothers of children with disabilities in his study because their over-protection was "obvious".

Ross also addresses the issue of maternal over-protection in his 1964 work The Exceptional Child in the Family. He observes that:

features in the mother's personality, including her acceptance of the feminine role, her maternal role satisfaction, her marital adjustment, and her perception of the specific child, may have engendered repressed hostile-destructive impulses toward this child which she defends against by their dynamic opposite of over-protection (p.16).

Again, this theory of over-protection, never empirically tested with a control group of mothers of children without

disabilities, is framed in a negative manner.

The concept of maternal hostility toward a child with disabilities is also evident in earlier literature. In the book The Backward Child and His Mother (1964), Mannoni describes mothers of children with developmental disabilities as suicidal and homicidal. He observes that:

the mother-child relationship will always, in such cases, have an aftertaste of death about it,...of death disguised usually as sublime love, sometimes as pathological indifference, and occasionally as conscious rejection; but the idea of murder is there, even if the mother is not always conscious of it (p.4).

Perhaps the most influential of these early works is Bruno Bettelheim's cornerstone book on autism The Empty Fortress (1967). In this book he portrays mothers of children with autism as cold and unfeeling, and he asserts that it is their wish that their child didn't exist that causes her/his autism. In a section on maternal ambivalence he writes:

The utter demandingness inherent in these children's disturbance, their needfulness of the mothering person, the rarity of positive responses-this and much more will generate ambivalence. At its core lies resentment of the degree to which they enslave, through negation and passivity... (p.126).

Though few of the writings in the past two decades have portrayed mothers of children with disabilities in as negative a vein as their predecessors, current literature still maintains many of the stereotypes of this population

that have evolved over time. For example, Singer and Farkas, in their 1989 study of 27 mothers of children with disabilities indicated that they expected the mothers to express high levels of stress related to caring for their disabled children. Byrne and Cunningham (1984) state that "the assumption that psychological impairment is an inevitable consequence for family members has led in turn to the generalisation that families of mentally handicapped children form a homogeneous group" (p.847).

Purpose

The purpose of the study is to identify and explore the thoughts mothers of children with disabilities have about the people, agencies, and activities that contribute to their resilience. Its design is unique in that it uses a self-reporting format in the exploration of resilience. Beardslee (1989) states that "the place to begin in studying resilient individuals is with what they themselves report about their own lives, especially about what has sustained them" (p.267).

The research will have implications for professionals who work with families of children with disabilities because it offers a framework for understanding their needs, and addresses those aspects of their lives that provide support. The study will ultimately be helpful in the development of responsive, strength-based programming.

Summary

This chapter has suggested the need for a study of mothers of children with disabilities that identifies their resilience rather than their susceptibility to stress.

Mothers have been identified as the primary caregivers of children with disabilities (Sloper & Turner, 1993), and have been stereotyped in past and present literature. This study explores the factors that contribute to resilience in this population through the framework of resilience and social support theories.

Review of the Literature

Overview

This literature review investigates factors that contribute to resiliency in mothers of children with disabilities. The conceptual frameworks of resilience and social support are defined in the context of how they guide the study and help to understand the issue. Studies that identify coping strategies, the impact of supportive social networks, and type of disability as they relate to the degree of stress experienced will be highlighted.

Previous studies have been primarily negative in their depiction of this population (McCubbin & Huang, 1989). For example, Wallander, Pitt, & Mellins, in their 1990 study of 119 mothers of children with disabilities labeled these women "psychologically distressed", more so than mothers of "healthy" children. This terminology has served to stereotype mothers of children with disabilities as overly stressed and mentally unstable, and their children as unhealthy burdens.

Theoretical Frameworks

Resilience theory.

Because there have been no standardized instruments developed for the measurement of resilience (Beardslee, 1989), there is no empirical research to support this framework. Haggerty, Sherrod, Garmezy, & Rutter (1994) state that "The construct of resilience is potentially valid but research proof is needed to substantiate its meaning" (p.13). However, much has been written on the subject, and the literature generally seems to concur that resiliency is the

result of good adaptation to some type of severe stress (Beardslee, 1989; Higgins, 1994; McCubbin & McCubbin, 1988; Rutter, 1987).

Rutter, (1987) suggests that "resilience is concerned with individual variations in response to risk" (p.317). That is, it is really about how each person responds to potentially stressful situations. The questions about resilience attempt to understand why some people give up hope in the face of adversity, while others conquer it and manage to maintain their ability to "snap back".

Wolin and Wolin, in their 1993 book The Resilient Self, outline seven aspects of resilient individuals which they term "resiliencies" (p.5). These include: insight, independence, relationships, initiative, creativity, humor, and morality. They contend that people tend to cluster by personality type, and that few people can claim all seven resiliencies.

Higgins (1994), in her exploration of the theory of resilience, states that "an additional strength of the resilient is their ability to acknowledge and experience significant psychological pain and still maintain their ability to love well" (p.2). This ability to love unconditionally is a critical aspect of resilience in the population of mothers of children with disabilities identified for this study.

For this research resilience theory is used as a framework for understanding what has helped mothers of children with disabilities adapt to their potentially

stressful situations and continue to provide loving care to their children.

Social support theory.

Though there appears to be some conceptual ambiguity about the term and its corresponding theories (Shinn, Lehmann, & Wong, 1984; Shumaker & Brownell, 1984), social support has been defined by Shumaker & Brownell (1984) as "an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient" (p.11).

Social support has been further characterized as consisting of significant others who: (a) assist others in the mobilization of their own psychological resources in order to deal with emotional problems; (b) share people's tasks; (c) provide individuals with materials, money, skills, tools, information, and advice in order to help them with their particular stressful situation (Brownell & Shumaker, 1984).

Critical to the theory of social support is the belief that interpersonal relationships are central to the quality of an individual's life. Social support has also been hypothesized to mitigate stress and sustain health (Brownell & Shumaker, 1984).

Within this study social support is explored in an effort to examine its impact on the resilience of mothers of children with disabilities. As a theoretical construct it is used to look at how the people, agencies, and activities in the lives of these mothers enhance their well-being.

Issues Relevant to the Study of Resilience

Research on families of children with disabilities has been inconclusive in determining the levels of stress experienced by the parents (Dyson, 1991; Friedrich, 1979). One body of literature suggests that those parenting a child with handicaps encounter greater stressors than parents of children without disabilities (Flynt, Wood, & Scott, 1992; Sloper & Turner, 1993; Wallander, Pitt, & Mellins, 1990). Others have critiqued the methodology, and pointed out that empirical findings are too inconsistent to make such conclusions (Dyson, 1991; Friedrich, 1979).

The research about mothers of children with disabilities explored for this literature review studied factors related to the amount of stress experienced by this population. These variables include: type of disability of the child, social support, and financial stress.

Type of disability.

The characteristics of the child, including: 1) type of disability, 2) level of impairment, and 3) amount of care required, have been hypothesized by some researchers to be related to the amount of stress experienced by mothers. Beckman, in her 1983 study of 31 mothers with handicapped infants, specifically examined the relationship between child characteristics and the amount of stress experienced by the families through interviews using several instruments including the Questionnaire on Resources and Stress (Holroyd, 1974), and the Holmes and Rahe Schedule of Recent Experience (Holmes & Rahe, 1967). Data from these instruments, which

measure stress in families, were paired with the results of the Carolina Record of Infant Behavior (Simeonsson, 1979), which measures the characteristics of young children with handicaps. While her data suggested the hypothesized link between characteristics and stress, she maintained that her findings were largely inconclusive.

McCubbin and Huang (1989), also pointed out inconsistencies in findings relating stress to type of child disability. In their study of 166 families, which included instruments to measure the child's overall health as well as several measures of parental stress, only fathers were found to be negatively impacted by the disability level of the child, and then only at the most severe level of impairment.

The results of another research study with 119 mothers that used a variety of measures in comparing the child's functional level to the degree of maternal stress experienced concluded that there is no association between child functional independence and maternal stress (Wallander, Pitt, & Mellins, 1990).

However, Sloper and Turner (1993), found that child characteristics, particularly communication problems, did impact the stress levels of mothers. They studied 107 mothers of children with a variety of disabilities. The study consisted of a self-report questionnaire and a lengthy interview process which sought to obtain information about the level of the child's disability, help-seeking, service support, and life satisfaction. Findings suggested the relationship between severity of disability and parental

stress among mothers in the study.

A study of 422 families utilizing early intervention programs, conducted by Bailey, Blasco, and Simeonsson (1992) also hypothesized that disability type affected stress levels of mothers. They found that scores on the Family Needs Survey (Bailey & Simeonsson, 1988) did not vary a great deal based on the type of child disability.

Social support.

Social support, as defined by Flynt, Wood, and Scott (1992), includes intimate relationships, friendships, and community support. Based on their study of 80 mothers of children with developmental disabilities that included the Questionnaire on Resources and Stress-Short Form (Friedrich, Greenberg, & Crnic, 1983), Flynt et al. (1992) concluded that more supportive social networks are associated with improved parental well-being.

Gill and Harris (1991), in their study of 60 mothers of children with autism, measured the effects of social support on the womens' response to the stresses of raising a child with a disability. Five instruments were used, including two that specifically measured social support: the Interpersonal Support Evaluation List (Cohen & Hoberman, 1983); and the Inventory of Socially Supportive Behavior (Barrera, Sandler, & Ramsay, 1981). Gill and Harris found that mothers of children with autism who perceived social support as more available experienced fewer stress-related and depressive symptoms.

Conversely, Frey, Greenberg, & Fewell (1989), in their

study of 96 parents (48 mothers and 48 fathers) of children with a range of disabilities, used ten instruments including the Questionnaire on Resources and Stress-Friedrich Edition (Friedrich, Greenberg, & Crnic, 1983), the Marital Adjustment Scale (Locke & Wallace, 1959), and the Brief Symptom Inventory (Derogatis, 1975). They found that the absence of social networks, as measured by the Family Support Scale (Dunst, Jenkins, & Trivette, 1984) contributes to the parenting stress of fathers, but not of mothers.

Gill and Harris (1991), state that "although social support has been consistently demonstrated to be related to coping ability and psychological well-being, it may not be the causal factor in determining the ability to cope or remain emotionally healthy" (p.408). They go on to hypothesize that individual personality traits, specifically hardiness (defined as control, commitment, and challenge), may be responsible for the ability to cope.

Intimate relationships, defined here as affectionate or loving close personal relationships, have been found to play a key role in buffering stress experienced by mothers of children with disabilities (McCubbin & Huang, 1989). According to Friedrich (1979), the most significant contributor to the mother's feelings of capability in coping with her child's handicaps are her feelings of security in the marital relationship.

Flynt, Wood, and Scott, in their 1992 study of 80 mothers of children who are developmentally delayed, compared results of the Questionnaire on Resources and Stress-Short

Form (Friedrich, Greenberg, & Crnic, 1983), and the Questionnaire on Social Support (Crnic, Greenberg, Robinson, & Ragozin, 1984), and found that respondents relied more on intimate support than on any other type of relationship.

In their study of 140 mothers of children with developmental disabilities, Friedrich, Wiltturner, & Cohen (1985), used a number of instruments to measure social support including the Marital Adjustment Inventory (Locke-Wallace, 1959), and the Family Relationship Index from the Family Environment Scale (Moos & Moos, 1981). They found that changes in marital happiness negatively impacted parent and/or family problems.

All of the studies examined for this literature review looked more closely at the support received from intimate relationships than from other types of social support systems. Extended family, friendships, and community support were all found to warrant further exploration in their role as coping resources for mothers of children with disabilities.

Additional variables.

There are several other variables that may be related to the resilience of this population that have not been fully explored in the research and subsequent literature. For example, financial resources, identified by both Bailey, Blasco, & Simeonsson (1992), and Sloper & Turner (1993) as critical to a family's ability to cope with a child with a disability, have not been examined in studies of coping ability.

None of the studies explored racial or cultural factors as they relate to the resilience of mothers of children with disabilities. The number and types of services received for the identified child has also been overlooked. Other factors, including the number of children with disabilities in each family and the total number of children in the home may play a role in resilience, but they have yet to be examined.

Summary

This review of literature has briefly outlined two theoretical frameworks used in this study: resilience theory, and social support theory. A look at the negative stereotypes portrayed in the literature of the past indicates the need for research based on factors that contribute to the resilience of mothers of children with disabilities rather than those that focus on stressors.

Research Question

Studies of mothers of children with disabilities have been found to focus on factors that contribute to stress, rather than those that contribute to resilience. Dyson, (1991), suggests that "Future researchers should explore family resilience to the task of raising a child with handicaps. Special consideration should be given to identifying factors protecting families from the potentially negative impact of raising such a child" (p.628).

This literature review has identified a lack of a strengths-based approach in the studies about mothers of children with disabilities. As a result, this research will focus on the question: What are the factors that contribute

to the resilience of mothers of children with disabilities?

Methodology

Overview

This chapter will outline the methodology used for this study to explore the research question: What are the factors that contribute to the resilience of mothers of children with disabilities?

Design

This study employs an exploratory design utilizing a self-report format. Three instruments were used to collect data from mothers of children with disabilities: the Participant Information Sheet, the Eco-map Diagram, and the Short Form of the Questionnaire on Resources and Stress (Holroyd, 1979).

Mothers were recruited from support groups provided by three Arc agencies: Arc of Anoka and Ramsey Counties, Arc Suburban, and Arc of Hennepin County. Arc, founded in 1946 as the Association for Retarded Citizens, is now known by its acronym and serves people with all types of disabilities and their families. Services offered by the agencies include advocacy, information and referral, and support and education.

The literature identified parent characteristics, child characteristics, and social support as contributors to the stress of this population, and these factors were explored in the study. The qualitative nature of the Eco-map instrument, which solicited input from participants, provided further opportunity for exploration of the nature of social system supports.

Concepts and Variables

A key concept for the framework of this research study is "resilience", which has been conceptualized by McCubbin and McCubbin (1988), as "characteristics, dimensions, and properties of families which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations" (p.247). This is operationalized through the use of the Eco-map and the Questionnaire on Resources and Stress Short Form (Holroyd, 1979).

Literature has identified several areas that contribute to either the stress experienced or the coping abilities of mothers of children with disabilities. These variables include child characteristics or type of disability, and social support. Other factors explored in this research include financial status, employment status of the mother, amount of services received for the child, number of children with disabilities in each family, and total number of children in the home.

The type of disability, a key variable, is conceptualized as developmental disabilities, autism, physical and sensory handicaps, communication disorders, and attention deficit/hyperactivity.

The term "developmental disabilities" has both a federal and a practice definition. It is defined by the Developmental Disabilities Act of 1994 (P.L. 103-230) as:

...a severe, chronic disability of an individual 5 years of age or older that: A) is attributable to a mental or physical impairment or combination of mental

and physical impairments; B) is manifested before the person attains age twenty-two; C) is likely to continue indefinitely; D) results in substantial functional limitations; E) Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services... (Minnesota Governor's Council on Developmental Disabilities, May 1995, p.1).

The practice definition of the term "developmental disabilities" is used in this study. Parents of children under the age of 18 use the term "developmental disabilities" to describe the condition formerly known as "mental retardation". Parents attending Arc support groups consider developmental disabilities to be separate from other disabilities, and especially distinguish it from autism (S. Swallen, personal communication, April 1, 1996). C. Bryan (personal communication, April 3, 1996) states that "Mental retardation is an outdated term that is now considered by many people to be offensive. The State of Minnesota Office of the Ombudsman for Mental Health and Mental Retardation now uses the term 'developmental disabilities' synonymously with 'mental retardation'". (See Appendix D).

The conceptualization of social support by Flynt, Wood, and Scott (1992) as intimate relationships, friendships, and community support has been used in this research. The Eco-map Diagram serves as a vehicle for the measurement of this concept, as participants were asked to indicate the nature of their relationships with each of these aspects of social support.

Financial status is conceptualized as income level, and number of services received includes those from both public and private agencies, including physical, mental, and occupational health services. All of these concepts are measured by name on the participant information sheet.

Sample

A purposive convenience sample of mothers of children with disabilities were identified for inclusion in this study. Three agencies in the Twin Cities area serving people with disabilities and their families agreed to distribute the data collection instruments to those mothers who attend support groups which the agencies sponsor (See Appendix B).

The mothers who responded were all voluntary participants in the groups, and had children under the age of 18 with disabilities.

Data Collection Instruments

Three data collection instruments were used for this study (See Appendix C). The first was a Participant Information Sheet. This was developed by the researcher in order to obtain information such as age, race, marital status, income, and type of disability of the child. This was used in conjunction with the Eco-map and QRS as a means of exploring how these variables relate to resilience.

The Eco-map was used in order to explore the sources of strength and stress in the lives of mothers of children with disabilities. Compton and Galaway (1989), in their description of this tool state that the Eco-map:

maps in a dynamic way the ecological system, the boundaries of which encompass the person or family in the life space. Included in the map are the major systems that are a part of the family's life and the nature of the family's relationship with the various systems (p.163).

An Eco-map Instrument was created for use in this study. It included preconstructed circles for participants' social support systems, finances, recreation and services. Respondents were encouraged to be creative and think about additional people, agencies, and activities that they could add.

The Eco-map Instrument was adapted by the researcher in response to feedback given in a non-research setting by a group of mothers of children with disabilities who had used an earlier version. As a result of their input about the clarity of the instructions and the perceived willingness of other mothers to complete the instrument, the researcher modified the format. These modifications include: the use of only the first initial and year of birth of the participant in the middle circle, inclusion of lines drawn from the middle circle to each of the outlying circles, and the omission of arrows that indicate the flow of energy in relationships. These changes were made to simplify the instrument. Study respondents were still asked to indicate the nature of their relationships with each Eco-map circle category by drawing a thick connecting line for strong relationships, and a line with hash marks for stressful

relationships. These lines served as a means of interpreting the extent to which each relationship is a source of strength or one of stress.

The third data collection instrument was the 66-item short form of the Questionnaire on Resources and Stress (QRS) created by Dr. Jean Holroyd. Developed in 1979, this questionnaire was designed specifically for respondents who have a family member with a disability. The reliability, or internal consistency has been estimated at .79 to .85. Median coefficients ranged from .31 on scale 6 to .82 on scale 2 (Holroyd, 1987). Three types of validity have also been established: content, criterion, and construct. Holroyd, (1987) states that:

the criterion validity studies demonstrate capability of QRS scores to differentiate groups representing different populations, different diagnoses, different external criteria of 'stress', different situations, and different cultures, as well as its utility as both predictor and criterion of stress...The QRS can be expected to be useful over a range of situations and samples (p.69-70).

The short form of the QRS is divided into eleven scales that have been validated with families of children and adolescents with a variety of physical and mental illnesses or developmental disabilities. Using eleven scales, the instrument covers three domains: patient problems, respondent attitudes, and family problems (See Table 1).

Table 1

QRS Scales in Three Domains

<u>Domain</u>	<u>Scale #</u>	<u>Scale Theme</u>
Patient Problems	1	Dependency & Management
	2	Cognitive Impairment
	8	Physical Limitations
Respondent Attitudes	4	Life Span Care
	6	Lack of Personal Reward
	7	Terminal Illness Stress
	10	Preference for Institutional Care
	11	Personal Burden for Respondent
Family Problems	3	Limits on Family Opportunities
	5	Family Disharmony
	9	Financial Stress

The QRS was chosen for its established reliability and validity, its widespread use in numerous research studies, and its applicability to a variety of populations. The 66-item short form requires considerably less time to complete than its 285-item counterpart, and was therefore deemed more feasible for use in a study with two other instruments.

Administration of Data Collection Instruments

Three agencies in the Twin Cities area that serve people with disabilities and their families agreed to distribute the

data collection instruments to mothers who attend support groups which they sponsor (see Consent Forms, Appendix B). Groups members were given a cover letter describing the study and its voluntary nature (see Appendix A) as well as a verbal explanation by the group facilitators. Those who indicated an interest in participating were given a packet containing a cover letter and the three instruments. They were asked to complete these and return them to the researcher in the stamped envelope that was provided.

Protection of Human Subjects(see Cover Letter, Appendix A)

The method of administering the instruments described above ensured anonymity and confidentiality of research subjects from the researcher. The researcher never met group participants, and no individual identifying information was collected in the study. Participants were instructed not to put their names or the names of their child(ren), or any other identifying information on the research materials.

Participants were given access to the researcher via address and phone number, and were encouraged to contact her if they had any questions. They were also informed that the materials in the study were of a personal and sensitive nature, and that if they experienced severe distress as a result of their participation in the study, they were to contact their support group facilitator.

Data Analysis

Data were analyzed based on variables identified in the literature such as type of child disability, financial status, and social support. Comparisons were made between

scores on the Eco-map and QRS instruments as they related to demographic variables from the Participant Information Sheet. Those people, activities, and agencies that were indicated by the participants on the Eco-map as helpful were compared to scores on Holroyd's questionnaire.

Strengths and Limitations

The methodology of this study has inherent strengths as well as limitations. The use of the three instruments is a strength because it provides convergent validity, that is, the results of one instrument are compared to the results of the other instrument; they measure the same thing (Rubin & Babbie, 1993). The Eco-map and QRS have a unique way of measuring both resources and stress, and comparisons can be made.

Reliability and validity have been established for the QRS Short Form (Holroyd, 1987). This widely used measure provides a stable basis from which to understand and interpret data from the other instruments.

The adapted Eco-map Diagram solicits qualitative responses from participants that can be interpreted through quantitative measures. Participants' thoroughness in the completion of this instrument made it a critical tool for the study.

There are four primary limitations to the methodology of the study. The first is that the convenience sampling method poses a threat to the external validity of the study because the participants are all drawn from the same area and service setting. The findings are not generalizable to other

populations of mothers of children with disabilities. Second, the mothers were all members of support groups and thus have already demonstrated an awareness of the need for support and an ability to seek support when it is needed. They may be more connected to helping resources than mothers who are not in groups. Third, the study materials take approximately thirty minutes to complete, and this may have been too long for mothers with small children. Because of the anonymity of the study, the researcher was unable to send reminder notices or additional study packets to participants, and this may have added to the low participation rate of the study.

Lastly, the respondents tend to be a homogeneous group. There is no racial or cultural diversity because the sample is 100% Caucasian despite the efforts of the researcher to target groups serving both African American and American Indian populations. The participants are almost all college educated, and most have an income level of over \$35,000 per year. The combination of these factors limits the transferability of the study findings to other populations.

Summary

This chapter described the methodology employed for the study, including the three instruments that were used. These included the Participant Information Sheet, the Eco-map Diagram, and the Short Form of the Questionnaire on Resources and Stress (holroyd, 1979). The instruments, used together, provide a clear picture of the supports and stressors in the lives of the participants. Concepts addressed in the study included resilience and social support. The sample population

of mothers of children with disabilities, obtained through three agencies offering support groups in the Twin Cities, was clearly defined. Strengths and limitations were also outlined.

Findings

Overview

This chapter includes the research findings of the study. Of the surveys distributed in the seven groups offered by the Arc agencies, sixteen mothers of children with disabilities completed and returned the survey materials. Because the potential population size was not known, a response rate is not able to be determined.

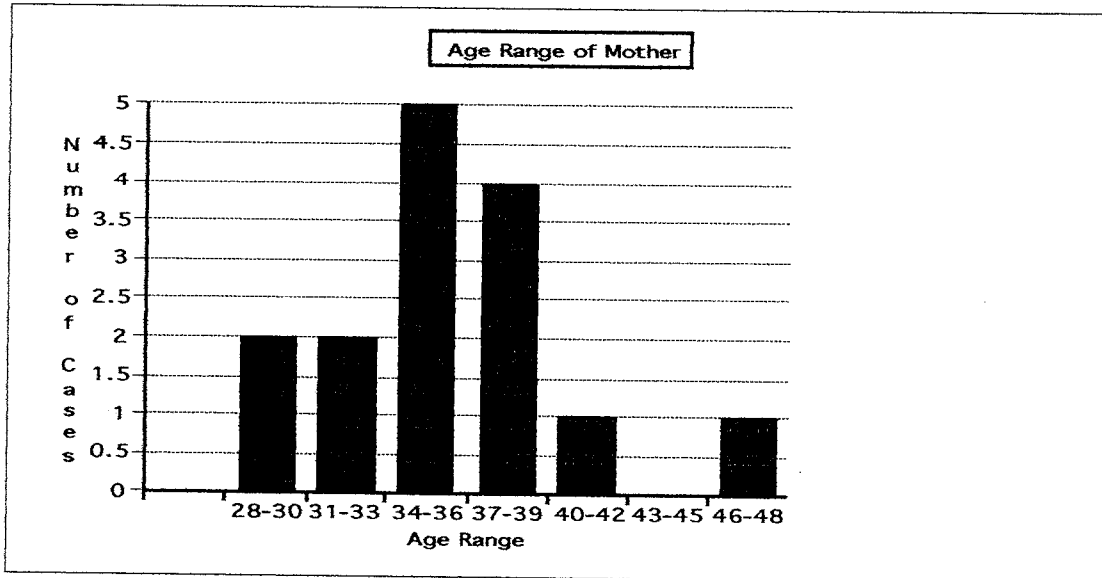
Each survey packet contained: 1) the Participant Information Sheet; 2) the Eco-map Diagram; and 3) the Questionnaire on Resources and Stress Short Form. The data from each of the three instruments were analyzed individually and comparatively. The results are presented in three main sections: demographics of respondents, characteristics of the children with disabilities, and findings related to disability type, social support, finances, employment, and number of children. The Questionnaire on Resources and Stress and the Eco-map are used comparatively to understand these variables.

In the tables in this chapter, "no response" by participants will be reflected with blanks.

Demographics of the Respondents

The mean age of the respondents was 36, with a range of 28-47 and a mode of 35 as depicted in figure 1.

Figure 1. Age Range of Respondents, N=15



Thirteen of the respondents were married, two were divorced, and one had never been married. The majority of the mothers had an education level of some college or beyond, while 13% (n=2), reported completion of high school only. One respondent had completed graduate school.

Eighty-one percent (n=13) of the participants reported a family income level of \$35,000 or more in 1994. One responded in each of the three remaining categories of \$15,000-\$24,999, \$25,000-\$29,999, and \$30,000-\$34,999.

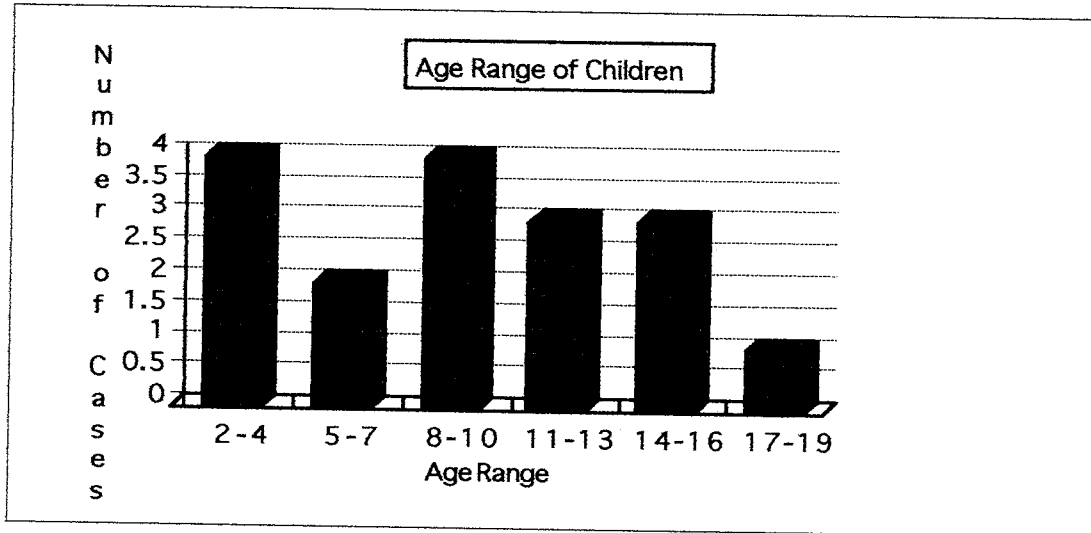
Characteristics of the Children with Disabilities

For the sixteen study participants there were a total of eighteen children with disabilities reported in the survey materials. Because respondents were instructed only to answer questions with which they felt comfortable, not all of the questions were answered by each mother. Characteristics of

age and gender were described for seventeen children, while all eighteen were identified by disability type.

As depicted in Figure 2, the age range of the children was 2-17 with a mean age of 9 and a median age of 10.

Figure 2. Age range of children with disabilities, N=17



Eleven of the children with disabilities being cared for by study respondents were male, while 6 were female. Table 2 shows age and gender for each child with disabilities.

Table 2

Gender and Age for Each Child with Disabilities, N=17

		Age Range					
		2-4	5-7	8-10	11-13	14-16	17-19
Gender	Female	2	1	2	1		
	Male	2	1	2	2	3	1

Mothers reported caring for 18 children with a variety of disabilities. As displayed in Table 3, the majority of respondents (n=12) reported that their child had developmental disabilities. Three respondents indicated their child had autism, while two reported physical disabilities. One mother answered that her child had cerebral palsy.

Table 3

Type of Disability

<u>Disability</u>	<u># of Mothers</u>	<u>%</u>
Developmental	12	67%
Autism	3	17%
Physical	2	11%
Cerebral Palsy	1	5%

Mothers were asked to identify the type of services they receive for their child(ren) with disabilities. As reported in Table 4, occupational and speech therapy, personal attendants and TEFRA (Tax Equity Family Reinvestment Act) services were most frequently reported. No one identified specialized nursing care as a service being received, however four participants indicated that they receive other services including Early Childhood Special Education, Account Management, County Case Management, and Residential Services. Respondents were asked to check all that apply for this question, therefore percentages equal more than 100%.

Table 4

Services Received in Each Family for Child(ren) With a Disability, N=16

<u>Service</u>	<u># of Responses</u>	<u>% of Total Responses</u>
Occupational Therapy	10	63
Speech Therapy	9	56
TEFRA	8	50
Personal Care Attendant	8	50
Respite Care	5	31
Physical Therapy	4	25
Other*	4	25

*Other services included: Early Childhood Special Education, Account Management, County Case Management, and Residential

Eco-Map Scores

Respondents were asked to identify their relationship with each eco-map category on the Eco-map instrument (See Appendix C). Nine eco-map categories were labeled in circles on the instrument:

- | | | |
|------------------|-------------|------------------|
| *Social Services | *Finances | *Spouse/Partner |
| *Work | *Religion | *Extended Family |
| *Health Care | *Recreation | *Friends |

Participants were invited to add their own eco-map categories. The additional categories were content-analyzed and aggregated by theme to include: Support Group, Home Health/PCA, School, and Other Children.

Participants were then asked to indicate helpful relationships by drawing thick lines between the inner circle (representing themselves) and each helpful eco-map category, and stressful relationships by drawing lines with hash marks. Each circle reported to be helpful was given a score of -1; each category that was stressful was given 1; no answer received 0 points. This method of scoring was established to parallel the QRS scoring. That is, as with QRS total and scale scores, the lower the score, the lower the stress. A score of 0 for no answer results in no affect on the overall score.

Table 5 illustrates the helpful and stressful responses for each eco-map resource identified.

Table 5

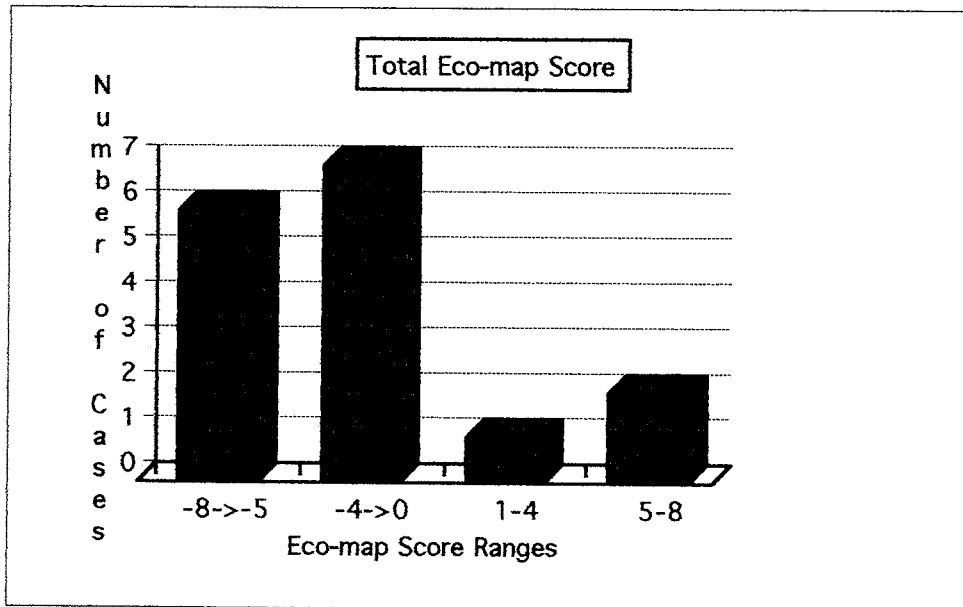
Number of Responses for Each Resource Category by Helpful or Stressful

<u>Resource</u>	<u>n</u>	<u>Helpful</u>	<u>Stressful</u>
Support Group	3	100%	0%
Extended Family	16	87%	13%
Friends	14	71%	29%
Recreation	14	71%	29%
Social Services	15	67%	33%
Work	11	64%	36%
Spouse/Partner	16	62%	38%
Finances	14	57%	43%
Health Care	16	56%	44%
Religion	14	50%	50%
Other Children*	6	50%	50%
Home Health/PCA	7	43%	57%
School	8	38%	62%

*Comments included: other children in family, 2 year old, puberty issues, daughter, and new baby.

As depicted in Figure 3, total Eco-map scores ranged from -8 to 8, with an average total score of -2.4. The lowest possible Eco-map score was -13.

Figure 3. Total Eco-map Score, N=16



Questionnaire on Resources and Stress (QRS) Scores

The short form of the Questionnaire on Resources and Stress (QRS) (see Appendix C) contains eleven scales with six questions in each scale. The highest possible QRS score for the short form is 66. Total QRS scores for this study ranged from 16 to 39, with an average score of 27 and a median of 26. For the purpose of this study, the QRS scores are used solely as a means of comparison to the Eco-map instrument and other study variables such as demographics and are not assigned an independent value.

Disability Type

The type of disability of the child(ren) in each case was compared to the score on the Patient Problems domain of the Questionnaire on Resources and Stress Short Form (QRS) which includes: scale 1, Dependency and Management; scale 2,

Cognitive Impairment; and scale 8, Physical Limitations. The score range for the Patient Problems domain was 2 to 15, with an average score of 8 and a median of 10. The lowest number of possible points for this domain was 0 which indicates the lowest level of stress. The highest level of stress is indicated with a score of 18. These results are listed in Table 6.

Table 6

Type of Child Disability Compared to Mothers' QRS Patient Problems Domain Score, a Summation of Scales 1, 2, & 8

Disability Type	QRS Patient Problems Domain Score			
	(least stress)	SCORE RANGE		(highest stress)
	1-4	5-8	9-12	13-16
Developmental (n=10)	4	1	4	1
Autism (n=3)		2	1	
Physical (n=2)		1		1
Cerebral Palsy (n=1)			1	

Social Support

Social support has been analyzed through a comparison of the Respondent Attitudes domain score of the QRS with the combined Eco-map score for the categories of Spouse/Partner, Extended Family, and Friends. This analysis was done for married respondents only.

The Respondent Attitudes domain of the QRS is labeled "Personal Problems Scales" in the long form of the QRS and includes scales determined by the author of the questionnaire to measure social support (Holroyd, 1984). The Respondent Attitudes domain of the short form of the QRS used in this study includes: scale 4, Life Span Care; scale 6, Lack of Personal Reward; scale 7, Terminal Illness Stress; scale 10, Preference for Institutional Care; and scale 11, Personal Burden for Respondent. The score range of married study participants for the Respondent Attitudes domain was 9 to 18, with an average score of 13 and a median of 13.

The Eco-map categories of Spouse/Partner, Extended Family, and Friends represent aspects of social support identified in the literature (Brownell & Shumaker, 1984). For analysis purposes, responses to each of these categories were combined to form a composite score. These combined Eco-map category scores were compared with the QRS Personal Problems domain scores for married respondents (Table 7).

The lowest number of points, indicating lower levels of stress was 0 for the QRS and -3 for the Eco-map categories.

Table 7

Comparison of Married Mothers' QRS Respondent Attitudes Domain Score and Combined Eco-map Scores of Friends, Spouse/Partner, and Extended Family Categories, N=13

		QRS Respondent Attitudes Domain		
		9-11	12-14	15-18
<u>Eco-map</u>	-3->-2	1	4	2
<u>Friends,</u>				
<u>Spouse/</u>				
<u>Partner,</u>	-1->0	1	1	1
<u>Extended</u>				
<u>Family</u>	1->2		1	
	3		1	1

Finances

For the Family Problems domain of the QRS, only the Financial Stress scale was analyzed for this study because of the importance of exploring the variable of financial stress identified in the literature (Sloper & Turner, 1993). It is compared to the finances category in the Eco-map instrument.

In Table 8, the QRS score on Scale 9 (Financial Stress) was compared to the Eco-map score in the finances circle for mothers indicating a family income of \$35,000 or more (N=13). The Eco-map score is -1 if the relationship was reported as helpful, 0 if there was no answer, and 1 if the relationship

was reported as stressful. QRS scores are based on a possible of 6 points total for each scale, with high scores indicating higher levels of stress.

Table 8

\$35,000+ Annual Income Level Compared to QRS Score on Financial Stress Scale and Eco-map Score on Finances, N=13

		QRS Financial Stress Score			
		0	1	2	3
<u>Eco-map</u> <u>Score</u> <u>Finances</u>	-1	6		1	1
	0	1			
	1		1	2	1

In addition to those (Income \$35,000+) reported in Table 8, one respondent had an annual income of \$30,000-\$34,999 with a QRS Financial Stress score of 6, and an Eco-map score in the finances circle of 1. One mother with an annual income of \$25,000-\$29,999 scored 3 on the QRS Financial Stress and -1 on the Eco-map finances. The participant who reported an income of \$15,000-\$24,999 scored 2 on the QRS Financial Stress and 0 on the Eco-map finances.

Employment

Tables 9 and 10 show an analysis of total QRS scores and total Eco-map scores using employment status of participants. Table 9 compares scores of mothers who indicated they are non-employed (N=7), and Table 10 compares scores of mothers who indicated being employed either full-time, part-time, or

temporary (N=9).

The lowest possible total QRS score was 0, and the lowest possible total Eco-map score was -13. Lower scores indicate lower levels of stress. The highest possible total QRS score, signifying higher levels of stress was 66, and the highest possible total Eco-map score was 13.

Table 9

Comparison of Non-employed Mothers' Total QRS and Total Eco-map Scores, N=7

		Total QRS Score			
		16-21	22-27	28-33	34-39
<u>Total</u> <u>Eco-map</u> <u>Score</u>	-8->-5	3			
	-4->-1		1	1	1
	0->3		1		

Table 10

Comparison of Employed Mothers' Total QRS and Total
Eco-map Scores, N=9

		Total QRS Score			
		16-21	22-27	28-33	34-39
<u>Total Eco-map Score</u>	-8->-5	1	3		
	-4->-1		1	1	1
	0->3				
	4->8			1	1

In Table 11 the employment status of the participants was compared to the age of the child with disabilities for families with only one child with a disability in the home. One mother did not respond to this question. One employed respondent had two children with disabilities ages 8 and 10. Another participant who had two children with disabilities, ages 2 and 4, was non-employed.

Table 11

Mothers' Employment Status Compared to Age Range of the Children, Number of Children=13

		Age Range of Children					
		2-4	5-7	8-10	11-13	14-16	17-19
Mothers' Employment Status	Non-Employed	1	1		3	1	
	Employed	1	1	2		2	1

Number of Children with Disabilities

Two participants reported having two children with disabilities, and fourteen reported only one child with a disability living in the home. In Table 12, the average total QRS scores and average total Eco-map scores for both populations are compared.

Table 12

Number of Children With Disabilities Compared to Average Total QRS and Average Total Eco-map Scores

# Children w/ Disabilities	# of Mothers	Average Total QRS Score	Average Total Eco-map Score
1	14	26	-3
2	2	30	3

Total Number of Children in the Home

Nearly half of the respondents reported having three children living in their home. Table 13 compares the total number of children in the home to average total QRS and Eco-map scores. Total QRS scores ranged from 16 to 39, while total Eco-map scores ranged from -8 to 8. Lower scores on both instruments indicated lower levels of stress experienced by participants.

Table 13

Number of Children Living in the Home Compared to Average Total QRS and Average Total Eco-map Scores

<u>Total # Children</u>	<u>#of Mothers</u>	<u>Average Total QRS Score</u>	<u>Average Total Eco-map Score</u>
1	1	25	-2
2	7	27	-5
3	7	27	.4

Number of Services Received

The majority of the respondents indicated that they received three or more services specifically for their child(ren) with a disability. As depicted in Table 14, the number of services received were compared to the average total QRS and Eco-map scores.

Table 14

Number of Services Received Compared to Average QRS and Eco-map Scores

<u># Services Received</u>	<u>n</u>	<u>Average Total QRS Score</u>	<u>Average Total Eco-map Score</u>
0	1	18	-5
1	3	24	-6
2	2	17	-5
3	3	33	.7
4	3	32	-.3
5	4	27	-2

Summary

This chapter described the findings of the research study. Demographics of both participants and their children were outlined along with analysis of scores of the Questionnaire on Resources and Stress and the Eco-map diagram. Comparisons were made based on demographic information as it related to individual and composite aspects of both instruments.

Discussion and Implications

Overview

This chapter includes a discussion of the research findings as they relate to the original research question: What are the factors that contribute to the resilience of mothers of children with disabilities? Implications for social work practice and policy have been explored along with a discussion of the strengths and limitations of the study. In conclusion, suggestions for further research in this area have been outlined.

Discussion of Research Findings

A review of literature found that research studies with mothers of children with disabilities have focused on stressors rather than strengths of this population. The purpose of this study was to explore the factors that contribute to resilience in mothers of children with disabilities.

The 16 study participants, all of whom were support group members, were a very homogeneous group. The majority of the women were college-educated, middle to upper income, stay at home mothers. All of the respondents were Caucasian. Their children with disabilities, while falling into a wide age range, were primarily reported to have developmental disabilities.

Type of Disability

The literature showed disagreement about the type of disability of the child as a factor in the family's reaction to stress (Beckman, 1993; McCubbin & Huang, 1989; Sloper &

Turner, 1993). In Table 6 the respondents' QRS scores in the Patient Problems domain were compared to the type of disability of the child in order to see if any patterns in scoring existed based on disability type. A wide range of scores can be observed within this table.

Similar to previous research discussed in the literature, findings related to the affect of disability type on stress were inconclusive in this study. For some mothers the issues of dependency and management, cognitive impairment, and physical limitations that were measured by the QRS had a greater impact on their level of stress than for others. The variability within these scores (Table 6) suggests that no conclusions can be made about how the type of disability impacts the mother.

Finances

The income level of the family as it relates to the mothers' resilience was explored in Table 8. The majority of the respondents (n=13) reported incomes of \$35,000 or more, and their QRS scores on the Financial Stress scale were compared to their scores in the finances circle of the Eco-map. Six of the mothers who scored 0-1 on the QRS also scored -1 on the Eco-map finances category. The fact that both of these instruments reflect low levels of stress for the same population suggests that there is convergent validity between them on this variable.

The literature identified financial resources as being critical to the family's ability to cope with a child with a disability (Bailey, Blasco, & Simeonsson, 1992; Sloper &

Turner, 1993), yet it also suggested that there has not been much research in this area. In this study there was not enough variation in annual income to determine whether higher income contributes to resilience, therefore further research relating to income is indicated by these findings.

Employment

Mothers who are not currently employed reported lower levels of stress on both the QRS and the Eco-map (see Tables 9 and 10). The same three non-employed mothers had the lowest scores on both instruments (indicating the least amount of stress), again suggesting some relationship between the two instruments. Mothers working part-time, full-time, and temporary jobs had a wide variety of scores on both the QRS and Eco-map. These findings suggest that mothers of children with disabilities who are not employed are likely to feel less stress than employed mothers.

Because the variable of mother's employment status has not been explored in previous studies, these findings raise questions about employment as it relates to the ability to cope with raising a child with a disability and suggest the need for further research.

Social Support

Some previous studies identified the marital relationship as an important indicator of stress level and coping ability (Friedrich, 1979; McCubbin & Huang, 1989). In order to explore marital status as it relates to social support, the QRS score on the Respondent Attitudes domain was compared to the combined score of the Eco-map categories of

friends, extended family, and spouse/partner in Table 7 for married respondents. The majority of the married participants (n=13) indicated on the Eco-maps that their relationships with extended family, friends, and their spouse or partner offered them support and were helpful. These strong relationships were demonstrated through low scores on the Eco-map instrument, indicating low amounts of stress. QRS scores on the Respondent Attitudes domain show variability and do not represent any specific conclusions.

These findings raise further questions about the importance of social support that was identified in the literature (Flynt, Wood, & Scott, 1992; Frey, Greenberg, & Fewell, 1989). While participants indicated the helpfulness of their relationships with friends, extended family, and their spouse or partner (Table 7), there is a need for further exploration into each of these components of social support.

Number of Children with Disabilities

The affect of having more than one child with a disability was analyzed in Table 12 by comparing the number of children with disabilities living in the home to average QRS and Eco-map scores. Only two participants had more than one child with a disability, and average QRS scores were only slightly higher for these mothers. However, average Eco-map scores were much higher for mothers of two children with disabilities than for those with only one. While it has limited scope, this finding suggests that mothers of one child with a disability are more likely to experience less

stress than are mothers of two children with disabilities.

There is no evidence in the literature review to support this suggestion since mothers of children with more than one child with a disability have not been identified in previous studies. There is a need for future research about the impact of multiple children with disabilities on the family's ability to cope.

Total Number of Children in the Home

Average QRS and Eco-map scores were compared to the total number of children in the home in Table 13. Of the fifteen who answered the question, only one mother reported having one child in the home, while the remaining fourteen were split evenly between two and three children. There was little variability between the QRS scores of mothers of one, two, or three children. Eco-map scores, however, reflected a much lower level of stress for mothers of one or two children. Participants who indicated having three children in the home reported fewer helpful relationships on the Eco-map instrument. This finding suggests that mothers of children with disabilities who have only one or two children living in their home may have more supportive resources.

Number of Services Received

In Table 14, the number of services received for the child(ren) with disabilities was compared to average QRS and Eco-map scores. Mothers receiving two or less services indicated less stress on both instruments. For those receiving three or more services, scores were higher, indicating greater stress and less helpful relationships.

There are several possible explanations for these findings. First, mothers who have come to rely on more services may feel stress because of the uncertainty of continued funding for such programs as PCA and TEFRA. The prospect of losing these services may be particularly stressful because of the potential for financial burden on the family. Second, they may feel overwhelmed by the amount of services needed for their child(ren) and the energy required to coordinate these services. Finally, mothers of children with disabilities may find these services to be invasive, particularly those that are offered in the home. This lack of privacy may lead to the feeling that their lives are an open book to anyone who has a service to provide.

Strengths and Limitations

The primary strengths of this study lie in its unique design and measurement of the concept of resilience of mothers of children with disabilities, a population that has historically been studied based on predictors of stress. The use of the three instruments offered a number of ways in which to look at resilience because of the multiple variables examined and the format variety.

The Eco-map was unlike other study instruments because it engaged the participants and encouraged them to be creative and explore their own sources of support. In this way it may have served as a tool for empowering mothers of children with disabilities because it gave them an opportunity to look at their strengths and to make known the things that are important to them.

The small sample may be attributed to the fact that mothers receiving TEFRA (Tax Equity Family Reinvestment Act) services (50% of the participants), received a 10-page questionnaire about their use of TEFRA during approximately the same time period that packets were distributed for this study. The researcher was unaware of the TEFRA questionnaire during the design of this study. Mothers may simply have been tired of completing survey materials after completing the TEFRA questionnaire, or there may have been ambiguity about the differences between the two studies.

Limitations include the sampling method which yielded a group of mothers with similar demographic characteristics. No people of color returned the survey materials. Because previous studies of mothers of children with disabilities did not identify race or culture as significant variables, it was the hope of this researcher that these variables could be explored within this study.

Implications for Social Work Practice and Policy

The findings of this study will assist social workers who work with mothers of children with disabilities in the development of programming based on factors contributing to the resilience of this population. Understanding that mothers have historically been stereotyped as overly stressed, (McCubbin & Huang, 1989) may be an important factor in beginning to look at the things that increase resilience such as social support, non-employment, and the presence of only one child with a disability in the home.

Social workers interested in examining the resilience of

this population should begin with an assessment of these variables. While the social support available to the mother, her employment status, and the number of children she has living in the home have all been found in this study to be contributors to resilience, the variation of the study results suggests that each mother of a child with disabilities has unique strengths that warrant individual exploration.

The Eco-map could be used for initial assessments with new clients in a variety of practice settings, and may be altered depending on the client and the setting. It may be useful in obtaining a picture of the people, activities, and resources with which the client interacts as well as the nature of those relationships.

Implications for social work policy include the need to assess programs available to families of children with disabilities and their effectiveness in meeting the needs of this population. Findings of this study suggest that current services may not contribute to resilience but add to stress levels. Possible reasons may include the uncertainty of the continued existence of the programs, or the amount of time and energy required to coordinate these services. A commitment to continued funding of programs serving families of children with disabilities is important to the resilience of this population.

Suggestions for Future Research

A larger number of participants resulting from a random sampling method may result in a more diverse sample that is

more generalizable to the population of mothers of children with disabilities. With a larger sample factors such as socioeconomic status and the impact of disability type could be more fully explored. Future studies including mothers from different racial and cultural backgrounds would be important for social workers to understand how these variables impact resilience.

The Eco-map was an important instrument in this study, and it would be beneficial to use it in future studies and to continue to develop and explore its many applications. In the process of simplifying the instrument the arrows which indicate the direction of the flow of energy between the circles were omitted. Future researchers should consider including these arrows in the Eco-map. This would be particularly helpful when using the instrument in the context of social exchange theory.

The Eco-map could also be used with mothers of children with disabilities to look specifically at the services they use and to assess their helpfulness. Each of the circle categories could represent a different agency or service, and in this way the effectiveness of specific services could be explored.

While it provided a standard measure for some important comparisons, the Questionnaire on Resources and Stress did not seem to have the focus on strengths that was needed for a study of resilience. Because resilience is difficult to measure empirically (Beardslee, 1989), it would be helpful to future researchers to find or develop an instrument,

accessible to a wide population, that focuses on the more concrete variables of social support and social exchange. Future studies may incorporate other research methods such as in-person interviews, qualitative designs which incorporate respondent feedback about findings, or designs which include control groups.

Summary

This study explored resilience in mothers of children with disabilities who have been stereotyped in literature and examined in past studies based only on their levels of stress. The research question "What are the factors that contribute to the resilience of mothers of children with disabilities?" evolved from a review of this literature.

The study was exploratory in nature and used a convenience sample of 16 mothers of children with disabilities who attend support groups offered by three agencies in the Twin Cities area. It focused on variables identified in the literature as contributors to either the support or stress of this population. Findings were generally similar to those of previous studies. They were inconclusive about how the type of disability of the child impacts the stress level of the mother. Some factors that were found to contribute to the resilience of mothers of children with disabilities as indicated by lower scores on the QRS and Eco-map instruments included the presence of social support, the mother's status of "non-employed", the presence of only one child with a disability in the home, and the receipt of fewer than three services for the child(ren) with disabilities.

This study will ultimately be important for social work practitioners in the development of programming based on strengths and social work policy that is committed to providing reliable and accessible services to families caring for children with disabilities.

References

- Bailey, D., Blasco, P., & Simeonsson, R. (1992). Needs expressed by mothers and fathers of young children with disabilities. American Journal on Mental Retardation, 97, 1-10.
- Beardslee, W. (1989). The role of self-understanding in resilient individuals: The development of a perspective. American Journal of Orthopsychiatry, 59, 266-278.
- Beckman, P. (1983). Influence of child characteristics on stress in families of handicapped infants. American Journal of Mental Deficiency, 88, 150-156.
- Bettelheim, B. (1967). The empty fortress: Infantile autism and the birth of the self. New York: The Free Press.
- Brownell, A., & Shumaker, S. (1984). Social support: An introduction to a complex phenomenon. Journal of Social Issues, 49(4), 1-9.
- Byrne, E, & Cunningham, C. (1985). The effects of mentally handicapped children on families: A conceptual review. Journal of Child Psychology and Psychiatry, 6, 847-863.
- Compton, B., & Galaway, B. (1989). Social work processes (3rd. ed.). Pacific Grove, California: Brooks/Cole.
- Crnic, K., Greenberg, M., & Ragozin, A. (1984). Maternal stress and social supports: Effects on the mother-infant relationship from birth to eighteen months. American Journal of Orthopsychiatry, 54, 224-235.
- Derogatis, L. (1975). Brief Symptom Inventory. Baltimore, Maryland: Clinical Psychometric Research.

Dyson, L. (1991). Families of young children with handicaps: Parental stress and family functioning. American Journal on Mental Retardation, 95, 623-629.

Flynt, S., Wood, T., & Scott, R. (1992). Social support of mothers of children with mental retardation. Mental Retardation, 30, 233-236.

Frey, K., Greenberg, M., & Fewell, R. (1989). Stress and coping among parents of handicapped children: A multidimensional approach. American Journal on Mental Retardation, 94, 240-249.

Friedrich, W. (1979). Predictors of the coping behaviors of mothers of handicapped children. Journal of Consulting and Clinical Psychology, 47, 1140-1141.

Friedrich, W., Greenberg, M., & Crnic, K. (1983). A short-form of the Questionnaire on Resources and Stress. American Journal of Mental Deficiency, 88, 41-48.

Friedrich, W., Wiltturner, L., & Cohen, D. (1985). Coping resources and parenting mentally retarded children. American Journal of Mental Deficiency, 90, 130-139.

Gill, M., & Harris, S. (1991). Hardiness and social support as predictors of psychological discomfort in mothers of children with autism. Journal of Autism and Developmental Disabilities, 21, 407-416.

Haggerty, R., Sherrod, L., Garmezy, N., & Rutter, M. (1994). Stress, risk and resilience in children and adolescents: Processes, mechanisms, and interventions. Cambridge: University Press.

Higgins, G. (1994). Resilient adults: Overcoming a cruel past. San Francisco, California: Jossey-Bass.

Holmes, T., Rahe, R. (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 family response to a handicapped family member. Journal of Community Psychology, 2, 92-94.

Holroyd, J. (1987). Questionnaire on Resources and Stress. Vermont: Clinical Psychology Publishing.

Levy, D. (1943). Maternal overprotection. New York: Columbia University Press.

Locke, H., & Wallace, K. (1959). Short marital adjustment and prediction tests: Their reliability and validity. Marriage and Family Living, 21, 251-255.

Mannoni, M. (1964). The backward child and his mother: A psychoanalytic study. New York: Pantheon Books.

McCubbin, M., & Huang, T. (1989). Family strengths in the care of handicapped children: Targets for intervention. Family Relations, 38, 436-443.

McCubbin, H., & McCubbin, M. (1988). Typologies of resilient families: Emerging roles of social class and ethnicity. Family Relations, 37, 247-254.

Moos, R., Insel, P., & Humphrey, B. (1974). Family Environment Scale. Palo Alto, California: Consulting Psychologists Press.

Ross, A. (1964). The exceptional child and the family. New York: Grune & Stratton.

Rubin, A., & Babbie, E. (1993). Research methods for social work (2nd. ed.). Pacific Grove, California: Brooks/Cole.

Rutter, M. (1987). Psychosocial resilience and protective mechanisms. American Journal of Orthopsychiatry, 57, 316-331.

Scott, R., & Sexton, D. (1989). Structure of a short form of the Questionnaire on Resources and Stress: A bootstrap factor analysis. Educational and Psychological Measurement, 49, 409-419.

Shinn, M., Lehmann, S., & Wong, N. (1984). Social interaction and social support. Journal of Social Issues, 40 (4), 55-76.

Shumaker, S., & Brownell, A. (1984). Toward a theory of social support: Closing conceptual gaps. Journal of Social Issues, 40(4), 11-36.

Simeonsson, R., Huntington, G., Short, R., & Ware, W. (1982). The Carolina Record of Individual Behavior: Characteristics of handicapped infants. Topics in Early Childhood Special Education, 2(2), 43-55.

Sloper, P., & Turner, S. (1993). Risk and resistance factors in the adaptation of parents of children with severe disability. Journal of Child Psychology and Psychiatry and Allied Disciplines, 34, 167-188.

Wallander, J., Pitt, L., & Mellins, C. (1990). Child functional independence and maternal psychosocial stress as risk factors threatening adaptation in mothers of physically or sensorially handicapped children. Journal of Consulting and Clinical Psychology, 58, 818-824.

Werner, E., & Smith, R. (1982). Vulnerable but invincible: A longitudinal study of resilient children and youth. New York: Adams, Bannister, Cox.

Wolin, S., & Wolin, S. (1993). The resilient self: How survivors of troubled families rise above adversity. New York: Villard Books.

APPENDIX A:

Cover Letter to Participants

December 18, 1995

Dear Mother:

You are invited to participate in a research study of mothers of children with disabilities. The purpose of the study is to identify the things that offer you support in your role as caregiver of a child with a disability. This information will be used to further understand the needs of caregivers, and will assist in the development of responsive programming. My name is Anne Humes, and I am conducting this study as part of my graduate studies in social work and as a partial fulfillment of my Master's thesis at Augsburg College.

There are three parts to the study enclosed within this packet. They include: (1) a participant information sheet, (2) an eco-map diagram of resources and support, and (3) the Questionnaire on Resources and Stress. Please fill out each part as completely as possible. IT WILL TAKE APPROXIMATELY 30 MINUTES TOTAL FOR YOU TO COMPLETE THESE MATERIALS. When you are finished, please return them to me in the envelope provided.

Your decision whether or not to participate by filling out the enclosed materials is voluntary and will not affect your current or future relationship with any ARC agency or Augsburg College. Your participation in this study is completely anonymous to the researcher. Because I do not have any identifying information, please do not put your name, the name of your child(ren), or any other identifying information on the survey materials.

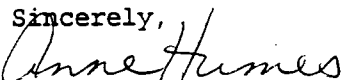
At any time you may choose not to answer a question. Please leave the space blank and continue completing those materials with which you feel comfortable.

While I am collecting the data, all records will be kept with me. The anonymous final results will be incorporated into my thesis and shared with Arc of Hennepin County, Arc of Anoka County, and Arc Suburban. It will be made available to you through these agencies.

The materials in this study are of a personal and sensitive nature. If at any point this causes you to feel extreme discomfort or distress, please call your support group leader.

If you have any questions regarding the study, you may contact me at 730-9532, or my research advisor, Carol Kuechler, at 330-1439.

Thank you for your participation in this very important study.

Sincerely,

Anne Humes
Principal Investigator

APPENDIX B:
Agency Consent Forms

Arc of Anoka & Ramsey Counties

Advocacy October 26, 1995
and support Rita Weisbrod
 Chair, Institutional Review Board
for people Augsburg College

with
developmental Dear Ms. Weisbrod,

disabilities Ann Humes has permission to disseminate materials to our
and their parent support group in support of her research project.
families I understand that these materials will be given by the Arc
 support group facilitator to distribute. And, that the
 study will be anonymous, confidential and voluntary.

Sincerely,
Sally Swallen
Sally Swallen
Director of Family Services



Blaine Office • 1201 89th Avenue NE • Suite 305 • Blaine, MN. 55434-3373 • 612 783-4958 • FAX 783-4700
Saint Paul Office • 425 Etna Street • Suite 36 • Saint Paul, MN. 55106 • 612 778-1414 • FAX 778-0449

Arc Suburban

*Advocacy
and support
for people
with
developmental
disabilities
and their
families*

Date: October 17, 1995

To: Rita Weisbrod
Chair, Institutional Review Board
Augsburg College

From: Celeste denDaas, Director of Programs

RE: Research study Approval

Anne Humes has the approval of Arc Suburban to ask facilitators of our support groups for assistance in reaching parents to help in research for her Masters thesis. It is my understanding that she will be giving materials to support group facilitators to distribute to those mothers who give their consent to participate in the study. I understand that participation in the study will be anonymous, confidential, and strictly voluntary.

We look forward to seeing the results of the study.



Serving Dakota, Scott and South Washington Counties

1526 East 122nd Street

Burnsville, MN 55337

612-890-3057 V/TTY

612-890-3527 FAX

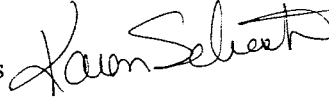
Arc of Hennepin County

Advocacy and support for people with developmental disabilities and their families

DATE: October 26, 1995

TO: Rita Weisbrod
Chair, Institutional Review Board
Augsburg College

FROM: Karen Sebesta, Director of Programs



RE: Research study approval

Anne Humes has Arc of Hennepin County's approval to conduct research through the agency for her Masters thesis. It is my understanding that she will be giving materials to support group facilitators to distribute to those mothers who wish to participate in the study. I understand that participation in the study will be anonymous, confidential, and strictly voluntary.

We look forward to seeing the results of the study, and feel confident that they will be beneficial to those we serve.

*Diamond Hill Center, Suite 140
4301 Highway 7
Minneapolis, MN 55416-5810
612 920-0855*

65

*Fax 612 920-1480
TDD/TTY 920-4392*

APPENDIX C:

Data Collection Instruments

1. Participant Information Sheet
2. Eco-map Diagram
3. Questionnaire on Resources and Stress

**Participant Information
Sheet**

This questionnaire asks for information about yourself and your family. If you choose not to answer a question for any reason, please skip it and move on to the next question. PLEASE DO NOT PUT YOUR NAME ON THIS QUESTIONNAIRE.

This is Part 1 of 3

THANK YOU FOR YOUR TIME AND COMMITMENT

PARTICIPANT INFORMATION SHEET

1. Your present marital status: (Circle number)
 1. NEVER MARRIED
 2. MARRIED
 3. DIVORCED
 4. SEPARATED
 5. WIDOWED

2. Your present age: _____ YEARS

3. Which is the highest level of education that you have completed? (Circle number)
 1. NO FORMAL EDUCATION
 2. SOME GRADE SCHOOL
 3. COMPLETED GRADE SCHOOL
 4. SOME HIGH SCHOOL
 5. COMPLETED HIGH SCHOOL
 6. SOME COLLEGE
 7. COMPLETED COLLEGE
 8. SOME GRADUATE SCHOOL
 9. COMPLETED GRADUATE SCHOOL OR BEYOND

4. Your racial or ethnic identification: (circle number)
 1. AFRICAN AMERICAN
 2. AMERICAN INDIAN
 3. LATINO
 4. ASIAN
 5. CAUCASIAN
 6. OTHER (Please specify) _____

5. Please give total number of children, under 18, living at home. _____

6. Please give total number of children WITH DISABILITIES, under 18, living at home. _____

7. For each child with a disability living in your home, please answer the following:
Child 1: Age _____ Sex _____
Child 2: Age _____ Sex _____

THANK YOU FOR YOUR TIME AND COMMITMENT

For each child please circle the one number that best describes her/his PRIMARY diagnosis.

Child 1:

1. DEVELOPMENTAL DISABILITY
 2. COMMUNICATION DISORDER
 3. AUTISM
 4. ATTENTION DEFICIT/HYPERACTIVITY
 5. PHYSICAL HANDICAPS
 6. SENSORY HANDICAPS
(Visual or hearing impairment)
 7. OTHER (Please Specify)
-

Child 2:

1. DEVELOPMENTAL DISABILITY
 2. COMMUNICATION DISORDER
 3. AUTISM
 4. ATTENTION DEFICIT
 5. PHYSICAL HANDICAPS
 6. SENSORY HANDICAPS
(Visual or hearing impairment)
 7. OTHER (Please Specify)
-

8. What type of services do you receive for your disabled child(ren)? (Circle all that apply)

1. RESPITE CARE
2. TEFRA
3. PERSONAL CARE ATTENDANT
4. OCCUPATIONAL THERAPY
5. SPEECH THERAPY
6. PHYSICAL THERAPY
7. SPECIALIZED NURSING CARE
8. OTHER (Please specify) _____

9. Which of the following best describes your current source of income? (Circle number)

1. EMPLOYED FULL-TIME
2. EMPLOYED PART-TIME
3. UNEMPLOYMENT/DISABILITY
4. SOCIAL SECURITY/RETIREMENT/PENSION
5. AFDC/GENERAL ASSISTANCE
6. CHILD SUPPORT/ALIMONY
7. SPOUSE/PARTNER'S INCOME
8. OTHER (Please specify) _____

10. Which of the following best describes your total family income during 1994? (Circle number)

1. LESS THAN \$5,000
2. \$ 5,000-\$9,999
3. \$10,000-\$14,999
4. \$15,000-\$24,999
5. \$25,000-\$29,999
6. \$30,000-\$34,999
7. \$35,000 OR MORE

THANK YOU FOR YOUR TIME AND COMMITMENT

ECO-MAP DIAGRAM OF RESOURCES
AND SUPPORT

The eco-map is a helpful tool for looking at the people, agencies, and activities in your life that offer you support, as well as those that cause stress. Please refer to the following guide for assistance with completion of your eco-map. You may choose to leave any circle blank for any reason. Please do not put your name on the eco-map.

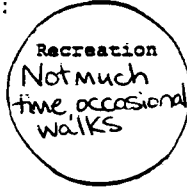
THIS IS PART 2 OF 3

Directions

1. You are the circle in the middle of your eco-map. Please fill in the first initial of your name and the year you were born. For example, my circle would look like this:



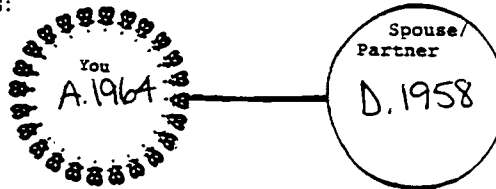
2. The circles around you on the eco-map represent people, agencies, and activities that are important to you. These can be either helpful OR stressful. I have labeled several of these such as friends, work, and health care. Please fill in empty circles with additional things that play a significant role in your life. Be creative and as specific as possible. For example, your recreation circle may look like this:



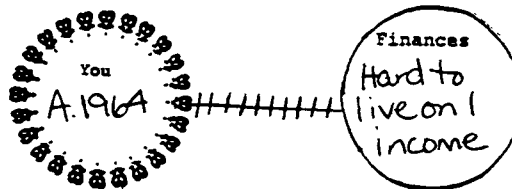
Your extended family may look like this:



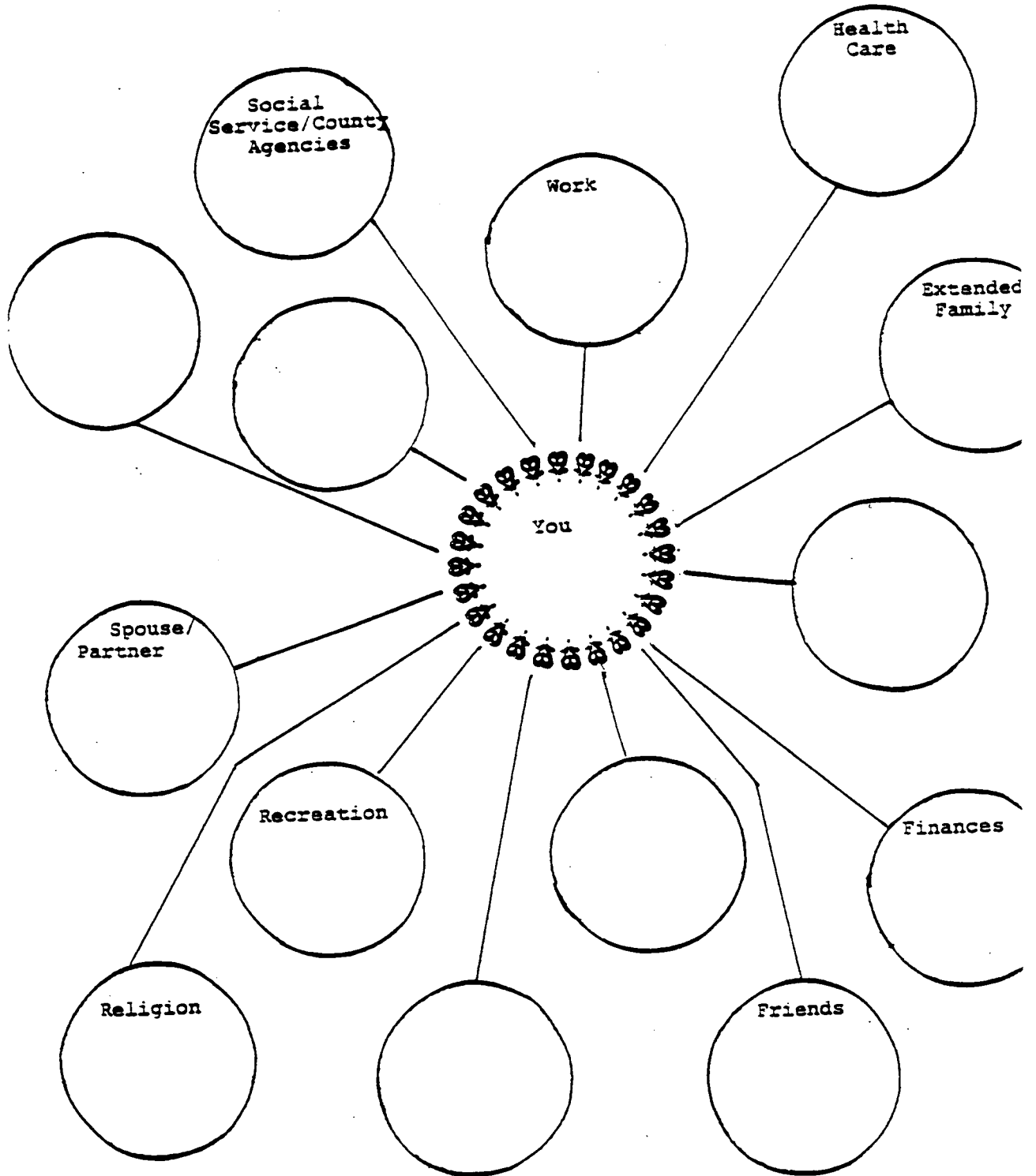
3. The final step in the eco-map process is to indicate the nature of your relationship with each of the circles. If the relationship is stressful, indicate this by hash marks on the connecting line like this: #####. If it is a helpful relationship, make the line thick like this: _____ . For example, if I get a lot of support from my spouse, that relationship on my eco-map would look like this:



If I'm having trouble paying my bills, that relationship would look like this:



Your eco-map is complete when it gives an accurate picture of the things that are most important in your life. Thank you for sharing this information.



QUESTIONNAIRE on RESOURCES
and STRESS

by Dr. Jean Holroyd
University of California, Los Angeles

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 is true or false, answer in terms of what 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 does not have. Nevertheless, these questions still can be answered true or false. Example: "We get special funds because of _____'s problem." If you are responding about a family member who does not have any problem, the answer would be false. There is no problem for which you would get special funds.

SIMPLY IMAGINE YOUR RELATIVE'S NAME IN THE BLANKS PROVIDED.

PLEASE CIRCLE TRUE (T) OR FALSE (F) FOR EACH QUESTION.
If you choose not to answer a question, skip to the next one.

This is Part 3 of 3

True/False (Please Circle)

- | | | |
|---|---|---|
| T | T | 1. _____ demands that others do things for him/her more than is necessary. |
| F | T | 2. _____ is cared for equally by all members of our family. |
| F | T | 3. Members of our family praise each other's accomplishments. |
| F | T | 4. The doctor sees _____ at least once a month. |
| F | T | 5. _____ would be in danger if he/she could get out of the house or yard. |
| F | T | 6. People who don't have the problems we have don't have the rewards we have either. |
| F | T | 7. Other members of the family have to do without things because of _____. |
| F | T | 8. If _____ were more pleasant to be with it would be easier to care for him/her. |
| F | T | 9. I don't worry too much about _____'s health. |
| F | T | 10. Our family agrees on important matters. |
| F | T | 11. The constant demands for care for _____ limit growth and development of someone else in our family. |
| F | T | 12. I worry about what will happen to _____ when I can no longer take care of him/her. |
| F | T | 13. I am able to leave _____ alone in the house for an hour or more. |
| F | T | 14. _____ is limited in the kind of work he/she can do to make a living. |
| F | T | 15. I have given up things I have really wanted to do in order to care for _____. |
| F | T | 16. I would not want the family to go on vacation and leave _____ at home. |
| F | T | 17. There is no way we can possibly keep _____ in our house. |
| F | T | 18. _____ can feed himself/herself. |
| F | T | 19. As the time passes I think it will take more and more to care for _____. |
| F | T | 20. We can afford to pay for the care _____ needs. |
| F | T | 21. It bothers me that _____ will always be this way. |
| F | T | 22. _____ uses special equipment because of his/her handicap. |
| F | T | 23. _____ is easy to live with. |
| F | T | 24. The doctor sees _____ at least once a year. |
| F | T | 25. Wheelchairs or walkers have been used in our house. |
| F | T | 26. Caring for _____ has been a financial burden for our family. |
| F | T | 27. I worry that _____ may sense that he/she does not have long to live. |
| F | T | 28. We enjoy _____ more and more as a person. |
| F | T | 29. _____ knows his/her own address. |
| F | T | 30. _____ is aware of who he/she is (for example, male 14 years old). |
| F | T | 31. Sometimes I need to get away from the house. |
| F | T | 32. Having to care for _____ has enriched our family life. |
| F | T | 33. _____ doesn't do as much as he/she should be able to do. |
| F | T | 34. Our family has been on welfare. |
| F | T | 35. We take _____ along when we go out. |
| F | T | 36. _____ is accepted by other members of the family. |
| F | T | 37. _____ spends time at a special day center or in special classes at school. |
| F | T | 38. Our family income is more than average. |
| F | T | 39. Caring for _____ gives one a feeling of worth. |
| F | T | 40. One of us has had to pass up a chance for a job because _____ could not be left without someone to watch him/her. |
| F | T | 41. I worry about how our family will adjust after _____ is no longer with us. |
| F | T | 42. The part that worries me most about _____'s going on his/her own is his/her ability to make a living. |

True/False (Please Circle)

- T F 43. I worry about what will be done with _____ when he/she gets older.
- T F 44. _____ can get around the neighborhood quite easily.
- T F 45. There is a lot of anger and resentment in our family.
- T F 46. Our family has managed to save money or make investments.
- T F 47. We own or are buying our own home.
- T F 48. 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.
- T F 49. _____ is better off in our home than somewhere else.
- T F 50. _____ can describe himself/herself as a person.
- T F 51. It is easy to keep _____ entertained.
- T F 52. In the future _____ will be more able to help himself/herself.
- T F 53. _____ needs a walker or wheelchair.
- T F 54. I have become more understanding in my relationships with people as a result of _____.
- T F 55. _____ cannot get any better.
- T F 56. Outside activities would be easier without _____.
- T F 57. My family understands the problems I have.
- T F 58. I am pleased when others see my care of _____ is important.
- T F 59. We can hardly make ends meet.
- T F 60. Members of my family are able to discuss personal problems.
- T F 61. Most of _____'s care falls on me.
- T F 62. _____ is very irritable.
- T F 63. It is easy for me to relax.
- T F 64. I rarely feel blue.
- T F 65. _____ can walk without help.
- T F 66. Because _____ uses special equipment and facilities, it is difficult to take him/her out.

* Thank You for Completing these Materials.
Please Return Them in the Envelope Provided.

APPENDIX D:

State of Minnesota Office of Ombudsman for Mental
Health and Mental Retardation Brochure

**FACTS ABOUT THE
OFFICE OF THE OMBUDSMAN**

In 1987, the Legislature created the Office of the Ombudsman for Mental Health and Mental Retardation to:

...promote the highest attainable standards of treatment, competence, efficiency, and justice... for persons receiving services or treatment for mental illness, mental retardation or a related condition, chemical dependency, or emotional disturbance...

The Office is an **independent** state agency.

The Governor appoints the Ombudsman.

The Ombudsman appoints Regional Advocates.

The Governor also appoints a 15 member Ombudsman Committee for Mental Health and Mental Retardation to advise the Ombudsman. From this group a Medical Review Subcommittee is selected to work with office staff in the review of deaths and serious injuries.

The Ombudsman, after consultation with the Governor, can go public with findings and recommendations.

Death and Serious Injury Reporting
An agency, facility, or program is required to report to the Ombudsman Office the death or serious injury of a client within 24 hours. You may call:
(612) 296-8671 or 1-800-657-3506

**HOW DO I CONTACT THE
OMBUDSMAN OFFICE**

You may call, write, or visit:

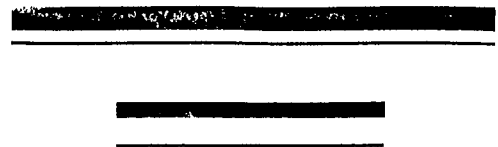
121 7th Place E, Ste 420
Metro Square Building
St. Paul, Minnesota 55101-2117

(612) 296-3848
Toll Free: 1-800-657-3506

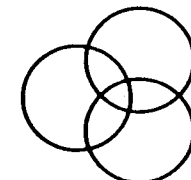
Client Advocates are located in St. Paul and at each of the Regional Treatment Centers. They provide assistance to clients living in the Community as well as at the Regional Treatment Centers.

- Anoka:** (612) 422-4269
- Brainerd:** (218) 828-2366
- Cambridge:** (612) 689-7155
- Faribault:** (507) 332-3380
- Fergus Falls:** (218) 739-7364
- Metro:** (612) 296-3848
- Moose Lake:** (218) 485-5300, ext. 302
- St. Peter:** (507) 931-7669
- Willmar:** (612) 231-5962

TTY/TDD - Minnesota Relay Service
(612) 297-5353 or 1-800-627-3529



State of Minnesota



**Office of the
Ombudsman
for
Mental Health and
Mental Retardation**

Assisting Persons
Receiving Services
for:

77

- MENTAL ILLNESS**
- DEVELOPMENTAL DISABILITIES**
(Mental Retardation)
- CHEMICAL DEPENDENCY**
- EMOTIONAL DISTURBANCE**
(Children and Adolescents)

