

THE UNIVERSITY OF CALGARY

Quality of Life for Parents of a Child with a Developmental Disability

by

Leif W. Rasmussen

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES  
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE  
DEGREE OF MASTER OF SCIENCE

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

CALGARY, ALBERTA

JULY, 1993

© Leif W. Rasmussen 1993



National Library  
of Canada

Acquisitions and  
Bibliographic Services Branch

395 Wellington Street  
Ottawa, Ontario  
K1A 0N4

Bibliothèque nationale  
du Canada

Direction des acquisitions et  
des services bibliographiques

395, rue Wellington  
Ottawa (Ontario)  
K1A 0N4

*Your file    Votre référence*

*Our file    Notre référence*

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

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

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

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

ISBN 0-315-88610-2

Canada

Name LEIF WILLIAM RASMUSSEN

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

EDUCATIONAL PSYCHOLOGY

SUBJECT TERM

0529

SUBJECT CODE

U·M·I

## Subject Categories

### THE HUMANITIES AND SOCIAL SCIENCES

#### COMMUNICATIONS AND THE ARTS

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

#### EDUCATION

General ..... 0515  
Administration ..... 0514  
Adult and Continuing ..... 0516  
Agricultural ..... 0517  
Art ..... 0273  
Bilingual and Multicultural ..... 0282  
Business ..... 0688  
Community College ..... 0275  
Curriculum and Instruction ..... 0727  
Early Childhood ..... 0518  
Elementary ..... 0524  
Finance ..... 0277  
Guidance and Counseling ..... 0519  
Health ..... 0680  
Higher ..... 0745  
History of ..... 0520  
Home Economics ..... 0278  
Industrial ..... 0521  
Language and Literature ..... 0279  
Mathematics ..... 0280  
Music ..... 0522  
Philosophy of ..... 0998  
Physical ..... 0523

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

#### LANGUAGE, LITERATURE AND LINGUISTICS

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

#### PHILOSOPHY, RELIGION AND THEOLOGY

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

#### SOCIAL SCIENCES

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

Ancient ..... 0579  
Medieval ..... 0581  
Modern ..... 0582  
Black ..... 0328  
African ..... 0331  
Asia, Australia and Oceania ..... 0332  
Canadian ..... 0334  
European ..... 0335  
Latin American ..... 0336  
Middle Eastern ..... 0333  
United States ..... 0337  
History of Science ..... 0585  
Law ..... 0398  
Political Science  
General ..... 0615  
International Law and  
Relations ..... 0616  
Public Administration ..... 0617  
Recreation ..... 0814  
Social Work ..... 0452  
Sociology  
General ..... 0626  
Criminology and Penology ..... 0627  
Demography ..... 0938  
Ethnic and Racial Studies ..... 0631  
Individual and Family  
Studies ..... 0628  
Industrial and Labor  
Relations ..... 0629  
Public and Social Welfare ..... 0630  
Social Structure and  
Development ..... 0700  
Theory and Methods ..... 0344  
Transportation ..... 0709  
Urban and Regional Planning ..... 0999  
Women's Studies ..... 0453

### THE SCIENCES AND ENGINEERING

#### BIOLOGICAL SCIENCES

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

#### Biology

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

#### Biophysics

General ..... 0786  
Medical ..... 0760

#### EARTH SCIENCES

Biogeochemistry ..... 0425  
Geochemistry ..... 0996

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

#### HEALTH AND ENVIRONMENTAL SCIENCES

Environmental Sciences ..... 0768  
Health Sciences  
General ..... 0566  
Audiology ..... 0300  
Chemotherapy ..... 0992  
Dentistry ..... 0567  
Education ..... 0350  
Hospital Management ..... 0769  
Human Development ..... 0758  
Immunology ..... 0982  
Medicine and Surgery ..... 0564  
Mental Health ..... 0347  
Nursing ..... 0569  
Nutrition ..... 0570  
Obstetrics and Gynecology ..... 0380  
Occupational Health and  
Therapy ..... 0354  
Ophthalmology ..... 0381  
Pathology ..... 0571  
Pharmacology ..... 0419  
Pharmacy ..... 0572  
Physical Therapy ..... 0382  
Public Health ..... 0573  
Radiology ..... 0574  
Recreation ..... 0575

Speech Pathology ..... 0460  
Toxicology ..... 0383  
Home Economics ..... 0386

#### PHYSICAL SCIENCES

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

#### Applied Sciences

Applied Mechanics ..... 0346  
Computer Science ..... 0984

#### Engineering

General ..... 0537  
Aerospace ..... 0538  
Agricultural ..... 0539  
Automotive ..... 0540  
Biomedical ..... 0541  
Chemical ..... 0542  
Civil ..... 0543  
Electronics and Electrical ..... 0544  
Heat and Thermodynamics ..... 0348  
Hydraulic ..... 0545  
Industrial ..... 0546  
Marine ..... 0547  
Materials Science ..... 0794  
Mechanical ..... 0548  
Metallurgy ..... 0743  
Mining ..... 0551  
Nuclear ..... 0552  
Packaging ..... 0549  
Petroleum ..... 0765  
Sanitary and Municipal ..... 0554  
System Science ..... 0790  
Geotechnology ..... 0428  
Operations Research ..... 0796  
Plastics Technology ..... 0795  
Textile Technology ..... 0994

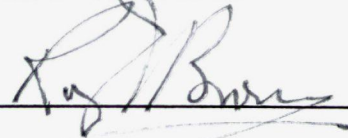
#### PSYCHOLOGY

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

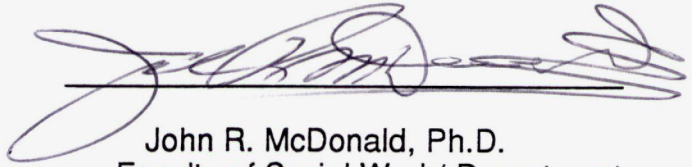


THE UNIVERSITY OF CALGARY  
FACULTY OF GRADUATE STUDIES

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Quality of Life for Parents of a Child with a Developmental Disability" submitted by Leif Rasmussen in partial fulfilment of the requirements for the degree of Master of Science.



Supervisor, Roy I Brown, Ph.D.  
Department of Educational Psychology



John R. McDonald, Ph.D.  
Faculty of Social Work/ Department  
of Educational Psychology



Beverly Anderson, Ph.D. C  
Faculty of Nursing

28<sup>th</sup> July 93  
Date



## ABSTRACT

This study was designed to explore the effects of children with a developmental disability on the quality of life of their parents. Families with a child who had a developmental disability were compared to families of children without disabilities. A questionnaire (Flanagan, 1978) designed to assess an individual's subjective impressions of life domains within a quality of life model was completed by each parent. Results indicated differences between groups, as well as demonstrating considerable intra-group variability. The results have relevance to family adaptability, and systems of family functioning. The need for support for families of a child with a developmental disability, the utility of studying fathers, and the importance of assessing variability was also stressed.

## ACKNOWLEDGEMENTS

My parents whose love and financial support helped me achieve all my goals. Further, for always being there when I needed them.

Pam "Hammer" Wandler for her clerical support, without which this document would not have been completed, and for having the love and patience to put up with my complaints.

All the good friends I made in graduate school particularly, Stacey Page, as well as the undergraduate students in Rehabilitation Studies.

Greg McKenna, who was the best roommate a graduate student could have (he put up with my dirty socks).

Jane Baer, who provided me with a great deal of friendly competition.

All the staff and faculty of Rehabilitation Studies for their help and excellent instruction.

My friends on Vancouver Island (Pam, Brenda & Tom) who forced me to finish.

Especially, to Dr. Roy I. Brown, for his mentorship and instruction. For taking a young long-haired kid and turning him into a competent professional (I hope). I appreciate his support and patience over the past four years. And for his sense of humour, which was helpful in reading my first drafts of this document.

## DEDICATION

To my parents who loved and supported me throughout my academic life. And, to all the individuals with developmental disabilities with whom I have been involved, because they provided me with the motivation to seek a greater knowledge of the field of disability.

## TABLE OF CONTENTS

APPROVAL PAGE .....	ii
ABSTRACT .....	iii
ACKNOWLEDGEMENTS .....	iv
DEDICATION .....	v
TABLE OF CONTENTS .....	vi
LIST OF TABLES .....	ix
CHAPTER ONE: INTRODUCTION .....	1
Purpose of Study .....	3
CHAPTER TWO: REVIEW OF RELEVANT LITERATURE .....	4
Quality of Life in Families .....	4
Definitions .....	4
Models of Family Functioning .....	7
Stages of Development.....	11
Age and Disability .....	14
Introduction to the Effects of a Child's Disability on his/her Parents ...	16
Impact of a Child with a Disability: Stress? .....	17
Specific Effects of the Presences of a Child with a Disability .....	21
Factors Associated with Adapting to a Child with a Disability .....	28
Social Support .....	32
Disability Conclusions .....	32
Quality of Life: General Issues	
Background to Quality of Life .....	34
Definition of Quality of Life .....	35
Subjective vs. Objective Measurement .....	40
Choice of Measurement Instrument .....	46

Psychological Concepts and Their Relation to Quality of Life and the Family .....	48
Disability, the Family and Quality of Life .....	50
Summary of Review Literature .....	52
CHAPTER THREE: METHODOLOGY .....	54
Subjects .....	54
Test Material .....	56
Reliability and Validity .....	59
Procedure .....	60
Method of Analysis .....	61
Rationale for the Use of Fisher's Exact Test .....	63
Other Analyses of the Data .....	63
CHAPTER FOUR: RESULTS .....	66
Demographics .....	67
Results from Questionnaires .....	68
Reporting Results of Fisher's Exact Test .....	69
#1 Passive Recreation .....	69
#2 Active Recreation .....	92
#3 Socializing .....	92
#4 Occupational Role .....	92
#5 Material Well-Being .....	93
#6 Health and Personal Safety .....	93
#7 Relationship with Spouse .....	94
#8 Having and Raising Children .....	95
#9 Relationship with Other Relatives .....	95
#10 Relations with Friends .....	95
#11 Activities Related to Helping and Encouraging Other People .....	96
#12 Activities Relating to Local or National Governments .....	96
#13 Intellectual Development .....	96
#14 Personal Understanding and Planning .....	98

#15 Creativity and Personal Expression .....	98
Questions Related to Abbey and Andrew's Model .....	98
Quality of Life Questions .....	99
CHAPTER FIVE: DISCUSSION .....	107
Demographics .....	110
#1 Passive Recreation .....	115
#2 Active Recreation .....	119
#3 Socializing .....	123
#4 Occupational Role .....	126
#5 Material Well-Being .....	131
#6 Health and Personal Safety .....	133
#7 Relationship with Spouse .....	136
#8 Having and Raising Children .....	138
#9 Relationship with Other Relatives .....	139
#10 Relations with Friends .....	142
#11 Activities Related to Helping and Encouraging Other People .....	143
#12 Activities Relating to Local or National Governments .....	144
#13 Intellectual Development .....	145
#14 Personal Understanding and Planning .....	147
#15 Creativity and Personal Expression .....	148
Quality of Life Questions .....	148
Conclusions .....	153
Implications of Parents, Practitioners and Policy Makers .....	159
Recommendations for Future Study .....	160
Limitations of Present Study .....	162
Summary .....	163
REFERENCES .....	165
APPENDIX A: QUALITY OF LIFE QUESTIONNAIRE .....	177
APPENDIX B: INTRODUCTION LETTER AND CONSENT FORM .....	202

## LIST OF TABLES

<u>Table</u>	<u>Page</u>
1. Demographic Variables for Parents with a Child with a Developmental Disability and Parent's without a Developmental Disability .....	70
2. Percentage of Parents of (A) Children With Developmental Disability and (B) Children Without Developmental Disabilities Rating "Importance" as "Very High", "High" or "Moderate" .....	71
3. Percentage of Parents of (A) Children With Developmental Disability and (B) Children Without Developmental Disabilities Rating "Needs Being Met" as "Very High", "High" or "Moderate" .....	75
4. Percentage of Parents of (A) Children With and (B) Children Without a Developmental Disability Whose Discrepancy Between Their Rating of "Importance" and "Needs Being Met" Range Between 0 and +4 .....	78
5. Fisher's Exact Test Results for Mothers (M) V. Fathers (F) of a Child with a Developmental Disability on Ratings of Importance, Needs Being Met and the Discrepancy Between Importance and Needs .....	82
6. Fisher's Exact Test Results for Mothers (M) V. Fathers (F) of a Child Without a Developmental Disability on Ratings of "Importance", "Needs Being Met" and the Discrepancy Between Importance and Needs .....	84
7. Fisher's Exact Test Results for Fathers of a Child With a	

	Developmental Disability (DDC) V. Fathers of a Child Without a Disability (NDC) on the Ratings of "Importance", "Needs Being met" and the Discrepancy Between Importance and Needs Being Met .....	86
8.	Fisher's Exact Test Results for Mothers of a Child With a Developmental Disability (DDC) V. Mothers of a Child Without a Disability (NDC) on the Ratings of "Importance", "Needs Being Met" and the Discrepancy Between Importance and Needs Being Met .....	88
9.	Number of Parents of (A) Children With and (B) Children Without Developmental Disabilities Rating Each Question As "Very High", "High", or "Moderate" .....	100
10.	Number of Parents of (A) Children With and (B) Without Developmental Disabilities Identifying QOL Domains Making Them Satisfied with their QOL At the Present Time .....	102
11.	Number of Parents of (A) Children With and (B) Children Without Developmental Disabilities Identifying QOL Domains As Detracting From Their Satisfaction With Their QOL At the Present Time .....	103
12.	Number of Parents of (A) Children With and (B) Children Without Developmental Disabilities Identifying QOL Domains That Were Affected Positively by Their Children .....	104
13.	Number of Parents of (A) Children With and (B) Children Without Developmental Disabilities Identifying QOL Domains That Were Affected Negatively by Their Children .....	105



## Chapter 1

### INTRODUCTION

Assessments of quality of life have traditionally focused on a narrow range of populations. Areas that have been commonly assessed include aging, mental illness, physical disabilities and developmental disabilities (Brown, 1988). However, little research has been done on the impact a person with a disability has on the quality of life of other people. Further, relatively little work has been directed towards members of the family. Seligman and Darling (1989) state that "It is only in recent years that conceptions of family functioning have been taken seriously by professionals who work with families with a chronically disabled member" (pp.1). Similarly, Beckman (1984) notes that the parents are critical determinants of the intervention results for children with developmental disabilities, and thus the ability of parents to cope with the presence of a child with a developmental disability has become a critical issue for researchers.

Goode (1988) in describing several principles of quality of life, states that the quality of life of an individual is intrinsically related to the quality of life of other persons in his/her environment. Disease or disability within a family member is likely to influence the quality of life of the family as a whole, which in turn is likely to modify the quality of life and rehabilitation opportunities of the disabled family member. Harris, Carpenter and Gill (1988) ask the question:

"Do the families of developmentally disabled children have unique experiences that distinguish them from other families? Or is raising a handicapped child fundamentally similar to raising any other child and therefore not demanding of special study or understanding?" (p. 47).

It would be interesting to see what effects these similarities, or differences, have on the results of a quality of life assessment.

One reason that quality of life should be studied, is that previous research has tended to concentrate on the negative impacts a child with a disability has on the parents. For example, parents of the developmentally disabled have been assessed in terms of stress, anxiety, or depression. This perspective gives "the impression of unending gloom and tragedy" (Miezio, 1983, p.3), and does not assess effects that may be seen as positive, or take into account families who have adjusted without developing any of the pathologies suggested above.

MacKeith (1973, as cited in Simeonsson and Simeonsson, 1981 p.70) identified four crisis periods associated with parents of children with any type of handicap. The second of which is the child's entrance into the school system. For this reason, families with a child with disability between the ages of six and nine (school entrance) have been selected.

Additionally, both the mother and the father will be assessed in this study, since, as Cummings (1976) has pointed out a great deal of prior research has focused upon only the parent who was the primary care-giver: the mother. By studying both parents, information on differences between parents may become evident.

### **Purpose of Study**

The purpose of this thesis is to study the effects of a child with a developmental disability on significant others in his/her life, namely the parents. Further it is hoped that both positive and negative impacts will be outlined. The effects of the child with the developmental disability will be assessed in two ways. First, parents of the child with a developmental disability will be compared to a group of parents of a child of the same approximate age that does not have a developmental disability, to see if there is a difference between these two types of families. Additionally, the mothers will be compared to the fathers, to determine if the child with the developmental disability has differential effects on either parent.

According to a review of the literature, quality of life in parents of a child with a developmental disability has never been studied before, and, therefore, it is unclear what may be found. As a result, this study will be exploratory in nature. However, it will address other areas that have been indicated by the literature as relevant, such as marital problems, and household chores. The intention is to add to the present body of knowledge on parents of a child with a developmental disability and, perhaps, open questions for continued study. Another goal is to provide some insight or useful data to practitioners working with parents of the disabled.

## Chapter 2

### REVIEW OF RELEVANT LITERATURE

#### Quality of Life In Families

It is the intent of this thesis to explore the effects which a child with a developmental disability has on the quality of life of the parents. In order to address this properly several aspects from the literature need to be outlined. Firstly, what has previous research on parents of children with developmental disabilities focussed upon; secondly, what have these studies found and; finally, how are the findings relevant to this thesis. However, it may be best to start by defining a few concepts that will be used throughout this thesis.

#### Definitions

There are several aspects of this study that need to be defined, in order to provide a clearer perception of the approach to be taken throughout. The three primary concepts that need to be defined are: developmental disability, family and quality of life.

A disability has been viewed differently in a number of situations. For example, the World Health Organization (1980), defines the disability as the physiological damage, and the handicap as that imposed by societal perceptions. This suggests that the state of being handicapped is relative to other people (Parmenter, 1988). Parmenter supports this view from a symbolic interactionist perspective. He points out that the word handicap is not a symbol for a condition that exists in advance, but is partly a creation of the society in which it exists. In other words, a handicap is partly a function of the society in

which the individual lives. Understanding what constitutes a handicap depends on the setting that individual is in, his socio-cultural system, and the developmental stage and age of that person (Parmenter, 1988).

Similarly, Minde et al (1972) view the handicapped person as someone who reacts to not only his/her physical disability but to the real or imagined expectations society has of his/her handicap. In the study described by Minde et al. (1972) they treated all handicaps as identical since the literature had suggested that there are no specific psychological reactions to specific physical handicaps.

It should be noted that throughout the literature terms such as mental retardation, mental handicap or developmental disability may have been used interchangeably. This study will use the term 'person or child with a developmental disability'.

A definition of developmental disability is provided by the International Classification of Diseases (1978). They define mental retardation as:

"... a condition of arrested or incomplete development of mind which is especially characterized by subnormality of intelligence. The coding should be made on the individual's current level of functioning without regard to its nature or causation, such as psychosis, cultural deprivation, Down's syndrome, etc. Where there is a specific cognitive handicap - such as in speech - the diagnoses of mental retardation should be based on assessments of cognition outside the area of specific handicap. The assessment of intellectual level should be based on whatever information should be available, including clinical evidence, adaptive behaviour, and psychometric findings" (pp. 1098).

A widely accepted definition of mental retardation is that proposed by the American Association on Mental Deficiency (1959) and revised by Grossman

(1983): "Mental retardation refers to significantly subaverage general intellectual functioning resulting in, or associated with deficits in adaptive behaviour, and manifested during the developmental period" (p.11). This definition requires three criteria for a diagnosis of developmental disability: subaverage intellectual functioning (IQ under 70), deficits in adaptive behaviour and age of onset under 18 years (Singh & Wilton, 1985). The degree of developmental disability may be subdivided in terms of deficits in adaptive behaviour, and the severity of deficit in intellectual functioning. The levels are: mild mental retardation (IQ 50-55 to 70), moderate mental retardation (IQ 35-40 to 50-55), severe mental retardation (IQ 20-25 to 35-40) and profound mental retardation (below 20-25). It is this definition, and levels of classification that will be used in this thesis.

Singh and Wilton (1985) note that these last two definitions of developmental disability are two-dimensional. They both incorporate the concepts of low intelligence and deficits in adaptive functioning. Further they note that developmental disability is not an all or nothing phenomenon, but that degrees of disability exist.

The definition of family used in this thesis is more straight-forward. Although, specific definitions of a family may differ, many of them share the concept that *the family reflects the relationship between children and their parents* (Simeonsson and Simeonsson, 1981). This brief definition of the family is adequate for the purpose of this thesis because it covers the central tenet of the thesis: that children, by the nature of the relationship, affect their parents and

that the family affects the child.

### **Models of Family Functioning**

There is little doubt that the presence of a child with a developmental disability in a family has a profound effect on the structure, function, and development of the family (Simeonsson and Simeonsson, 1981). However, it also appears evident that the family also affects the child. Hornby (1989) has outlined three models of family functioning that may explain this relationship.

The first is a transactional model, which argues that development is the result of a continual interplay between a changing organism and a changing environment (Sameroff and Chandler, 1975, as cited in Hornby, 1989). In other words, families are considered to both affect and be affected by their children with a handicap. Further, an infant with a disability will have a different effect on the parent from that of an adolescent with a disability.

The second model is a family systems theory which argues that the behaviour of the family is a function of the system of which the members are a part, and a change in the family system will inevitably lead to a change in the behaviour of each member of the family.

The final model is an ecological model, which states that human development and behaviour cannot be understood independently of the context in which it occurs (Bronfenbrenner, 1979). Therefore, according to this model, parents of a child with a disability are strongly influenced by the environment in which they are living, including the extended family, the services available and community attitudes (Hornby, 1989). Further, social ecology asserts that a child

or family can be affected by events occurring in settings in which the person is not even present. For example, a child may be affected by the conditions of his parents employment (Seligman & Darling, 1989).

Bronfenbrenner's (1979) model may be described as a set of hierarchical interlocking blocks. They are the *microsystem*, the *mesosystem*, the *exosystem*, and the *macrosystem*.

In Bronfenbrenner's (1979) words the *microsystem* is a "pattern of activities, roles, and interpersonal relations experienced by a developing person in a given setting with particular physical and material characteristics" (pp.22). The *mesosystem* comprises the interrelationships between two or more settings or microsystems, such as the interaction between a child's home and school. The *exosystem* describes those setting in which the developing person is not necessarily an active participant, such as the school class of an older sibling, in the case of a young child. Lastly, the *macrosystem* comprises the ideological systems inherent in the social institutions of a particular society such as religious economic and political beliefs (Bronfenbrenner,1979)

Therefore, according to Hornby (1989), "the effects on parents caring for a child with special needs are strongly influenced by the environment in which they live including the extended family, the services available and community attitudes" (pp.213). The immediate family of the child with a disability is considered to constitute the microsystem, which is influenced by the range of settings in which the family actively participates, such as the extended family, school and work (the mesosystem). The microsystem and the mesosystem are



embedded in the exosystem, which consists of settings that the family with a child with a disability is not actively involved such as mass media, education system and voluntary agencies. Lastly, the macrosystem consists of the social institutions that the above systems exist within, such as religious, economic and political beliefs.

Similar to Hornby (1989), Mitchell (1985) states that the developmental systems model (Bronfenbrenner, 1979) also applies to families who have a member with a disability. He states that it is assumed that families of a person with a developmental disability constitute an interpersonal system which is embedded in other systems of varying degrees of abstractness, according to Bronfenbrenner's model. He also has said "handicapped persons do not live in a social vacuum" (pp.126).

The experiences and behaviours of a family with a person having a mental handicap are influenced not only by the interactions within its own microsystem, and interactions with the social system, but as Bronfenbrenner (1979) states, "the properties of the person and the environment, the structure of the environmental settings, and the processes taking place within and between must be viewed as interdependent and analyzed in system terms" (pp.41).

Mitchell (1986) further recommends that the planning, management and evaluation of programs and services for people with disabilities should be based on a developmental systems model, such as the one proposed by Bronfenbrenner (1979). This view takes into account two premises

- 1) services should take into account the ecology of the environment for the

person with a handicap.

2) services should be responsive to the changing needs of the person and his family at the different stages of the life cycle.

With these premises in mind, Mitchell (1986) outlined the components of the total ecology which may be relevant to a family, comprised of a father, mother, child with a handicap and his/her siblings.

Turnbull and Turnbull (1986) have also proposed a framework to organize family systems. This framework has four major components:

1. *Family Resources*, which consists of the descriptive elements of the family including characteristics of the exceptionality (eg. type and level of severity); characteristics of the family (eg. size, form, cultural background, socioeconomic status); and personal characteristics (eg. health, intellectual capacity and coping styles)
2. *Family interaction*, which refers to the relationships among subgroups of family members.
3. *Family Functions*, which refer to the different categories of needs the family is responsible for addressing. The purpose of the family interaction is to produce responses to fulfil the needs associated with family functions.
4. *Family life-cycle*, which is the sequence of developmental and non-developmental changes that affect families. These changes alter family resources (eg. birth of a child) and family functions (eg. mother stops working outside the home, which provides more time for child-rearing, yet less income).

Turnbull, Brotherson & Summers (1986, as cited in Seligman & Darling,

1986) have noted that much of the literature on families with members who have a disability is based on the assumption of family homogeneity. However, families differ with regard to a number of characteristics. For example extended family members may or may not reside in the household, the family may be a single parent family, the family's breadwinner may be unemployed, or there may be a major psychological disorder in the family such as substance abuse, or mental illness. This is mirrored by Turnbull and Turnbull (1986), who state that "every family is idiosyncratic, if not unique" (pp. 24).

### **Stages of Development**

Mitchell (1986) states that from a life-cycle perspective, families with a member with a disability are considered to pass through a series of stages. Theorists have identified between 6 and 24 developmental stages (Carter & McGoldrick, 1980). Each stage is characterized by a set of developmental tasks (Havinghurst, 1972, as cited in Mitchell, 1986). These tasks result from interactions within the microsystem, and between the family and the social systems that they are within. From this it is argued that these tasks must be at least partially mastered for families to adapt adequately to the presence of a member with a handicap (Simeonsson & Simeonsson, 1981). These stages are bounded by what Wilker (1981) calls transition points, which occur when there is a major discrepancy between expected achievement and actual performance. This is also consistent with the definition of quality of life proposed in this thesis (Brown, et al., 1989), which states that quality of life is the discrepancy between achieved and unmet needs.

Seligman and Darling, (1989) report that perceptions of unmet needs varied over the life-cycle. Perceived needs for family support, respite care, and counselling services were highest among parents of preschoolers and young adults and lowest among parents of school-aged children.

Turnbull, Summers & Brotherson (1986, as cited in Seligman & Darling, 1989) relate the developmental stages derived from systems theorists to the stress families with disabled children experience (based on the stages described by Olsen et al., 1984). Seligman & Darling (1989) list some illustrative stress factors:

1. Child bearing: Getting an accurate diagnosis; making emotional adjustments; informing other family members.
2. School age: Clarifying personal views regarding mainstreaming versus segregated placements; dealing with reactions of child's peer group; arranging for child care and extracurricular activities.
3. Adolescence: Adjustment for chronicity of child's disability; dealing with issues of sexuality; coping with peer isolation and rejection; planning for a child's vocational future.
4. Launching: Recognizing and adjusting to the family's continuing responsibility; deciding on residential placement; dealing with the lack of socializing opportunities for disabled members.
5. Postparental: Reestablishing relationship with spouse that is if child has been successfully launched); interacting with disabled

member's residential service providers.

A similar model was outlined by Mitchell (1985). He stated that there were four broad stages of development for parents adapting to the presence of a disabled child. These include:

- Initial diagnosis
- Infancy and toddlerhood
- Childhood and early adolescence
- Late adolescence and adulthood

Mitchell (1985, 1986) states that during the childhood and early adolescence stages persons who are developmentally disabled, and their families, become increasingly exposed to a range of settings at the mesosystem level, including special education, the local community, and recreational groups. The stage is usually terminated when the individual effects the transition from special education to a vocational setting and in some cases from home living to a residential facility of some kind. Further, the developmental tasks faced by parents include establishing relationships with professionals, accepting prolonged dependence by the child, acceptance of the child by the community, and helping the child understand his/her disability.

Fewell (1986) has stated that children with disabilities are slower at reaching certain life-cycle or developmental milestones. As a child with a disability approaches critical periods, parents are faced with six periods that may be particularly difficult, which are similar to the stages listed above by Mitchell (1985) and Turnbull, Summers and Brotherson (1986). They are:

- 1) Encountering the Disability
- 2) Early Childhood
- 3) School Entry
- 4) Adolescence
- 5) Beginning Adult Life
- 6) Maintaining Adult Life

Parents may experience anxiety when they realize that their child fails to fit into the mainstream of the traditional education system (Fewell, 1986). "This stage can be characterized as the period when the family 'goes public', when they venture beyond the boundaries of the family" (pp. 22, Fewell, 1986).

### **Age and Disability**

One presumption of a developmental systems approach is that it is related to age. Bronfenbrenner's (1979) model of the ecology of human development defines an ecological transition as occurring "whenever a person's position in the ecological environment is altered as result of a change in role setting or both" (pp.26).

Brown (1988) reports that "certain aspects of quality of life are more likely to be associated with one particular age group than another" (p.3). This may be true because at different ages people are faced with different problems or life crises. MacKeith (1973) has identified four major crisis periods associated with having a child with a handicap. The first is when the parents become aware that their child is handicapped. The second is when the child becomes eligible for educational services. It is, then, when parents realize the level and permanence of their child's developmental disability in terms of academic expectations. The third crisis occurs when the child leaves school,

and, finally, the parents are faced with a crisis when they are aging and can no longer assume responsibility for their offspring.

The primary reason that parents of children with developmental disabilities in their first three years of school were selected for the study involves the stresses involved in transition from one life stage to another, - i.e., the child with a disability entering school. This is consistent with MacKeith's (1973) second life crisis for parents of a child with a developmental disability.

Weisgerber (1991) supports this by stating "important transitions occur upon entry and advancement in educational environments" (p.8). Further he states that school activities are centred around structured learning in a social context, that requires a continuous assessment of one's personal performance in comparison with that of others. The school environment strongly influences self-esteem. Finally, he adds "personal characteristics that are shaped at this time, such as the determination that a young person with a disability displays in the face of challenges, may be at least as important as acquisition of knowledge and skills" (Weisgerber, 1991, p.10). During school years there is a great deal of concern over ensuring that individuals benefit from schooling. From this perspective we may lose sight of what is truly important, such as employability and self-sufficiency (Weisgerber, 1991).

The early school years, characterized by the provision for special education and/or habilitative services, may be the first opportunity for the child with a handicap to become aware of how they differ from other children (Simeonsson and Simeonsson, 1981). Minde, et al. (1972) found that children

with physical handicaps go through a well-defined crises between the ages of 5 and 9, following the realization that their handicap is permanent.

Paul and Porter (1981) explain that the child's entry into school is the point at which parents are legally required to deal with a public institution. From this point onward the relationship between the parents, the child and the school will become increasingly important and more complex. Some children (with physical handicap for example) can adapt to most of the school curriculum. However, others may not be handicapped until they reach school (the "six hour retarded child") (Paul and Porter, 1981). Other stresses are evidenced by Mercer (1973) who concluded that schools were significant in the "epidemiology" of mental retardation.

### **Introduction to the Effects of a Child's Disability on his/her Parents**

If one is to study parents of children with a mental handicap, it seems important to briefly review the literature on mental handicap to provide some hypotheses about how children with developmental disabilities affect their parents. In the past, research studies have looked at individual members reacting passively to the presence of a handicapped member. This view also presumes that the families will inevitably experience stress and psychological impairment. However, studies, are beginning to view families of mentally handicapped children differently (Byrne and Cunningham, 1988). Miezio (1983) points out that the detailing of how a child with a disability affects the members of a family seems unsatisfactory, because it gives "the impression of unending gloom and tragedy" (p.3).



However, as Beckman (1984) illustrates, stress is not the inevitable consequence of the presence of a disabled member.

*"It has become increasingly clear that an understanding of the stress experienced by the families of handicapped children requires much more than a focus on the way in which individual members react to the occurrence of a single event. Rather, it involves an understanding of the process by which this complex system responds to an ever changing set of circumstances. (pp. 282)."*

Factors, such as multiple stressors, the life-cycle stage of the family, the family's interpretations of their situation, and the integration of the family prior to the birth of a child with a disability, are related to stress and anxiety (Byrne and Cunningham (1988). Similarly, Turnbull and Turnbull (1986) report that the life cycles of individual members of a family are highly interactive. The feelings and behaviours of parents may be influenced by several factors, including the prospect of a severe handicap, the degree to which the handicap is obvious to others, the attitudes of others toward the handicap and the time at which the handicap became evident to the parents (MacKeith, 1973). Further the family with a child with a disability, like all families, are constantly changing and growing (Miezio, 1983). In other words, although the presence of a child with a disability may be a predictor of stress, there are many other important factors that may influence the impact of that child.

### **Impact of a Child with a Disability: Stress?**

The revised perspective on the family unit discussed above is also reflected by Harris, Carpenter, and Gill (1988). They express that although the

presence of a child with a mental handicap may be stressful, most families manage to integrate the child with the handicapped while still addressing the needs of the family as a unit and of other individuals within the family. Although this may take somewhat more effort than other families, it should not be construed as negative or pathological. A child with a developmental disability often needs more time, energy, attention, and money than a normal child, and, frequently, returns less success, achievement, parenting pride, privacy, and well-being (Paul and Porter, 1981).

A great deal of the literature on families of children with a disability discuss stress as an outcome, therefore, stress will be briefly addressed. It will be touched upon for two reasons. First, it has been broadly studied in the literature as a force to be contended with by parents of children with disabilities. Second, stress is an important component of the model of quality of life that is used in framing this study (Abbey & Andrews, 1986). Therefore, it is important to determine the role that stress will play in this study of quality of life.

Beckman (1984) reports Rabkin and Strueing define stress as "the organism's response to stressful conditions or stressors, consisting of a pattern of physiological and psychological reactions, both immediate and delayed" (p.27). Stress is seen by Beckman (1984) from a transactional point of view. She sees stress in the family as an interaction between parent and child, and this relationship is not static over time.

The presence of a child may be seen as a long term stressor that sets the family apart from other families in the community (Simeonsson and

Simeonsson, 1981). Stress on the family may occur with the birth of a disabled child. Each parent reacts not only to the event and what it has meant to him/her, but to other persons around them (Miezio, 1983). Similarly, discrepancies between actual experiences of parents and their expectancies about family life can constitute a critical area of stress (Simeonsson and Simeonsson, 1981). Developmental transitions (moving from one stage to another) can be a major source of stress and possible family dysfunction (Turnbull, Summers and Brotherson, 1986).

According to Byrne and Cunningham (1988) "the most comprehensive and meaningful view of families is one which acknowledges the competence of families, recognizing that many cope with and adapt to stresses they experience" (p.85). It is their conclusion, similar to the ones discussed above, that stress is by no means an inevitable outcome for mothers of children with Down syndrome. This is comparable to a statement by Paul and Beckman-Bell (1981):

"Despite the unique nature of the problems faced by the parents of each handicapped child, most of these parents have some things in common. Regardless of how well parents adjust, there are few who have not had to come to grips with a variety of different emotions. They often share the struggle of trying to find appropriate services for their child" (Paul and Beckman-Bell, 1981, p.125).

In a study by Byrne and Cunningham (1988) it was found that families, regardless of the fact that their children received similar early intervention programs, appeared to adapt differently. Some who appeared stressed,

described relationship problems, difficulty with children, and feelings of restriction and isolation. They report that 44% of mothers found it most difficult to cope with the child's behaviour, however, only 2% of the mothers reported that they could think of nothing that pleased them. This indicates that the children are not solely a bundle of stress for the mothers, but, rather part stressful and part joy-bringing.

In the paper entitled *Measuring the effects of stress on the mothers of handicapped infants: Must depression always follow?* Burden (1980) provides a similar perspective. He stated that although it appears fairly well established in the literature that mothers of infants with a disability were prone to stress and mental-illness, this information begs the issue of causality. Further it was argued that it is not necessarily the fact of having a child with a disability that leads to problems, but rather that the presence of a child with a handicap leads to certain family needs. It is these needs that if unmet lead to stress and difficulties. This view is consistent with both the definition of quality of life (Brown et al., 1989) used for this thesis, and the method of assessment used (Flanagan, 1978).

Baxter (1986) found that certain situations produce considerable stress for the parents of a child with a disability:

1. Formal social occasions where the child does not conform to norms
2. Other persons' homes where coping with the child's behaviour is difficult

3. Public settings where behaviour management is a problem
4. Restrictive settings that do not readily allow parents to withdraw from the situation
5. Social situations where the child engages in deviant forms of interaction with other people

### **Specific Effects of the Presence of a Child with a Disability**

Turnbull and Turnbull (1986) state that there are three important considerations about the way a disability affects the family (See figure 2). First, the characteristics of the exceptionality (i.e., disability) shapes the family's reaction. For example, the severity of the exceptionality creates differences in families. Second, the characteristics of the families shape their reaction to the exceptionality. This includes a family's cultural background, socioeconomic status, and size. Finally, every family is composed of individuals, each of whom has personal resources and problems.

It seems evident from the above discussions that a child with a disability within the family may have some broad effects on the parents. However, if a family is experiencing stress or a feeling of loss of control, what particular part of their lives is producing the stress? The literature provided examples of many specific areas of peoples' lives that have been affected by the presence of a disabled child.

Parke (1981, as cited in Seligman & Darling, 1989) has noted that fathers have been purposely ignored in research studies because of the presumption that they are less important than the mother in influencing the developing child.

Much of the literature to date has focussed on the problems faced by the mother of a child with a disability (Cummings et al, 1965; Burden, 1980), however, the focus of research is changing to include the fathers as an important part of the family with a disabled member (Cummings, 1975; Minde et al., 1972). Therefore, for this study, both mothers and fathers have been examined.

The problems that face parents of a child with a developmental disability are many and varied. For example, Travis (1976, as cited in Simeonsson and Simeonsson, 1981) identified several tasks that families of children with handicaps or chronic conditions face. They include: sleep interruptions beyond the infancy period; provision of complicated diets or treatments; extra cleaning and housework; physical or structural adaptation of the home; and additional financial demands.

One area of difficulty cited by many sources is that of the amount of additional household work that faces the family, particularly the mother. A study by Byrne and Cunningham (1988) illustrated the areas of difficulty for mothers in regards to household and child related tasks. Some of their results showed that mothers are involved in most household task, but perform most of them alone. They receive some help with child related tasks, more care is given for the child with the disability than with his/her siblings, and fathers help more than any other family member. As a result the mothers indicated that they would like more help in the home and they would like more time to themselves. It has also been reported that a higher number of mothers of children with Down syndrome and Prader-Willi Syndrome remain in the home as housewives, while slightly

more mothers of non-handicapped children return to work (James and Brown, 1992)

Other differences have been indicated between mothers and fathers. Several authors also report that mothers of children with developmental disabilities are more likely to experience depressive symptoms than are the fathers, although the fathers may experience some depression (Holroyd, 1974; Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981, and DeMyer, 1979). James and Brown, (1992) note that, mothers of children with Down Syndrome and Prader-Willi Syndrome had higher levels of distress than the mothers of non-handicapped children. Distress in fathers of children with Prader-Willi was greater than that of the fathers of children with Down Syndrome. They also found that fathers tended to show stress reactions in terms of bodily functions while mothers tended to show obsessive- compulsive behaviour, sensitivity to interpersonal relations and alienation when compared to mothers of non-handicapped children. This provides us with some evidence that the presence of a child with a handicap does have a differential effect on the parents.

Although the child may affect the mother differently than the father, the child still affects both parents. As a result, it should be no surprise that the relationship between the parents is affected. However, there appears to be some contradictory evidence in regards to how the child with a disability affects the parents marriage. Byrne and Cunningham (1988) found that 67% of their respondents indicated that their relationship with their spouse was unchanged or had improved. However, Byrne and Cunningham (1988) report other studies

(Lonsdale, 1978; Pahl and Quine, 1984) where a greater proportion of marriages have deteriorated. They predict that the differences in the studies may be due to the fact that their study used relatively young children, or only children with Down's syndrome.

Miezio (1983) states that the relationship between parents changes with the birth of any child, and the stress of a child with a disability may add additional dimensions that prove difficult. For example, DeMyer (1979, as cited in Harris 1983) reported that the presence of an autistic child tended to affect the parents relationship by being a chronic source of stress, and taking the joy out of life. Each parent may look to the other for support, and may not be able to meet the needs of the other. Additionally, the repeated crises may erode coping ability and increase the separation between marital partners.

However, the crisis may be beneficial in that it brings family members together (Miezio, 1983). Harris, Carpenter and Gill, (1988) indicate that marital satisfaction was the best predictor of coping ability in the families of handicapped children. Further, the mother security in the marital relationship appears to influence her ability to cope with the child's needs. Similarly, Bristol (1984) emphasized that the availability of formal support, including baby-sitters and respite care, and informal support, such as relatives and friends, affected marital adjustment and the quality of maternal parenting.

Another area of difficulty associated with having a child with a developmental disability may be a disruption in the sexual relationship of the parents. Sexual behaviour may be influenced in two ways. First the child may



produce fatigue in the parents, and second they parents may be faced with a lack of privacy. These two factors may be caused by a child who sleeps poorly, wanders around the house at night, or by the parents who are simply too tired from caring for the child during the day. Additionally, parents may be faced with the fear of conceiving another disabled child (Harris, 1983). DeMyer (1979) reports that mothers of autistic children may be too tired to engage in intercourse.

With problems facing the relationship between the parents, time to be shared just by the two of them should be beneficial, however, going out or having friends over may be a trial. For parents with a child with a handicap, routine events may be stressful, such as structuring the behaviour of their child, finding a baby-sitter, or having guests over. A study by Hewitt (1970, reported in Byrne and Cunningham, 1988) indicated that parents of a child with cerebral palsy had more trouble getting out. Conversely, the data provided by Byrne and Cunningham (1988) indicates that for a family with a child with Down syndrome there appears to be little problem with parental outings. Additionally, of those parents who wanted to go out more often, 15% felt that it was their child with Down syndrome that prevented this. However they qualified this by stating that this was because they were unable to find good baby-sitters.

Children with disabilities may not achieve levels of independence that other children may. This may include such things as being able to go about the neighbourhood without supervision, or eventually staying home alone without a babysitter, which typically would result in a decreasing the demands on the

parents .

*"Several sets of parents have admitted they have never been on vacation alone, and very few go out on the weekend because it is nearly impossible to locate a babysitter who will tackle this unusual charge for a reasonable fee. Respite care is rare and dear luxury". (Klein, 1977, p.311)*

Although most families may be faced with financial difficulties, parents of a disabled child are faced with some anxiety that other parents may not be faced with. There is anxiety about paying high costs for the child's care, or how the child will receive assistance when the parents are no longer able to provide it. This anxiety may lead to later difficulties (Miezio, 1983). Children with disabilities generally require more specialized medical care and more frequent hospitalizations than normal children. Additionally, they may require more related medical care such as occupational, physical and speech therapy (Seligman and Darling, 1989).

The child may need assistance throughout his/her life, which means the parents may need to play the parental role for the rest of their lives (Miezio, 1983). According to Minde et al. (1972) most parents found it difficult to deal with the development of their child on a long-term basis.

Childhood disabilities have an economic impact on families in addition to their psychosocial costs. These impacts include both direct costs, such as child-care, medical care, therapy and special equipment; and indirect costs, which may include, lost work time, special residential needs and interference with

career advancement (Seligman & Darling, 1989). Other direct costs that have been a problem for parents of children include, expensive babysitting, physician visits, hospitalizations, and, physical and occupational therapy (Seligman & Darling, 1989).

Miezio, (1983) cites Wikler (1981) as reporting that parental stress is exacerbated as the child reaches and passes critical life stages. She gives the examples of walking, talking, and, relevant to this thesis, starting public school. The infant who is mentally retarded or physically disabled needs the same amount of care as any other infant, however as the infant gets older and the critical stages are passed the differences become more and more evident. Similarly, Minde et al (1972) describes the frantic search by parents for a solution as they realize that their child is approaching school age.

Another issue to be addressed are the reactions and feelings of a parent in regards to their child with a handicap. MacKeith (1973, p. 525) outlines mixed feeling that may result when parents discover that their child has a handicap. They include:

- 1) *Two biological reactions*: protection of the helpless; revulsion of the abnormal
- 2) *Two feelings of inadequacy*: inadequacy at reproduction; inadequacy at rearing
- 3) *Three feelings of bereavement*: at the loss of the normal child they expected, with almost infinite potentialities: a) anger; b) grief; and c) adjustment which takes time
- 4) *Feeling of shock*
- 5) *Feeling of guilt*,
- 6) *Feeling of embarrassment*; which is a social reaction to what the parents think other people are feeling

Irvin, Kennell & Klaus (1975) describe a series of stages that parents go

through when they discover their child has a disability:

1. Shock
2. Denial
3. Sadness, anger, anxiety
4. Adaptation
5. Reorganization

Olshansky (1962, as cited in Seligman & Darling, 1989) argued that parents of children with a mental handicap never completely abandon the grief process, but that they suffer from chronic sorrow.

One must remember that this is not an all-inclusive list of ways in which parents may be affected by their child. There are others that have been listed in the literature, but were not as common or as prominent as above.

From the information presented above one may reach the same conclusion as Paul and Beckman-Bell (1981): that children have an important impact on parental self-concept, the marriage, and family relationships. We now know that children with a disability have the potential to affect their parents negatively, however, this is not always the case. In other words, some parents are able to cope quite well with their child. What factors that affect coping, are the difference between families that are able to cope and those who are not?

### **Factors Associated with Adapting to a Child with a Disability**

Mitchell, (1986) lists the four process involved in accepting a child's handicapping condition described by Featherstone (1981). They are:

- 1) Acknowledging the existence of the handicap and its long-term significance.
- 2) Integrating the child and the disability into the family.

3) Learning to forgive their own errors and shortcomings.

4) Searching for meaning in their loss.

Seligman and Darling note that whether or not parents pass through such stages or have specific reactions to their child with a disability depends on several factors including:

- Socio-economic status
- Support Services (or the lack of them)
- Physician Attitude
- Presence of Other Children and Spouse in the Home
- Prior Information
- Availability of Support Persons in the Community
- Single Versus Two Parent Homes
- Religiosity
- Previous Births of Non-disabled Children
- Actual Physical Appearance of the Child

Other factors, described by Collins-Moore (1984) include:

- General emotional maturity of the parent
- Cultural attitudes
- Education
- Parent's age
- Birth order
- Child's sex
- Child's ability to respond to the parents
- Etiology of the disability
- Prognosis

Turnbull, Brotherson, and Summers (1985) report that some families perceive a major positive contribution of their child with a handicap which is related to guidance, affection, and self-definition. They describe positive attitudinal and value changes that they attribute to the retarded family members.

Mitchell (1986) presents a model that conceptualizes the factors that influence a family's reactions to the member with a handicap. There are three

factors that determine the family's vulnerability to stress. They are:

1. The amount of change required of the family as a result of the presence of a member with a disability. For some families, this may involve dramatic changes in earning power and lifestyle, while other families may make only minor changes.
2. The families perception of the seriousness of the changes will also affect the families response to the member with handicap. For example, families from the same cultural or social class agree on the magnitude of stress that various life events produce.
3. Family Adaptability. This is influenced by: a) personal resources, including educational accomplishments, health and self-esteem; b) the family system's internal resources, such as family size, religion, marital satisfaction; and c) the amount and quality of the informal and formal social supports available to the family from the mesosystem.

Turnbull and Turnbull (1986) list several functions that are required by the family. They are:

- 1) Economic (e.g., generating income, paying bills, and banking).
- 2) Domestic/health care (e.g. transportation, purchasing and preparing food, medical visits).
- 3) Recreation (e.g., hobbies, recreation for the family and for the individual).
- 4) Socialization (e.g., developing social skills, interpersonal

relationships).

5) Self-identity (e.g., recognizing strengths and weaknesses, sense of belonging).

6) Affection (e.g., intimacy, nurturing).

7) Educational/Vocational (e.g., career choice, development of work, ethic, homework)

Surprisingly, Kendall and Calman (1964) found no indications that intelligence or educational status of the parents was related to adjustment to the child and his/her handicap. However, Byrne and Cunningham (1988) indicated that educational level was significantly correlated with stress in families with Down syndrome, with less stress associated with higher levels of education.

One interesting finding by Heisler (1972, as cited in Miezio, 1983) was that families with a disabled child typically do not seek professional help for their problems. They think of the child as "their" problem. They forget that although the child cannot be "cured" that changes can be made to reduce stressors on the family. This is supported by Burden (1980), who notes that mothers of children with a handicap have special needs themselves which can be met by home visits by trained developmental therapists, who can help alleviate "mental ill-health".

Mitchell (1986) cites Challela (1981), as stating that while it is possible to detect broad trends in the literature on families with persons with a handicap, it is clear that particular individuals and particular families have unique reactions to the handicap.

### **Social Support**

*"Social support is often viewed as a mediation or buffering factor in meeting the demands of a stressful event (Cobb, 1976; Crnic, Greenberg, Ragozin, Robinson & Basham, 1983). The presence of a disabled child is considered a stressful event (Crnic, et al., 1983) and one that is considered chronic in nature (Olshansky, 1962)". Seligman & Darling, 1989 (p.108).*

One manner in which people adapt to stress is through social support (Seligman & Darling, 1989). Bristol (1984) states that families may have a harder time finding social supports than other families in the community. This may be due to the fact the very nature of the child's handicap has the potential to reduce social support and increase parental isolation.

Social support may also come from within the family. Some family characteristics that have helped parents cope, include degree of cohesiveness, degree of expressiveness, and the presence of active recreation in the family (Bristol, 1984). Families that were high in commitment and support for one-another coped better with a child with a handicap than did other families. In other words, social support within the nuclear family predicted effective coping.

### **Disability Conclusions**

An important reason to study the area of disabilities is suggested by Weisgerber (1991). He reports that Flanagan (1979) took a representative sample of the American populations and identified 15 areas that generally constitute quality of life. Weisgerber (1991) states that this is an established



reference point against which to compare persons with disabilities, however no comparable data has been collected from persons with disabilities. As a result Weisgerber (1991) recommends that research on this area needs to be carried out.

Further, Mitchell (1986) cites Hewett (1970) and Mittler and Mittler (1982) as cautioning that we should be wary of drawing too sharp a distinction between families of handicapped and non-handicapped persons, because they have more in common than is recognized.

## **Quality of Life: General Issues**

### **Background to Quality of Life**

The term quality of life (QOL) did not appear in the academic literature prior to the 1960's. Szalai (1980) reports that the term had only been heard prior to this in reference to "environmental pollution, the deterioration of urban living conditions, and the like" (p.7). It was only in general publications and not in a scholarly context. Weisgerber (1991) states that efforts to measure quality of life began with President Eisenhower, and were based on broad considerations of environmental and social factors, including education, health, economic growth, concern for individual welfare, and defense of the free world. Similarly, according to Schneider (1976), the original forces that stimulated the development of social indicators research came from the need of administrators in the 1960's for information measuring the impact of government programs and the effects of public policies. A social indicator may be defined as a statistic of direct normative interest which facilitates judgements about the condition of a major aspect of society.

In recent years, a great deal of research has focused on quality of life. In general, research on quality of life selects certain measurable parameters, dimensions, or indicators of life quality and rates the life quality of various groups and categories of people by this method (Szalai, 1980). From these types of research studies, several common issues arise. Ferrans (1990) frames these issues nicely by stating:

*"First, instruments should be selected that reflect the definition of quality of life selected. Second, it should be recognized that it is essential to include the perception of the individual whose quality of life is being evaluated. Third, because quality of life is a multidimensional construct, care must be taken to capture its broad nature, rather than focusing only on health concerns. Finally, differences in individual value should be addressed" (p.253).*

It is the intention of this thesis to address these issues. In the forthcoming sections it is hoped that a satisfactory definition may be outlined that is relevant to studying parents of children with mental handicaps. Additionally, a rationale for measuring the field subjectively versus objectively will be outlined, and, lastly, an instrument will be selected to measure the topic area.

### **Definition of Quality of Life**

It appears to be well accepted among researchers studying quality of life that there is no consistent definition for the term. For example, Brown (1988) states that "quality of life is a concept which has major implications for the field of rehabilitation, but it is a complex term and ill-defined" (p. 1). Ferrans (1990) further states that "There is not yet a universally agreed upon definition of quality of life nor is there a standard for its measurement" (p. 248). Szalai (1980) also states that the scholarly term, 'quality of life' has as no agreed upon definition. Lastly, Landesman (1986) states that the process of defining quality of life and personal life satisfaction is likely to be fraught with difficulties and disagreements.

Bard (1984), provides some insight into why there is so little consensus among researchers as to a definition of quality of life:

*"The major challenge to the use of the term quality of life ... is that the term is too broad and inclusive to be meaningful. Central to this position was the definitional problem, that is, that the term is operationally defined in very different ways by different investigators. Thus the failure to achieve a shared definition results in the use of measures that are assessing different things (Bard, 1984, p. 2327).*

In other words, the definition of the concept of quality of life has remained elusive because it has been equated with concepts such as life satisfaction, self-esteem, well-being, health, happiness, adjustment, value of life, meaning of life, and functional status (Dean, 1988). Therefore it is unclear what should be assessed.

The term "quality of life" is also described by Mukherjee (1980) as a value-laden concept because it refers to attributes that are 'desirable' or 'undesirable', selected out of all the qualitative attributes and their duly quantified indivisible elements which are involved with or respond to the life process of human beings. In other words the definition chosen, by the researcher reflects his/her biases. However, it is important to explicate ones biases, so persons reading the work may understand the researcher's perspective.

Quality of life has been defined in a number of different ways by different researchers, some more concrete than others. For example, cancer patients are often discussed in terms of disease free intervals and changes in the volume of the tumour (Holmes and Dickerson, 1987). Holmes and Dickerson (1987) report that with cancer patients "we tend to emphasis their survival rates ... but rarely do we comment on the quality of survival" (p.15). This is reflected

by the fact that definitions of quality of life in oncology patients fall into five broad categories: 1) normal life, 2) happiness/satisfaction, 3) achievement of personal goals, 4) social utility, and 5) natural capacity. Another concrete definition is one that emphasizes a person's ability to perform ordinary activities in daily life (Alexander and Willems, 1981). Lastly, Zautra and Goodhart outline objective measures of one's environment in a definition of quality of life.

Other definitions are more abstract than these. In a review of quality of life literature, Zautra and Goodhart (1979, p. 1) state that quality of life "pertains to the 'goodness' of life" and "that 'goodness' resides in the quality of life experience". Cohen's (1982) definition outlines an individual's ability to realize one's life-plans. Another definition states that quality of life "is a process which enables the individual to gain increasing control of his environment" (Brown, 1985, p.13).

Weisgerber (1991) describes the definition of quality of life from The Panel on the Quality of American Life (1980) as a sense of well-being, a dynamic blend of satisfactions, which presumes:

*First Tier:* Freedom from hunger, poverty, sickness, illiteracy and undue fear about the hazards of life ...

*Second Tier:* Opportunity for personal growth, fulfillment, and self-esteem, which includes

- Opportunity to establish and maintain social bonds with family, friends, community and co-workers
- Opportunity to participate in and derive meaning from religious,

civic, family, and work activities.

- Access to sources of aesthetic and intellectual pleasure, including museums, concerts, the use of public parks and libraries, participation in educational and other activities.

- Access to activities pursued for recreational purposes, such as hiking, athletics, reading, and TV viewing.

Milbrath (1982, as reported in Parmenter, 1988) defined quality of life as the fulfilment of one's values, goals, aspirations and needs. Similarly, quality of life can also be viewed as the discrepancy between a person's achieved and unmet needs and desires (Brown et al., 1989). Needs, as perceived by the client, include the economic, social, political and cultural needs of the individual, such as the need for love, companionship, sexual activity, employment, social integration, independence, citizen participation, mobility and so forth (Goode, 1988). Further, Goode (1988) states that it is assumed that the individual client will have certain needs that are considered more important than others and that the client will look for resources within the environment to meet his/her needs. "This QOL model proposes that discrepancies between the individual's perception of environmental resources/personal needs and between environmental demands/personal capabilities will influence the client's degree of satisfaction with specific life settings and the clients self-assessment of overall QOL." (Goode, 1988, p. 9)

Brown et al.'s (1989) definition of quality of life, being the discrepancy between a person's achieved and unmet needs, would be consistent with the

approach used by Flanagan (1978) to assess quality of life. Although Flanagan (1978) did not specifically define quality of life in his study, he did ask subjects how important each of 15 quality of life domains were, and how well their needs and wants were being met in that regard. As discussed later, Flanagan's approach will be used to assess quality of life. Therefore, Brown et al.'s (1989) definition of quality of life will be used in this thesis to define quality of life.

Brown (1985) states that "this definition assumes a discrepancy model" (p.248). The greater the discrepancy between an individual's achieved and unmet needs, the lower the quality of life. Further, Brown outlines several key concepts to this model, that are relevant to this thesis.

- 1) The model involves taking into account all aspects of an individual's life: education, vocation, social living, home living, and leisure and recreational involvement (this is true of Flanagan's (1978) approach also)
- 2) The individual's thoughts and feelings about himself/herself, which requires confidentiality and the individual's consent.

Similar to the definitions presented above by Flanagan (1978) and Brown et al. (1989), Goode (1988) states that the ecological approach assumes that personal need fulfillment is an important and desirable system goal. He states that "theoretically one's overall QOL would be a summary measure of the discrepancy between one's satisfaction with particular life concerns and one's perceptions of the importance of those life concerns" (p. 5). The QOL of an individual is intrinsically related to the QOL of other persons in his or her

environment" (Goode, 1988).

Additionally, definitions that focus on the person's perception seems to implicitly take into account the differential impact of various aspects of life (Ferrans, 1990). This is echoed by Goode (1988) who states that "any research or program agenda on QOL must be client driven and incorporate the life experiences of consumers and their families" (p. 1)

Goode (1988) states that life domains or life concerns need to be set in the context of client/family needs and aspirations. Similarly, this thesis will reflect Goode's (1988) ecological perspective where there is an interactive effect between the person and the environment. In other words, in this thesis, in order to measure and define quality of life, a persons environment must be considered, and this includes the people in one's environment. According to Goode (1988) the overall QOL indicators commonly measure an individuals self-assessment of his or her satisfaction with various life domains or life concerns.

### **Subjective vs. Objective Measurement**

Since there is such a wide discrepancy in the definitions of quality of life, it is not surprising to find differences in the way each researcher measures quality of life. In deciding upon a measurement instrument there are a number of issues to be addressed. Frank-Stromborg (1984) emphasizes four decisions a researcher must make in selecting an instrument to measure quality of life. The researcher must decide whether to use qualitative versus quantitative measures, subjective or objective reporters, subjective or objective dimensions, and single versus multiple instruments (Frank-Stromborg, 1984). This thesis



will argue for the use of a single, qualitative measure (Flanagan, 1978), in which a subjective reporter, gives information on subjective dimensions of their lives.

With so many possible approaches for the researcher to assess quality of life it is likely that confusion may arise in how a researcher has done his studies. Parmenter (1988) provides some clarity by stating that studies intended to measure quality of life have followed three major orientations: social indicators, measures of life satisfaction, and "more direct approaches" (p. 24). Social indicators are those which can be measured objectively, such as income. Measures of life satisfaction, may be approached in two ways by assessing an individual's affect or their cognitions (this will be further discussed later). Lastly, in line with Parmenter's "more direct approach", quality of life may be assessed on the basis of a person's behaviour in response to the environment (Parmenter, 1988).

Andrews (1974) stated that social indicators or measures of life quality may be divided into two broad categories: subjective and objective. The former consists of people's perceptions and feelings, and the latter consists of various types of phenomena. Objective measures include those that measure such elements as the person's living conditions (Brown, et al., 1989). Subjective measures are those deal with patterns and setting of personal relationships (Bateson, 1972). Szalai (1980) frames this humorously by saying "consider a headache: there are few people who would doubt that persistent headaches can make life pretty miserable, and most people would grant that no headache

can exist without the objective presence of a head and the subjective presence of an ache" (p. 17).

The measurement of quality of life relates to both subjective and objective criteria and includes aspects of external behaviour, personal perception and descriptors of the environment (Brown, 1988). While social indicators can be measured objectively, they present a rather narrow picture even of a communities quality of life (Parmenter, 1988)

Subjective measures are those that deal with patterns and settings of personal relationships (Bateson, 1972). Subjective measures also include measures of experience and reactions to life experiences (Zautra and Goodhart, 1979). Andrews (1974) suggests that subjective measures are those that tap into privately known and privately evaluated aspects of a person's life. Subjective parameters such as job satisfaction, health, and morale involve subjects being asked to make judgements about their own lives (Denham, 1983). Subjective aspects are influenced by cognitive and affective factors such as an individual's aspirations, values and immediate feeling states (McKennel and Andrews, 1983). Similarly, Schneider (1976) states that "there is no overwhelming consensus on actual measures of subjective life quality, there is widespread agreement that subjective life quality is related to such aspects of personal life as aspirations, expectations, happiness, and satisfaction" (p. 300).

In assessing subjective aspects of quality of life, there are, generally, two possible directions that may be taken. One may either assess an individual's

life satisfaction or their happiness. The difference between the two is that satisfaction implies a cognitive process of comparison against a standard, while happiness is primarily an affective process and deals with the emotions at the present time (Franklin et al. 1986). Abbey and Andrews (1986) differ slightly by stating that an evaluation of life quality might consist of three components. Those are a positive affective response, a negative affective response, and a cognitive evaluation. They state that "affect" refers to an emotional, 'from the gut' reaction, and 'cognitive' refers to an intellectual, 'from-the-head' evaluation.

Flanagan (1978) used the satisfaction perspective. In his study subjects were asked to rate the importance of a quality of life component, and then to rate how satisfied they were with this component, compared to their importance standard. He demonstrated that members of the general population differ as to how important various aspects of life are to their quality of life. In other words, people differ in how important different dimensions are to them. It would be interesting to see how different groups having experienced different life events perceive the same dimensions. For example, do parents who have a child with a disability perceive the importance of dimensions of life quality differently than parents having a typical child.

The recent trend has been to assess quality of life subjectively, or the individual's perception of life quality in order to provide information on both individuals and community units (Parmenter, 1988). Part of the rationale behind subjective measures of quality of life is that the term, quality of life, in part refers to the way in which individuals see their own lives. Scheer (1980) describes

the quality of life as that which depends on how we like our life; on the extent to which it satisfies us and makes us feel that it is worth living. One implication of this is that there must be a connection between the feelings of the participants and the measure of quality of life (Rodgers and Converse, 1975). Ferran (1990) states that "there is a growing consensus that the individual himself is the only proper judge of his quality of life" (p. 251). It only seems reasonable to find out from the individual how they perceive the social system designed to serve them (Andrews, 1974). This statement is mirrored by Brown (1985) who states "it should be stressed that perceptions by the individual are critical ... the perception of feeling well may be more important to behaviour than actually being well" (p.251). The individual's own judgement is crucial because different people value different things. It is this rationale that has been adopted for this thesis, therefore, the subjects will be measured in a subjective manner, by being asked for their opinion.

As pointed out by Andrews (1974), it is important to measure perceptual indicators for two reasons:

*"One is a 'basic knowledge' function. With sufficient data we hope to be able to achieve a better understanding of the causes and conditions which lead to individuals' feelings of well-being, and of the effects of such feelings on their behaviour. ... Another function which perceptual indicators could play is of more immediate and short-range impact. They could be used to identify 'problems' especially meriting attention, bureaucratic study, and societal action" (p.284).*

It is this second function of measuring perceptual indicators that this thesis hopes to address. It is hoped that possible 'problem' areas in families

with a child with a developmental disability or medical disability may be identified.

One advantage of a subjective approach is that it may be more sensitive to changes than objective measures. "Stability correlations", not unlike a repeated measurement, were calculated by Rodgers and Converse (1975). They revealed that there were changes in their respondents feelings over time. Such changes may not be observed if objective measures are used. Additionally, it is important to note that if measurement takes place at only one point in a person's life, the true picture of their quality of life may not be evident (Frank-Stromborg, 1988). Abbey and Andrews (1986) also reflect this when they report there are only modest relationships between self-assessment of quality of life and standard demographic or social classification variables, such as age, sex, race income, education etc..

Andrews outlines four areas of criticisms that may be levied against subjective measures. First, one may question their validity. It is suggested that either answers vary over time, or are biased because people have not thought enough about their quality of life. Second, the degree to which one may interpret subjective measures are constrained because their subjectivity does not allow for comparison across groups. Third, one may argue that the areas included in subjective measures may not always be complete. Finally, some have questioned the utility of the data.

### **Choice of Measurement Instrument**

Although, from the above discussion, it has been concluded that a subjective measure of quality of life should be used, it is still unclear which measure should be used and why. "Overall, the choice of the instrument will depend on the goal of the research, as well as pragmatic considerations (e.g., resources available to do content analysis of qualitative data, computer availability, stamina of the sample being assessed that may influence the length of the instrument desired)" (Frank-Stromborg, 1988, p.84). In a discussion of how to conceptualize quality of life, Dean (1988) outlines some dimensions that have been used to measure quality of life by different authors. They include physical, social and emotional dimensions; emotional functioning, social role functioning and participation in activities of daily living and recreational pastimes; depression, self-esteem, life satisfaction, alienation, and locus of control; or income, sexual activity and lifestyle.

It is evident that there are still a number of issues to be addressed in deciding on an instrument to be used. In order address these issues as they are presented, the instrument that has been selected will be presented here. The assessment approach used by Flanagan (1978) has been selected. Briefly, he asked subjects to rate, on a five point scale Likert-type scale, how important they felt each of 15 quality of life dimensions were and whether or not their needs were being met in that dimension.

Schipper (1983) outlines five major methodological concerns to be kept in mind by the social scientist in developing a measure of quality of life. The

concerns are: 1) the investigator must achieve a consensus of factors relevant to quality of life, 2) the questionnaire must be compact enough to be used repeatedly, while comprehensive enough to evaluate all components of quality of life, 3) each component of the questionnaire must be interpretable by all subjects (eg. a focus on the workplace might be meaningless to a domestic engineer), 4) the instrument must be sensitive enough to detect changes in the overall quality of life and its component factors, and 5) the necessity of comparisons between subjects.

Of the 5 issues presented above, all have been addressed by Flanagan (1978, 1982) with the exception of the third: "each component of the questionnaire must be interpretable by all subjects". Flanagan (1982) recommends that if his instrument is to be used in regards to populations with a disability, that the questions may need to be adapted to address the appropriate issues. Therefore, areas of importance pertinent to parents of children with handicaps have been added to Flanagan's instrument (discussed further in the methodology section).

Other choices to be made include "global versus domain-specific measures, societal versus individual perspectives and cognitive versus affective evaluations" (Dean, 1988, p. 98). A global approach implies unidimensionality, while a domain specific approach seeks variables related to a multidimensional concept. Global indices may convey no clues about why functioning may be impaired and may neglect important quality of life dimensions (Frank-Stromborg, 1988). The 15 dimensions presented in Flanagan' instrument

imply that Flanagan's view is domain specific, however, it also has elements of a global approach because the subjects are also asked to rate their overall quality of life.

Another issue in measuring quality of life is deciding whether to use a multiple or a single instrument. The reasons for the use of a multiple instrument approach include the need for reliable, comparable, valid and sensitive measurements. Additionally, they allow for flexibility in conceptualization of quality of life while permitting comparability across of specific dimensions across studies (Dean, 1988). Some of the drawbacks to multiple instruments include feasibility, design and, costs (Frank-Stromborg, 1988). A single instrument (Flanagan, 1978, 1982) was selected, essentially to avoid the drawbacks of multiple instrument.

### **Psychological Concepts and their Relation to Quality of Life and the Family**

Abbey and Andrews (1986), present a model that incorporates social psychological concepts related to quality of life. The five psychological constructs, stress, control over one's own life, control others have over one's life, social support, and performance in personal life, appear very pertinent to the study of families with a child with disabilities.

In the above model, stress was defined as role ambiguity (extent to which a person is unsure how to carry out a particular role), social conflict (extent to which significant other people affect and disregard and fail to validate the individual's feelings), and, most relevant to this thesis, negative life events.



Perceived stress was hypothesized to negatively affect an individual's quality of life. Control over one's life versus control others have over one's life refers to the extent to which individuals believe that they personally determine what happens in their own lives. Perceived control for an individual is hypothesized as related to negative life quality (Abbey and Andrews, 1986). For example, the burden of a disabled family member affects both the control a person has over their own life, and the control others have over one's life.

Social support is the extent to which individuals perceive their significant others to be supporting and encouraging them. Abbey and Andrew (1986) state that there is a significant body of literature that demonstrates the beneficial effects of social support on well-being. For example, social support has been demonstrated as important for families with a child with a disability (Goode, 1988). They also report that social support has been related to decreased depression and anxiety, and improved quality of life (Abbey, Abramis, and Caplan, 1984, as cited in Abbey and Andrews, 1986). Lastly performance refers to an individuals perception of how successfully they are fulfilling their role demands.

This model of the social psychological effects in relations to quality of life will be used as a framework for quality of life in families with a child with a disability. As a result, some questions reflecting this model will be posed in the questionnaire (See appendix, A). Similarly, this model will be used in the discussion to interpret data and responses.

The model also include the psychological constructs of depression and

anxiety, as intermediary variables between the social psychological constructs and quality of life. However, due to the size of this thesis these concepts will not be addressed (Abbey and Andrews, 1986).

### **Disability, the Family and Quality of Life**

When talking about a child with a disability and his/her influence upon the family, one is generally not talking about small, brief life problems, but about a child who may be a constant disruptive force at meal times, who may constantly seek parental attention, or who may have poor social skills, and hence may have difficulty getting along with others (Paul and Porter, 1981). Some specific stressors that face these families that are predictable, are, for example, grief over the handicapped child's delays, behavioural abnormalities and restricted opportunities (Paterson and McCubbin, 1983). Other problems faced by parents of a child with a developmental disability include the child tantruming through the night, or creeping around the house at night getting into trouble. The consequence may be chronic exhaustion for these parents (Harris, 1983). Free time may also be taken up care for the child, leaving little time for electives. Similarly, parents of a child with a developmental handicap may be faced with extra financial burdens (Harris, 1983). In other words a child with a disability may be constantly affecting those around him/her.

Goode (1988), in describing several principles of quality of life, states that the quality of life of an individual is intrinsically related to the quality of life of other persons in his/her environment. "Typically, when the term 'quality of life' is used we are concerned with the individual who is living the life. However, we

also need to take into account the effects of disability on the quality of life of significant others, particularly the immediate family" (Wiesgerber, 1991, p.7).

Goode (1988) states that the quality of life of a developmentally disabled person will vary directly and significantly with the quality of life of those "significant others" surrounding him or her. This may be stated as the general principle that significant others in life settings are the source of the greatest amount and/or most important kind of stressors. It seems plausible that the same would be true for the families. In other words the presence of a child with a developmental disability would have a significant impact on the quality of life of his/her parents.

Parmenter (1988) describes quality of life for the person with a disability as "the degree to which an individual has met his/her needs to create their own meanings so they can establish and sustain a viable self in the social world" (p.15). Parmenter (1988) also states that indices of quality of life for persons with disabilities should include control over one's life, meaningful participation in decision making processes, the development of an adequate self-image and satisfaction with one's lifestyle. Similarly, this should be true for the parents of children with a handicap. This perspective of quality of life is also consistent with the model of quality of life discussed above (Abbey and Andrews, 1986).

It has been stated that the discrepancy between a client and his or her family, or between a family and professionals, regarding the needs and capabilities of the client or the resources and demands within the environment may have a significant influence on an individual's self-assessment of overall

quality of life (Goode, 1988). If this is true it should also be true that the family's self-assessment of quality of life could also be related to the unmet needs of the client. This is corroborated by one author who suggests that it is not the presence of the child with the handicap that produces stress for the parents, but the stress produced by inadequate services for the child. (Wilken, 1979).

The literature illustrates many factors that have been used as indicators of quality of life for persons with a disability. Goode (1988) discusses recent studies that identify social support as a critical quality of life concept. Other indicators of quality of life that appears relevant to mental handicaps that are important to the current study are family supports, and assessment of individual needs and aspirations.

### **Summary of Reviewed Literature**

A review of the literature for this study focused on three major topic areas: 1) the field of developmental disability; 2) family interaction and functioning; and 3) previous research into quality of life. This review lead to several conclusions pertaining to these areas of study.

An exploration of the information pertinent to persons with developmental disabilities lead to a functional definition of developmental disability. Further, this literature lead to a discussion of age and its relation to disability, the effects of a child's disability on his/her parents, and factors, such as social support, that are associated with adapting to the presence a person with a developmental disability.

The family literature leads to a definition of the family and a discussion of

a variety of different models of family functioning. Further, previous literature on the relationship between individuals with a developmental disability and family interaction was examined.

An exploration of the quality of life literature leads to a definition of quality of life and the choice of measurement instrument. Lastly, quality of life was discussed in the context of the family literature and the literature on developmental disability.

## Chapter 3

**METHODOLOGY****Subjects**

In this study there were two groups: 1) parents of children with developmental disability, and 2) parents of children without a disability. Unlike many other studies, the subjects (the parents) were not selected for their own characteristics, but the characteristics of their children. The families included were selected on the basis of three characteristics:

1) The families are an intact two-parent family. A single parent family with a disabled child may face additional stresses compared with a two parent family. Cummings (1976) suggests that most research has focussed only on the mother, and in this instance, data has also been collected from the father.

2) The parents must have their child living with them at the time of study. It was important to ensure the sample was made up from intact families to control for the variable of living conditions. Children who did not live with their parents, would likely have had a far less significant an effect on their parents.

3) The child must be between the ages of six and nine years old. This age range reflects early school-aged children.

The proportion of male children with developmental disabilities is higher than that of females, though parents were chosen so that an equal number of male and female children were represented. Subjects were selected so both of

the groups had twenty-four pairs of parents. Therefore, there were 48 pairs of parents, and a total of 96 subjects. The participants were identified through the use of a sponsoring agency responsible for providing services to persons with a developmental disability. Parents of children with developmental disabilities were selected from client files at the agency, and parents of "normal" children were selected from the staff at the agency who had children.

On behalf of the researcher, a letter (see Appendix B) identifying the researcher along with instructions on how to become involved in the study, was sent to the potential subjects by the agency. The letter was accompanied by a covering letter from the agency stating that the agency supported the work of the researcher. Subjects interested in participating in the study were asked to contact the researcher by phone, or by returning, to the cooperating agency, a form (see Appendix B) included with the original letter.

For the parents to have been selected as potential subjects, their child must have been previously identified by the agency as moderately to profoundly developmentally disabled. If, for example, a child was identified as developmentally disabled, and actually had average ability, or, if a "normal" child had an IQ far below average, then groups would have overlapped. Therefore, it was necessary to be very careful in deciding whether a child belonged to the developmentally disabled group or to the "normal" group.

Additionally, children with a dual diagnosis were excluded. In other words, the child's primary disability had to be that of a developmental disability, and not accompanied by any other serious disabilities. This was necessary to

limit the interplay of other possible stressors (eg. additional medical costs or doctor's visits).

### **Test Material**

The assessment approach used was similar to that used by Flanagan (1978). It was originally devised, by Flanagan (1978) based on information from 3,000 people from the general population in the United States. It was not initially designed for persons with disabilities, or their families. Flanagan (1978) established 15 categories that were found consistently among the 3,000 people that were surveyed by the American Institutes for Research (AIR).

They were:

- 1) Material well-being and Financial Security
- 2) Health and Personal Safety
- 3) Relations with Spouse
- 4) Having and Raising Children
- 5) Relations with Parents, Siblings or Other Relatives
- 6) Relations with Friends
- 7) Activities related to helping or encouraging other people.
- 8) Activities relating to local and national governments
- 9) Intellectual development
- 10) Personal understanding and planning
- 11) Occupational role
- 12) Creativity and personal expression
- 13) Socializing



14) Passive and observational recreation activities

15) Active and participatory recreational activities

For the present study, Flanagan's original format was adapted to take into account research issues that were possibly relevant to persons with a disability and their families. This requirement was based on a statement from Flanagan's 1982 paper. He stated that:

*"it is likely some revisions and additions would be needed to develop a measure sensitive to measuring deficiencies and changes for persons with a disability" (p. 59).*

Additionally, he added that the 15 categories could be subdivided to provide access to issues relevant to disability. Therefore, each of the 15 categories were expanded to provide more information on each of the 15 categories. These expansions were based on the work of Flanagan (1978, 1982), Brown and Bayer's (1991) Quality of Life questionnaire, Abbey and Andrews' (1986) model of links between quality of life concepts and social-psychological concepts, plus a review of the family and disability literature.

Based on the above sources, the 15 categories were subdivided into an additional 106 subsections. For each of the subsections the respondent was asked to rate, on a five point Likert-type scale the "Importance" of that subcategory to their life, and if their "Needs were Being Met" in that domain.

These sources lead to the addition of several questions. They were questions about "sleeping", "health care", "sex", "help with household duties", and "teaching your child(ren) appropriate behaviour". Additionally, a section

based on Abbey and Andrew's model of quality of life was added. This section asked subjects to rate the amount of stress in their life; the amount of control they have over their own lives; the amount of control others have in their lives; and the amount of social support they receive.

A second section was added that asked subjects to list 3 of Flanagan's 15 general domains, which A) made them satisfied with their quality of life at the present time; B) detracts from their quality of life at the present time; C) their children have had a positive effect upon; and D) their children have had a negative effect upon.

The last section that was added asked subjects to rate their overall quality of life as either "excellent", "very good", "good", "fair", or "poor". Further subjects were asked to describe how the presence of their child has affected their overall quality of life, and, if applicable, how the presence of a child with a developmental disability has affected their overall quality of life.

The questionnaire was first pretested with 5 practitioners in the field of rehabilitation. Additionally, the questionnaire was pretested with 10 pairs of parents (they did not necessarily have a child with a developmental disability). The pilot subjects were asked to assess the questionnaire for clarity and interpretability of questions.

Based on this pretesting, the questionnaire was subject to very minor changes in wording that increased the interpretability of the questions. For example, the question "having and appreciating my political freedom", was changed to "having my political freedom (eg. living in a democratic society)". It

was suggested that this question, as originally written, was ambiguous and did not explain what was being asked. Additionally, changes were made to the five point rating scale that was employed. Originally, subjects rated the importance of questions as “highly” or “moderately”. These categories were changed to “high” and “moderate” to improve the clarity of responses given. Hopefully, piloting the questionnaire improved the validity of questions for the parents that were subjects in the study.

### **Reliability and Validity**

In terms of reliability, Flanagan (1978) reported high correlations for all of the 15 general domains. Further, Flanagan compared different age groups (50 and 70 year olds) and found high correlations. However, as Flanagan points out, the information that this questionnaire elicits is a subjective self-report, and subjective self-reports are likely to change over time. An individual's subjective perspective is situation dependent and will change as the situation changes. The ability to assess an individual's personal view is a major strength of Flanagan's method.

Flanagan also provided information pertaining to the validity of his method. Questions pertaining to the 15 quality of life domains were presented to a new pool of subjects in three different age categories (30, 50 and 70 years of age). High correlations across the three age groups indicated that the 15 domains were meaningful for different cohort groups. This indicated that the domains seemed to measure what was intended. Further, the definition of quality of life in this study reflected a discrepancy model, where quality of life

was assessed by the difference between achieved and unmet needs. Therefore asking parents directly about their needs in specific life areas appears to have face validity.

The author, Dr. John Flanagan, was asked in writing for permission to use his questioning method. A response was received from the American Institutes for Research, stating that Dr. John Flanagan had retired and that using his method was permissible, provided that appropriate credit was given to Dr. Flanagan.

### **Procedure**

Parents selected were sent a letter (see appendix B) introducing the study and the researcher. The letter included a description of the subject's involvement. The package sent to the potential subjects also contained a form they could return to the agency if they wished to participate, and a phone number where they could contact the researcher.

When those subjects who were willing to participate contacted the researcher, a time and place to meet, convenient for all parties, was arranged. The total time involved did not exceed approximately one and one half hours. At the time of the interview, each of the parents were asked to complete a form (see appendix B) giving their consent to participate in the study. If the amount of time available was a problem, subjects were asked to complete the questionnaires on their own, and left with a stamped, addressed envelope to return the questionnaires.

After consenting to participate, parents filled out the quality of life

questionnaire (see Appendix B). While filling out the questionnaire, the parents also had an opportunity to ask the researcher about questions in the questionnaire that may have been unclear, while, the researcher had the opportunity to ask the parents to clarify any of the responses had given.

Subjects were then thanked for their involvement and given the researcher's phone number in case they wished to contact him. At this time subjects were asked to provide a mailing address if they wished to receive a summary of the study upon completion.

### **Method of Analysis**

The information provided through the questionnaires was analyzed in several ways to illustrate any differences between the two types of families. Subjects were asked to rate the "Importance" of various aspects of their life and, for each aspect, whether their "Needs were Being Met". Each of the aspects were rated as "Very High", "High", "Moderate", "Low" or "Very Low". Thus the data were not equal interval, but ordinal in nature. As parametric analysis does not handle non-interval data well, it was decided that non-parametric statistics would be employed. Further, (as will be seen) the sample size obtained was not large enough to make non-parametric tests such as the Mann-Whitney and the Wilcoxon effective at illustrating differences between groups.

Therefore, all the subject's ratings of Importance were compressed into one of two super categories - High Importance or Low Importance. If a subject rated the Importance of an aspect of life as "Very High", "High", or "Moderately", their response was compressed into the High Importance super category. If the

aspect was rated as "Low" or "Very Low", they were compressed into the Low Importance super category. Two super categories were also utilized for a subject's ratings of Needs Being Met - High Needs Being Met or Low Needs are Being Met . High Needs Being Met included ratings of "Very High", "High", or "Moderately", and Low Needs Being Met included ratings of "Low" and "Very Low".

To best determine if a subject's needs were being met in one area of life it was also useful to recognize whether or not that aspect was important in their life. Since an individual's assessment of whether their needs were being met is intrinsically anchored to their assessment of how important that part of their life was to them, it seemed intuitively correct to relate an individual's assessment of whether his/her needs were being met to how important that part of their life may have been to the individual. For example, an individual may rate his or her need to watch television as very well met, however the individual may find the importance of watching TV very low. Therefore, if watching TV is not very important to an individual it would be relatively easy to meet their needs. In order to assess an individual's assessment of whether needs were met relative to a subject's ranking of Importance, every subject's rating of Need Being Met was subtracted from their rating of "Importance". Both Importance and Needs Being Met were rated on a 5 point scale ranging from 1 (High) to 5 (Low). Subtracting Needs Being met from Importance resulted in a 9 point range of difference scores from -4 to +4. In order to analyze the discrepancy scores they were put into either a "Higher" group or a "Lower" group. If a

discrepancy score was between or including -4 to -1 it was put in the "Lower" group. If the score was between 0 or +4 it was put in the "Higher" group.

### **Rationale for the use of Fisher's Exact Test**

Reducing the data into categorical data allowed for an analysis using a 2x2 table. Often, for the non-parametric analysis of a 2x2 table, a Chi-square test is advised. However, given the smaller than expected sample size that was obtained the Chi-square analysis would have been regarded as suspect. It was for this reason that Fisher's Exact Test was used. Both Siegel (1956) and McNemar (1962) state that Chi-Square test may be compromised if any cell expected value is less than ten even with the use of Yate's Correction for Continuity. Further, when any cell value is less than five, McNemar (1962), recommends the use of Fisher's Exact Test. As the majority of sample sizes in this study were less than 30, the likelihood of obtaining a cell size less than five was high. Additionally, Siegel (1956) recommends that for total sample sizes less than 29 Fisher's Exact Test be employed. Fisher's Exact Test was selected to analyze the data presented, and was used for all the analyses to provide consistency across comparisons.

For this study, a two-tailed p-value was employed as there were no formal directional hypotheses. To obtain a two-tailed p-value both Siegel (1956) and McNemar (1962) suggest that the obtained probability for Fisher's Exact Test be doubled.

### **Other Analyses of the Data**

Two other examinations were performed upon the data. Although, in a

number of instances, no significance was obtained in comparison of specific questions, visual inspection of the data suggests that the comparisons of questions relating to a particular category tended to follow the same direction. Therefore, other analyses to examine answers in all of the questions for each of the 15 general domains were employed.

For each of the fifteen major categories both a Sign test and a t-test were performed. For the Sign analysis, each sub-aspect of the questionnaire was analyzed to determine whether more families (DDC) or families (NDC) had rated an aspect as more Important, or as having greater Needs Being Met. If more parents (DDC) than families (NDC) rated an aspect as higher, it was scored with a +1; if less it was scored as a -1. A zero score was obtained if parents in each group had rated an aspect equally. Within each category, the signs given to each question were summed. For example, in an inspection of the seven questions relating to category #1 - Passive Recreation (See Table 2), it is seen that for each question the percentage of fathers (NDC) rating Importance as high is greater than the percentage of mothers (NDC). Since there are 7 questions a Sign value of +7 is obtained. Examination of an appropriate significance table for the Sign Test indicates that this value is significant at the 0.01 level.

The second set of analyses involved several sets of t-tests. t-test were not used previously because the data to be examined was not continuous. By summing a subject's scores for all questions the question in each domain, continuous data was simulated, therefore it is argued parametric analysis could



be employed. A subject's rankings for Importance, Needs Being Met and the difference between these two ratings were summed for the sub-aspects of each of the 15 major quality of life categories. For example, one mother's importance ratings for the seven questions regarding passive recreation were added together to produce a total score of 26. The same procedure was used for each subject for each of the 15 general categories of quality of life. This produced numerical scores from 5 to 35 for which a t-test could be employed. Each of the fifteen major life domains were examined in this manner. This allowed for a comparison between mothers and fathers of both a child with a developmental disability and an ND child, for both the rankings of Importance and Needs Being Met. Similar analyses were carried out between parents of a child with a developmental disability parents of an ND child for "Importance", and "Needs are Being Met" .

An informal content analysis of the qualitative data was also performed. Direct quotes that related to parenting a child with a developmental disability were selected and included in the body of the text. Anecdotal information was intended to reflect the diversity in individual subjective viewpoints, and not to necessarily represent the views of the group as a whole. All relevant quotes were included.

## Chapter 4

### RESULTS

The questionnaire was given to parents of children with developmental disabilities, and to parents of children without disabilities. The analysis revealed many significant differences between groups. In order to ease the interpretation of information, the questionnaires were analyzed in the order of the questions and sections presented in the questionnaire. Where appropriate, tables are used to summarize information that is not presented in the body of the text.

Completed questionnaires were returned by a total of 32 families, involving 61 individual parents, in the two groups. There were 15 families with a child with a developmental disability (DDC families) in one group, and 17 families with a child without a developmental disability (NDC families) in the other. The families (DDC) were obtained by soliciting names from four agencies with clients who had developmental disabilities, and from families who attended a conference on Down syndrome. The families (NDC) were obtained by soliciting names of employees from the same agencies.

Originally, thirty-four families with children having a developmental disability agreed to participate from an initial group of 51 families that were approached. Of these 34 families, only 15 returned completed questionnaires. Two of the 15 families only returned the mother's information. At final count there were 13 completed questionnaires from fathers (DDC) and 15 from mothers (DDC). Similarly, 17 of 25 families (NDC) approached returned

questionnaires, though one of the families did not return the mother's questionnaire. The final analysis was based on the results from, 17 fathers and 16 mothers from families with ND children, and 15 mothers and 13 fathers with DD children.

### **Demographics**

Family demographics are described in Table 1. This table provides information on the age, gender and number of children in each family; age of both parents; household income and the level of education of both parents. The table indicates that families (DDC) had more children ( $t=2.29$ ,  $df=31$ ,  $p<0.03$ ), and a lower household income ( $t= 35.9$ ,  $df=31$ ,  $p<0.001$ ), than NDC families. Further, it appears that mothers (DDC), compared to mothers of ND children, had less education ( $t= 2.55$ ,  $df=30$ ,  $p<0.016$ ). It is important to note that there were no differences between the education levels of DDC and NDC fathers. This result fits with the bias that individuals with mild disabilities are from lower socio-economic groups. This result also supports the contention that educational level and salary may only be a minor component here as the majority of children were of severe and moderate handicaps. Moderate and severe handicaps are more prominent where socio-economic differences are not so clearly found (Clarke and Clarke, 1974).

Lastly, mothers of a child with a developmental disability were younger than mothers in the ND group ( $t=35.9$ ,  $df=30$ ,  $p<0.001$ ). However, it is important to note that all but one of the mothers of a child with a developmental disability reported their ages, but nearly 1/3 of mothers of an ND child did not report their

ages. By visually inspecting the data, it appears that the mothers of ND children who did not report their ages, had younger children. This might suggest that these mothers were also younger. Therefore, the average age of the mothers (NDC) is possibly lower than is indicated in Table 1 and the significance reported above may be spuriously high.

All of the DD children were reported by their parents to be in the moderately to severely/profoundly developmentally disabled range. Types of disabilities included two children with Down Syndrome, one with Pervasive Developmental Disorder, and one with William's Syndrome however, the majority of the children were diagnosed with a mental handicap with an unknown etiology.

### **Results from Questionnaire**

As described previously, all the subject's ratings of both Importance were compressed into one of two super categories - High Importance or Low Importance. Two super categories were also utilized for a subjects ratings of Needs Being Met - High Needs Being Met or Low Needs are Being Met . The percentages of those parents rating items as High Importance are shown in Table 2 and the percentages of parents rating items as High Needs are Being Met are shown in Table 3. The percentages are given separately for mothers and fathers in both groups. This was done for all 92 questions that were rated.

The percentages of parents in both groups reporting a "high" importance versus needs discrepancy described above are reported in Table 4.

### **Reporting Results of Fisher's Exact Test**

The results of comparing mothers to fathers of a child with a developmental disability for ratings of "Importance", "Needs Being Met", and the difference between these two ratings using Fisher's Exact Test are shown in Table 5. Similarly, Table 6 lists the same results for the comparisons of mother and fathers of ND children. The results of comparisons of fathers of a child with a developmental disability with fathers of ND children are illustrated in Table 7. Table 8 illustrates the same comparisons between mothers of child with a developmental disability and mothers of ND children. These tables only report p-values equal to or less than 0.1.

To best present significant results for later discussion, the information in Tables 5 to 8 and the results of the Sign and the t-test, are summarized under the headings of the 15 major categories of Quality of Life that were assessed by the questionnaire.

#### **#1 Passive Recreation**

The statistical comparison of the information listed Tables 2, 3, and 4 from mothers and fathers in both groups provide several interesting results. Two significant differences were found when mothers (DDC) and fathers (DDC) were compared for the question about sleep. Significantly, more mothers ranked their Needs Being Met as low compared with fathers (Fisher's Exact Test  $p=0.019$ ). Similarly, more mothers (DDC) compared with fathers had a high "importance versus needs met" discrepancy (Fisher's Exact Test  $p=0.022$ ).

Two other difference for the question on sleep was found between

Table 1  
Demographic Variables for Parents with  
a Child with a Devel. Disability  
and Parents of a Child without a Devel. Disability

	# of Families†	# of Children (Mean)	Gender of Child with Developmental Disability		Gender of All Children In a Family		Age of Children (Mean)		Mother's Age* (Mean) Not Reporting		Father's Age* (Mean) Not Reporting	
			Male	Female	Male	Female	Only Children with a Devel. Disability	All Children In a Family				
Parents of a Child with a Devel. Disability	15	2.7	9	6	15	25	7.5	6.6	35.4	1	38.3	1
Parents of a Child without a Devel. Disability	17	1.9	N/A	N/A	19	10	N/A	8.1	41.9	5	41.5	5

Household Income per Year	0-10 000\$	10 001-20 000\$	20 001-30 000\$	30 001-40 000\$	40 001-50 000\$	50 000\$ +	Not Reporting	* At the time of the study
Parents of a Child with a Devel. Disability	0	1	3	4	4	3	0	
Parents of a Child without a Devel. Disability	0	0	0	2	2	11	3	

Education		Less Than High School	High School Diploma	College	University Degree	Not Reporting	‡ Number of Parents in Each Group
Parents of a Child with a Devel. Disability	Mothers	1	4	7	3	0	Parents of a Child with a Devel. Disability Mothers - 15 Fathers - 13
	Fathers	0	3	6	5	1	
Parents of a Child without a Devel. Disability	Mothers	0	3	3	8	3	Parents of a Child without a Devel. Disability Mothers - 16 Fathers - 17
	Fathers	0	1	3	10	3	

Table 2  
**Percentage of Parents of (A) Children  
 With and (B) Children Without Developmental Disabilities  
 Rating "Importance" as "Very High", "High" or "Moderate"**

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
<b>#1 Passive Recreation</b>				
a) TV	33	50	69	53
b) Music	80	69	85	82
c) Reading	93	93	77	95
d) Movies	53	50	46	53
e) Entertainment/Sports	27	67	54	82
f) Sleeping	100	94	85	100
f) Overall	75	87	92	89
<b>#2 Active Recreation</b>				
a) Sports	53	63	69	71
b) Hunting	0	0	8	24
c) Camping	73	63	46	71
d) Vacations	100	100	92	94
e) Travel and Sightseeing	93	94	92	88
f) Singing	33	33	23	12
g) Dancing	60	46	46	13
h) Playing an instrument	27	33	31	29
i) Cycling	47	56	46	53
j) Exercising	87	88	100	71
l) Overall	67	69	85	77
<b>#3 Socializing</b>				
a) Entertaining at Home	93	81	77	88
b) Attending Parties	80	81	85	71
c) Meeting New People	100	75	85	71
d) Participation In Social Clubs	60	50	46	47
f) Overall	87	94	85	82
<b>#4 Occupational Role</b>				
a) Having Interesting Work	73	88	100	100
b) Using Abilities on the Job	100	100	100	100
c) Obtaining Recognition	100	100	100	100
d) Accomplishing on the Job	100	100	100	100
e) Housework	93	88	69	77
f) Overall	100	100	100	100

Table 2 (cont.)

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
<b>#5 Material Well-Being</b>				
a) Good Food	93	100	100	100
b) Having a Home	100	100	100	100
c) Having Personal Possessions	100	100	100	100
d) Having a Motor Vehicle	100	100	100	100
e) Money	93	100	100	100
f) Financial Security	100	100	100	100
h) Overall	100	100	100	100
<b>#6 Health and Personal Safety</b>				
a) Sickness	100	100	100	100
b) Physical Fitness	100	100	100	100
c) Mental Health	100	100	100	100
d) Emotional Health	100	100	100	100
e) Freedom from Drugs and Alcohol	100	100	100	100
f) Health Care	100	100	100	100
h) Overall	100	100	100	100
<b>#7 Relationship with Spouse</b>				
a) Love	100	100	100	100
b) Companionship	100	100	100	100
c) Sex	87	88	92	94
d) Communication	100	100	100	100
e) Help with Household Duties	100	100	85	100
f) Going out with Spouse	100	100	100	100
g) Spending Time Alone with Spouse	93	100	100	100
i) Overall	100	100	100	100
<b>#8 Having and Raising Children</b>				
a) Having Children	100	100	100	100
b) Becoming a Parent	93	100	100	100
c) Watching Child's Development	100	100	100	100
d) Spending time with Children	100	100	100	100
e) Helping Your Children	93	100	100	100
f) Teaching your Children	100	100	100	100
g) Teaching Appropriate Behaviour	93	100	100	94
h) Being Helped to Care for Child	93	75	92	88
j) Overall	93	100	100	100
<b>#9 Relations with Other Relatives</b>				
a) Visiting Relatives	80	88	85	82
b) Helping Them	80	100	77	100
c) Being Supported by Them	93	63	85	50
d) Overall	69	88	85	94



Table 2 (cont.)

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
<b>#10 Relations with Friends</b>				
a) Having Close Friends	93	100	92	94
b) Sharing Activities	93	88	92	94
c) Being Supported by Them	100	88	85	65
e) Overall	100	100	92	94
<b>#11 Activities Related to Helping or Encouraging Other People</b>				
a) Helping Adults	93	75	69	77
b) Helping Children	100	94	85	100
c) Membership in an Organization That Benefits Others	93	69	85	77
e) Overall	100	94	85	77
<b>#12 Activities Relating to Local or National Governments</b>				
a) Keeping Informed Through the Media	73	94	92	100
b) Participating by Voting	93	100	92	94
c) Having My Political Freedom	93	100	100	100
d) Having My Religious Freedom	93	81	92	82
f) Overall	80	75	92	94
<b>#13 Intellectual Development</b>				
a) Learning	100	94	100	100
b) Attending School	93	88	54	77
c) Opportunity to Learn About Things I Want To Know About	100	100	92	94
d) Graduating	80	81	77	71
e) Self-Education Outside of School	75	100	100	88
g) Overall	100	100	100	100
<b>#14 Personal Understanding and Planning</b>				
a) Gaining Purpose for My Life	100	100	100	88
b) Insight into my Assets and Limitations	93	94	92	100
c) Develop a Greater Understanding of Myself	93	94	92	77
d) Decisions and Planning of Life Activities	100	100	100	100
e) Religious and Spiritual Activities	80	63	46	47
f) Overall	100	100	100	100

Table 2 (cont.)

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
<b>#15 Creativity and Personal Expression</b>				
a) Showing Ingenuity or Originality	87	100	92	88
b) Involvement in the Arts	80	75	46	35
d) Overall	100	100	85	88

Table 3  
**Percentage of Parents of (A) Children With  
 and (B) Children Without a Developmental Disability Rating  
 "Needs Being Met" as "Very High", "High" and "Moderately"**

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
<b>#1 Passive Recreation</b>				
a) TV	93	94	100	88
b) Music	80	50	77	82
c) Reading	60	88	77	82
d) Movies	67	88	92	53
e) Entertainment/Sports	80	88	77	82
f) Sleeping	27	88	77	82
f) Overall	80	88	85	88
<b>#2 Active Recreation</b>				
a) Sports	73	75	62	94
b) Hunting	73	44	69	59
c) Camping	73	69	46	76
d) Vacations	67	88	69	71
e) Travel and Sightseeing	60	82	69	82
f) Singing	67	56	69	65
g) Dancing	60	38	54	65
h) Playing an instrument	60	56	46	59
i) Cycling	53	56	54	71
j) Exercising	60	56	69	71
l) Overall	67	69	62	88
<b>#3 Socializing</b>				
a) Entertaining at Home	80	69	85	71
b) Attending Parties	80	88	69	88
c) Meeting New People	73	94	69	82
d) Participation In Social Clubs	73	75	69	76
f) Overall	73	94	77	94
<b>#4 Occupational Role</b>				
a) Having Interesting Work	67	94	92	100
b) Using Abilities on the Job	53	94	92	94
c) Obtaining Recognition	53	81	92	94
d) Accomplishing on the Job	53	88	100	94
e) Housework	80	75	85	76
f) Overall	80	88	85	100
<b>#5 Material Well-Being</b>				
a) Good Food	100	94	92	88
b) Having a Home	87	94	92	100
c) Having Personal Possessions	100	100	100	94
d) Having a Motor Vehicle	93	100	100	88
e) Money	100	94	85	88
f) Financial Security	87	88	92	82
h) Overall	100	94	100	94

Table 3 (cont.)

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
<b>#6 Health and Personal Safety</b>				
a) Sickness	80	88	92	94
b) Physical Fitness	53	75	77	77
c) Mental Health	80	100	92	100
d) Emotional Health	87	100	85	100
e) Freedom from Drugs and Alcohol	93	100	100	100
f) Health Care	93	100	100	94
h) Overall	87	88	92	100
<b>#7 Relationship with Spouse</b>				
a) Love	100	100	100	100
b) Companionship	100	94	100	94
c) Sex	80	88	77	88
d) Communication	87	88	92	100
e) Help with Household Duties	73	94	92	100
f) Going out with Spouse	60	94	54	71
g) Spending Time Alone with Spouse	60	94	46	71
i) Overall	87	100	85	100
<b>#8 Having and Raising Children</b>				
a) Having Children	100	94	92	100
b) Becoming a Parent	93	100	92	94
c) Watching Child's Development	93	100	100	100
d) Spending time with Children	93	100	92	100
e) Helping Your Children	93	100	100	100
f) Teaching your Children	93	100	92	100
g) Teaching Appropriate Behaviour	87	94	92	100
h) Being Helped to Care for Child	87	81	85	88
j) Overall	87	100	100	100
<b>#9 Relations with Other Relatives</b>				
a) Visiting Relatives	80	88	77	94
b) Helping Them	73	100	85	88
c) Being Supported by Them	73	88	77	71
d) Overall	80	100	69	94
<b>#10 Relations with Friends</b>				
a) Having Close Friends	87	100	77	88
b) Sharing Activities	93	100	77	94
c) Being Supported by Them	93	88	92	76
e) Overall	93	94	85	94
<b>#11 Activities Related to Helping or Encouraging Other People</b>				
a) Helping Adults	80	94	85	100
b) Helping Children	87	100	85	88
c) Membership in an Organization That Benefits Others	80	81	85	59
e) Overall	87	88	85	88

Table 3 (cont.)  
 Mothers                      Fathers

	(A)	(B)	(A)	(B)
<b>#12 Activities Relating to Local or National Governments</b>				
a) Keeping Informed Through the Media	60	100	92	88
b) Participating by Voting	93	94	100	94
c) Having My Political Freedom	93	100	100	100
d) Having My Religious Freedom	93	100	92	88
f) Overall	87	81	92	82
<b>#13 Intellectual Development</b>				
a) Learning	80	100	92	94
b) Attending School	60	94	62	82
c) Opportunity to Learn About Things I Want To Know About	60	94	77	82
d) Graduating	60	81	85	82
e) Self-Education Outside of School	80	94	100	88
g) Overall	67	100	100	100
<b>#14 Personal Understanding and Planning</b>				
a) Gaining Purpose for My Life	93	81	85	100
b) Insight into my Assets and Limitations	87	88	92	100
c) Develop a Greater Understanding of Myself	93	88	85	100
d) Decisions and Planning of Life Activities	80	88	92	94
e) Religious and Spiritual Activities	47	69	54	76
f) Overall	87	100	76	94
<b>#15 Creativity and Personal Expression</b>				
a) Showing Ingenuity or Originality	93	94	77	100
b) Involvement in the Arts	67	81	69	65
d) Overall	80	94	100	94

Table 4  
**Percentage of Parents of (A) Children  
 With and (B) Children Without a Developmental Disability  
 Whose Discrepancy Between Their Rating of "Importance" and  
 "Needs Being Met" Range Between 0 and +4**

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
<b>#1 Passive Recreation</b>				
a) TV	100	100	100	100
b) Music	93	100	77	53
c) Reading	40	69	85	59
d) Movies	73	88	85	71
e) Entertainment/Sports	80	94	92	71
f) Sleeping	20	69	70	71
f) Overall	67	81	62	59
<b>#2 Active Recreation</b>				
a) Sports	73	63	62	82
b) Hunting	100	100	77	100
c) Camping	67	88	64	76
d) Vacations	47	75	54	35
e) Travel and Sightseeing	47	38	54	53
f) Singing	73	88	77	94
g) Dancing	73	75	62	88
h) Playing an instrument	80	94	54	82
i) Cycling	73	75	85	71
j) Exercising	33	56	54	71
l) Overall	67	56	54	71
<b>#3 Socializing</b>				
a) Entertaining at Home	67	50	77	71
b) Attending Parties	80	81	70	88
c) Meeting New People	67	88	70	76
d) Participation In Social Clubs	87	88	85	94
f) Overall	67	75	62	76
<b>#4 Occupational Role</b>				
a) Having Interesting Work	60	50	77	82
b) Using Abilities on the Job	47	50	69	65
c) Obtaining Recognition	40	50	62	71
d) Accomplishing on the Job	27	63	46	59
e) Housework	53	56	92	65
f) Overall	60	50	62	71

Table 4 (cont.)

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
<b>#5 Material Well-Being</b>				
a) Good Food	80	69	85	76
b) Having a Home	73	88	92	82
c) Having Personal Possessions	93	81	85	88
d) Having a Motor Vehicle	87	81	92	88
e) Money	68	56	46	47
f) Financial Security	53	50	39	35
h) Overall	80	50	69	59
<b>#6 Health and Personal Safety</b>				
a) Sickness	40	56	62	71
b) Physical Fitness	27	31	31	29
c) Mental Health	40	50	62	71
d) Emotional Health	40	56	46	71
e) Freedom from Drugs and Alcohol	93	94	92	94
f) Health Care	93	81	85	82
h) Overall	33	69	77	76
<b>#7 Relationship with Spouse</b>				
a) Love	73	94	69	88
b) Companionship	47	88	69	82
c) Sex	73	94	39	62
d) Communication	33	44	62	71
e) Help with Household Duties	53	44	100	94
f) Going out with Spouse	47	63	31	53
g) Spending Time Alone with Spouse	40	75	31	29
i) Overall	53	75	46	71
<b>#8 Having and Raising Children</b>				
a) Having Children	73	88	92	94
b) Becoming a Parent	93	100	92	94
c) Watching Child's Development	73	88	54	82
d) Spending time with Children	53	63	54	47
e) Helping Your Children	53	63	54	53
f) Teaching your Children	47	56	31	59
g) Teaching Appropriate Behaviour	47	56	12	53
h) Being Helped to Care for Child	53	81	77	76
j) Overall	60	94	54	71

Table 4 (cont.)

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
<b>#9 Relations with Other Relatives</b>				
a) Visiting Relatives	67	69	62	82
b) Helping Them	67	62	85	82
c) Being Supported by Them	60	88	77	88
d) Overall	73	81	77	88
<b>#10 Relations with Friends</b>				
a) Having Close Friends	67	75	69	76
b) Sharing Activities	67	75	62	76
c) Being Supported by Them	73	81	77	76
e) Overall	80	69	77	65
<b>#11 Activities Related to Helping or Encouraging Other People</b>				
a) Helping Adults	67	87.5	84.6	88.2
b) Helping Children	80	100	61.5	82.4
c) Membership in an Organization That Benefits Others	73	94	85	82
e) Overall	73	88	77	82
<b>#12 Activities Relating to Local or National Governments</b>				
a) Keeping Informed Through the Media	67	88	100	82
b) Participating by Voting	87	94	92	94
c) Having My Political Freedom	87	81	92	82
d) Having My Religious Freedom	87	88	92	82
f) Overall	87	88	92	76
<b>#13 Intellectual Development</b>				
a) Learning	40	50	54	65
b) Attending School	47	69	77	82
c) Opportunity to Learn About Things I Want To Know About	40	50	39	41.2
d) Graduating	60	81	77	76
e) Self-Education Outside of School	67	56	77	65
g) Overall	40	63	62	76



Table 4 (cont.)

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
<b>#14 Personal Understanding and Planning</b>				
a) Gaining Purpose for My Life	67	63	54	71
b) Insight into my Assets and Limitations	73	63	62	82
c) Develop a Greater Understanding of Myself	80	50	69	65
d) Decisions and Planning of Life Activities	67	88	54	59
e) Religious and Spiritual Activities	60	81	77	82
f) Overall	67	69	69	71
<b>#15 Creativity and Personal Expression</b>				
a) Showing Ingenuity or Originality	53	62	62	65
b) Involvement in the Arts	67	88	69	76
d) Overall	67	63	85	76

Table 5  
**Fisher's Exact Test Results**  
**for Mothers (M) V. Fathers (F) of a Developmentally**  
**Disabled Child on Ratings of Importance, Needs Being Met and**  
**the Discrepancy Between Importance and Needs**

	Importance	Needs Being Met	Discrepancy Between Importance & Needs
<b>#1 Passive Recreation</b>			
e) Entertainment/ Sports			0.015 (F>)
f) Sleeping		0.02 (F>)	0.022 (F>)
<b>#2 Active Recreation</b>			
a) Sports			0.09 (M>)
<b>#3 Socializing</b>			
<b>#4 Occupational Role</b>			
d) Accomplishing on the Job		0.08 (F>)	
e) Housework			0.088 (F>)
<b>#5 Material Well-Being</b>			
c) Having Personal Possessions			0.09 (M>)
<b>#6 Health and Personal Safety</b>			
h) Overall			0.046 (F>)
<b>#7 Relationship with Spouse</b>			
e) Help with Household Duties			0.01 (M>)
<b>#8 Having and Raising Children</b>			
<b>#9 Relations with Other Relatives</b>			
<b>#10 Relations with Friends</b>			
a) Having Close Friends			0.046 (F>)
<b>#11 Activities Related to Helping or Encouraging Other People</b>			
<b>#12 Activities Relating to Local or National Governments</b>			

Table 5 (cont.)

	Importance Needs Being Met	Discrepancy Between Importance & Needs
<b>#13 Intellectual Development</b>		
b) Attending School	0.044 (M>)	0.1 (F>)
g) Overall		0.05 (F>)
<b>#14 Personal Understanding</b>		
<b>#15 Creativity and Personal</b>		

Table 6  
**Fisher's Exact Test Results**  
**for Mothers (M) V. Fathers (F) of a Child Without a Developmental**  
**Disability on Ratings of "Importance", "Needs Being Met" and**  
**the Discrepancy Between Importance and Needs**

	Importance	Needs Being Met	Discrepancy Between Importance & Needs
<b>#1 Passive Recreation</b>			
b) Music	0.0016 (F>)		0.004 (M>)
d) Movies		0.1 (M>)	0.06 (M>)
<b>#2 Active Recreation</b>			
d) Vacations			0.044 (F>)
<b>#3 Socializing</b>			
<b>#4 Occupational Role</b>			
a) Having Interesting Work			0.04 (F>)
<b>#5 Material Well-Being</b>			
<b>#6 Health and Personal Safety</b>			
c) Mental Health			0.09 (F>)
<b>#7 Relationship with Spouse</b>			
c) Sex			0.014 (M>)
e) Help with Household Duties			0.042 (F>)
g) Spending Time Alone with Spouse			0.02 (M>)
<b>#8 Having and Raising Children</b>			
<b>#9 Relations with Other Relatives</b>			
<b>#10 Relations with Friends</b>			
<b>#11 Activities Related to Helping or Encouraging Other People</b>			
<b>#12 Activities Relating to Local or National Governments</b>			
<b>#13 Intellectual Development</b>			
<b>#14 Personal Understanding and Planning</b>			

Table 6 (cont.)

Importance	Needs	Discrepancy Between
	Being Met	Importance & Needs

#15 Creativity and Personal  
Expression

Table 7  
**Fisher's Exact Test Results**  
**for Fathers of a Child With a Developmental Disability (DDC)**  
**V. Fathers of Child Without a Disability (NDC) on Ratings**  
**of "Importance", "Needs Being Met" and the**  
**Discrepancy Between Importance and Needs Being Met**

	Importance	Needs Being Met	Discrepancy Between Importance & Needs
<b>#1 Passive Recreation</b>			
d) Movies		0.07 (DDC>)	0.06 (DDC>)
<b>#2 Active Recreation</b>			
a) Sports		0.07 (NDC>)	
g) Dancing	0.08 (DDC>)		
i) Cycling			0.07 (DDC>)
j) Exercising	0.086 (DDC>)		
<b>#3 Socializing</b>			
<b>#4 Occupational Role</b>			
<b>#5 Material Well-Being</b>			
c) Having Personal Possessions		0.07 (DDC>)	
<b>#6 Health and Personal Safety</b>			
<b>#7 Relationship with Spouse</b>			
<b>#8 Having and Raising Children</b>			
<b>#9 Relations with Other Relatives</b>			
c) Being Supported by Them	0.1 (DDC>)		0.05 (NDC>)
<b>#10 Relations with Friends</b>			
<b>#11 Activities Related to Helping or Encouraging Other People</b>			
<b>#12 Activities Relating to Local or National Governments</b>			
<b>#13 Intellectual Development</b>			
b) Attending School	0.056 (NDC>)		
c) Opportunity to Learn About Things I Want to Know About	0.06 (NDC>)		
d) Graduating		0.1 (DDC>)	

Table 7 (cont.)

	Importance	Needs Being Met	Discrepancy Between Importance & Needs
<b>#14 Personal Understanding and Planning</b>			
a) Gaining Purpose for My Life			0.07 (NDC>)
<b>#15 Creativity and Personal Expression</b>			

Table 8  
**Fisher's Exact Test Results**  
**for Mothers of a Child With a Developmental Disability (DDC)**  
**V. Mothers of Child Without a Disability (NDC) on Ratings**  
**of "Importance", "Needs Being Met" and the**  
**Discrepancy Between Importance and Needs Being Met**

	Importance	Needs Being Met	Discrepancy Between Importance & Needs
<b>#1 Passive Recreation</b>			
e) Entertainment/Sports	0.08 (NDC>)		
f) Sleeping		0.0014 (NDC>)	0.022 (NDC>)
<b>#2 Active Recreation</b>			
<b>#3 Socializing</b>			
<b>#4 Occupational Role</b>			
<b>#5 Material Well-Being</b>			
c) Having Personal Possessions			0.014 (DDC>)
<b>#6 Health and Personal Safety</b>			
d) Emotional Health		0.086 (NDC>)	
h) Overall			0.086 (NDC>)
<b>#7 Relationship with Spouse</b>			
b) Companionship			0.034 (NDC>)
c) Sex		0.0824 (NDC>)	
f) Going out with Spouse		0.06 (NDC>)	
g) Spending Time Alone with Spouse			0.088 (NDC>)
i) Overall		0.06 (NDC>)	
<b>#8 Having and Raising Children</b>			
<b>#9 Relations with Other Relatives</b>			
b) Helping Them	0.002 (NDC>)	0.086 (NDC>)	
c) Being Supported by Them	0.091 (DDC>)		
d) Overall			
<b>#10 Relations with Friends</b>			
<b>#11 Activities Related to Helping or Encouraging Other People</b>			
c) Membership in an Organization That Benefits Others	0.088 (DDC>)		



Table 8 (cont.)

Importance	Needs Being Met	Discrepancy Between Importance & Needs
<b>#12 Activities Relating to Local or National Governments</b>		
a) Keeping Informed Through the Media	0.014 (NDC>)	
<b>#13 Intellectual Development</b>		
b) Attending School	0.061 (NDC>)	
c) Opportunity to Learn About Things I Want to Know About	0.061 (NDC>)	
d) Graduating	0.088 (NDC>)	
g) Overall	0.035 (NDC>)	
<b>#14 Personal Understanding and Planning</b>		
a) Gaining Purpose for My Life		
<b>#15 Creativity and Personal Expression</b>		

mothers in both groups. Mothers (DDC) were significantly more likely to rate "Needs Being Met" as low for sleep compared with mothers (NDC) (Fisher's Exact Test  $p=0.0014$ ). Lastly, there was a difference between the discrepancy of "Importance" and "Needs are Being Met" between mothers (DDC) and an mothers (NDC) for the variable of "Sleeping" (Fisher's Exact Test  $p=0.022$ ). Mothers of the child with a developmental disability felt that their needs were not being met given how important sleep was to them.

Significantly more fathers (DDC) than fathers (NDC) indicated the "Importance" of music as high (Fisher's Exact Test  $p=0.002$ ). Similarly, in relation to watching movies, more fathers (DDC) than fathers (NDC) rated their needs as being met although significance was not reached (Fisher's Exact Test  $p=0.07$ ).

More fathers (DDC) compared with mothers reported a high "importance versus needs met" discrepancy for the question "Watching Entertainment or Sports Events" (Fisher's exact  $p=0.016$ ). In other words, they had rated "Watching Entertainment or Sports Events" as important while reporting that their needs met were low.

In a comparison between mothers (NDC) and fathers (NDC), more mothers than fathers had a positive discrepancy between the "Importance" and "Needs are Being Met" for "Listening to Music" (Fisher's Exact Test  $p=0.004$ ) and while "Watching Movies" was not statistically significant (Fisher's Exact Test  $p=0.062$ ) although the value approaches significance. In other words, for both of these questions, mothers had rated their needs as being met as high relative

to the importance they had attributed to the question. A difference in rankings for the question "Watching Movies" approached statistical significance between fathers of a child with a developmental disability and a ND child, where fathers of the ND child felt that movies were important to them but their needs were not being met (Fisher's Exact  $p=0.06$ ).

The sign test found one significant difference and several differences approaching significance for the factor "Passive Recreation". For all 7 of the sub-questions in the factor "Participation in Active Recreation" a greater proportion of fathers of a ND child than mothers had reported that the question was of high importance. This gives a sign test value of +7 ( $p=0.01$ ). In other words, fathers of an ND child were more likely than the mothers to have attributed a high importance to questions involving passive recreation.

When groups were compared a sign value of +6 out of a possible 7 was obtained between mothers of a child with a developmental disability and an ND child. More mothers of an ND child had attributed high needs being met for questions involving passive recreation.

Ratings for the questions regarding passive recreation were also summed for each subject, providing a range of scores from 5 to 35. Applying an uncorrelated t-test to this data showed that, fathers of ND children were more likely than mothers to rate questions pertaining to passive recreation as important ( $t=2.092$ ,  $df=31$ ,  $p<0.045$ ).

## **#2 Active Recreation**

There were several analyses that approached significance for the domain "Active Recreation", and those results may be seen in Tables 5 to 8. However only one statistical analysis reached significance at the alpha level of 0.05. The question about "Vacations" showed differences between mothers (NDC) and fathers (NDC). More mothers than fathers had a high "importance versus needs met discrepancy" (Fisher's Exact Test  $p=0.044$ ).

A Sign analysis looking at active recreation was of particular interest. A comparison of mothers and fathers of children with a developmental disability in regards to their reports of "Needs Being Met" yielded a sign value of +10 out of a possible 11 ( $p=0.05$ ). A larger number of fathers (DDC) than mothers (DDC), according to the numerical value, felt that their needs in active recreation were being met. Similarly, fathers of ND children compared to fathers of children with a developmental disability yielded a numerical values of +9 of a possible 11 (A numerical value of +10 would have been significant) in terms of needs for active recreation being met. It is perhaps important to note that numerically more fathers (NDC) than fathers (DDC) felt their needs were being met in Active Recreation.

## **#3 Socializing**

No significant differences were found for the general category of socializing.

## **#4 Occupational Role**

Several differences were found in the general heading of Occupational

Role. One result involved the “importance versus needs met” discrepancy. More fathers (NDC) than mothers (NDC) were likely to state that “Having Interesting and Challenging Work at Home or Job” was important to them but that their needs were not being met (Fisher’s Exact Test  $p=0.038$ ).

A t-test was performed on all the data for the questions pertaining to occupation role. Mothers of ND children indicated they felt their needs were not being met for the questions relating to the domain of occupational role when compared to fathers (NDC) ( $t<2.057$ ,  $df=31$ ,  $p<0.048$ ).

#### **#5 Material Well-Being**

The question “Having Personal Possessions” was the only question that revealed any differences between groups for the general domain of Material Well-being. More mothers (NDC) than mothers (DDC) had a high “importance versus needs met” discrepancy for the question on personal possessions (Fisher’s Exact Test  $p=0.014$ ).

#### **#6 Health and Personal Safety**

The general category of Health and Personal Safety revealed only one significant difference amongst groups. The discrepancy scores between subjects rating of Importance and their rating of Needs Being Met showed a difference. More DDC mothers when compared with fathers showed a high “importance versus needs met” discrepancy for the question “Overall Health and Personal Safety” (Fisher’s Exact Test  $p= 0.046$ ). In other words, mothers (DDC) felt that their needs were not being met relative to the importance of this domain in their lives.

Neither the sign tests nor the t-tests for "Health and Personal Safety" showed any differences between groups.

### **#7 Relationship with Spouse**

Many differences were also shown for the overall domain of "Relationship with Spouse". There are differences between groups for comparisons of "importance versus needs met discrepancy". All of the fathers (DDC) showed a positive difference between their Importance scores and their Needs Being Met scores for the question "Help with Household Duties", unlike mothers (DDC) (Fisher's Exact Test  $p=0.009$ ). In other words, mothers were rating household duties as important but their needs were not being met, conversely the fathers rated the importance of household duties as high and needs being met. The same trend occurred when mothers and fathers of ND children were compared for the question "Help with Household Duties" (Fisher's Exact Test  $p=0.0034$ ).

The difference scores also showed further trends between fathers and mothers of ND children. More fathers (NDC) than mothers (NDC) had a high "importance versus needs met discrepancy" (Fisher's Exact Test  $p=0.012$ ). For this group the same trend was also true for the question "Spending Time Alone with Spouse" (Fisher's Exact Test  $p=0.018$ ). In other words, fathers (NDC) felt that "Spending Time Alone with Spouse" was important but that their needs were not being met.

Lastly, the difference scores illustrated trends between mothers of a child with a developmental disability and mothers of ND children. More mothers

(DDC) had a high "importance versus needs met discrepancy" than mothers (NDC) for the question on "Companionship" (Fisher's Exact Test  $p=0.035$ ). None of the other tests indicated differences between groups.

### **#8 Having and Raising Children**

None of the comparisons using Fisher's Exact Test revealed significant differences in "Having and Raising Children". The t-test analysis did, however, indicate overall significance for the domain of "Having and Raising Children". When parents scores for all the questions pertaining to "Having and Raising Children" were summed it was indicated that fathers (DDC), in general, rated their "Needs are Being Met" as low when compared with fathers of ND children ( $t=2.47$ ,  $df=28$ ,  $p<0.02$ ).

### **#9 Relationships with Other Relatives**

Two statistical differences were found for the domain "Relations with Other Relatives". Mothers (DDC) compared to mothers of ND children were more likely to report that the importance of helping their relatives was low (Fisher's Exact Test  $p=0.002$ ). More fathers (DDC) had a high "importance versus needs met" discrepancy for the question "Being Supported by Relatives" (Fisher's exact  $p=0.05$ ) when compared with fathers of ND children. In other words, the fathers (DDC) had rated this aspect as important to them, but that their needs were not being met relative to fathers (NDC).

### **#10 Relations with Friends**

Only one difference between groups was found for the domain "Relations with Friends" using Fisher's Exact Test. A greater number of fathers of children

with a developmental disability compared with mothers (DDC) had a large "importance versus needs met" discrepancy for the question "Having Close Friends" (Fisher's Exact Test  $p=0.046$ ). In other words, fathers (DDC) felt that having close friends were important to them, but their needs were not being met for this question.

The t-test that was performed also indicated an overall trend. Fathers (DDC) when compared to mothers (DDC) rated the importance of questions about "Relationships with Friends" as low ( $t=2.3$ ,  $df=26$ ,  $p<0.01$ ).

### **#11 Activities Related to Helping and Encouraging Other People**

No significance differences were found for the Fisher's Exact Test comparisons.

### **#12 Activities Relating to Local or National Governments**

One difference involved the question "Keeping Informed Through the Media". More mothers of a child with a developmental disability than an ND child reported that their needs were not being met for the question "Keeping Informed Through the Media" (Fisher's Exact Test  $p=0.014$ ).

### **#13 Intellectual Development**

Many differences are illustrated when statistical analyses are applied to the domain of "Intellectual Development". When asked about attending school more mothers of DD children than fathers rated "Attending School" as important (Fisher's Exact Test  $p=0.044$ ). Similarly, nearly significantly more fathers (NDC) than the fathers (DDC) rated "Attending School" as important (Fisher's Exact Test  $p=0.052$ ). Further for the question "Attending School" more mothers of a



child with a developmental disability rated their "Needs Are Being Met" as low than mothers of an ND child (Fisher's Exact Test  $p=0.061$ , not significant).

For the question "Opportunity to Learn About Things I Want to Know About" more fathers of a child with a developmental disability tended to rate "Importance" as low than did fathers of an ND child (Fisher's Exact Test  $p=0.06$ ). A Fisher's Exact Test also approached significance between the mothers of the two groups. A greater proportion of mothers (DDC) than mothers (NDC) tended to rate their "Needs Are Being Met" as low (Fisher's Exact Test  $p=0.062$ ).

Lastly, when parents were asked to rate their "Overall Intellectual Development" one trend appeared. More mothers of children with a developmental disability rated their "Needs are Being Met" as lower than mothers of ND children (Fisher's Exact Test  $p=0.035$ ).

The t-test that was performed illustrated three significant differences between groups pertaining to questions about intellectual development. Fathers (DDC) were less likely than both mothers of a child with a developmental disability ( $t=2.73$ ,  $df=26$ ,  $p<0.011$ ) and fathers of an ND child ( $t=3.47$ ,  $df=28$ ,  $p<0.0017$ ) to rate questions relating to their intellectual development as high in importance. Further, more fathers of a children with a developmental disability than fathers of ND children, in general, rated their needs as not being met for questions referring to intellectual development" ( $t=3.31$ ,  $df=28$ ,  $p<0.0026$ ).

#### **#14 Personal Understanding and Planning**

Only one difference appeared in the domain of "Personal Understanding and Planning". When asked to rate "Needs are Being Met" for the question "Gaining Purpose for My Life", more fathers of a child with a developmental disability than a ND child indicated a relatively low attainment of needs (Fisher's Exact Test  $p=0.007$ ).

A t-test was performed and an interesting statistical difference between mothers and fathers of a child with a developmental disability was found. Mothers (DDC) were more likely than fathers (DDC) to rate questions pertaining to "Personal Understanding and Planning" as important ( $t=2.11$ ,  $df=26$ ,  $p<0.045$ ).

#### **#15 Creativity and Personal Expression**

No differences were found for this domain.

#### **Questions Related to Abbey and Andrew's Model**

Each subject was asked to rate aspects of their life, as described in the model of Quality of Life by Abbey and Andrews (1986) presented earlier. Each subject was asked to rate four dimensions described in the model. They rated "Amount of Stress", "Control Over One's Own Life", "Control Other People Have Over Own Life" and "Amount of Social Support". These four aspects were rated on a five point scale, ranging from "Very High" to "Very Low". The subject's rankings were then compressed into either a high or low super category. A ranking of one through three was abbreviated to the high super category, and a rating of four or five was placed in the low super category. A final question not

described in the model, asked subjects to rate their "Overall Quality of Life" on the same five point scale. The data was interpreted in the same manner as described above.

The number of those parents who rated these questions as "Very High", "High", or "Moderate" can be seen in Table 9. The data were analyzed using Fisher's Exact Test on a two-by-two contingency table. The statistical analysis did not show any significant differences.

### **Quality of Life Questions**

The last section of the questionnaire asked subjects about general domains which had the greatest influence on parent's quality of life and that of their children. The questionnaire listed the fifteen general life domains outlined by Flanagan (1968). Of these fifteen domains, subjects were asked to pick three that : a) made them satisfied with their quality of life at the present time; b) detracted from their satisfaction with their quality of life at the present time; c)their children affected positively; and d) their children affected negatively impact. Subjects were also asked to list other aspects of life not covered by the questionnaire that may have been affected by the presence of children. Lastly parents (DDC) were asked how the presence of a child with a developmental disability had affected their overall quality of life.

The total number of times each domain was selected for each of the four questions described above is summarized in Tables 10 to 13. The information for each domain was analyzed using Fisher's Exact Test. Groups were compared on whether or not they had selected a domain as influencing

**Table 9**  
**Number of Parents of (A) Children With and (B) Children**  
**Without Developmental Disabilities Rating Each**  
**Question As "Very High", "High", or "Moderate"**

	<b>Mothers</b>		<b>Fathers</b>	
	<b>(A)</b>	<b>(B)</b>	<b>(A)</b>	<b>(B)</b>
<b>1) Amount of Stress</b>	8	8	5	6
<b>2) Control Over Own Life</b>	8	8	11	9
<b>3) Control Other People Have Over Your Life</b>	1	1	5	5
<b>4) Amount of Social Support</b>	11	7	10	10
<b>5) Overall Quality Of Life</b>	7	7	12	14

**Number of Parents in Each Group**  
**Parents of a Child with**  
**a Devel. Disability**

Mothers - 15  
Fathers - 13

**Parents of a Child without**  
**a Devel. Disability**

Mothers - 16  
Fathers - 17

their quality of life.

Each subject was asked which 3 general factors of the possible 15, made them satisfied with their quality of life at the present time. Analysis showed several interesting indicators. When fathers (DDC) were compared to NDC fathers (NDC), fathers (DDC) were more likely to report passive recreation as positively influencing their satisfaction with their quality of life (Fisher's Exact Test  $p=0.052$ ). Fathers of ND children, when compared to their spouses, were more likely to report that the domain of occupational role contributed positively to their quality of life at the present time (Fisher's Exact Test  $p=0.017$ ).

When parents were asked to name 3 domains from the 15 that detracted from their satisfaction with their quality of life at the present time, two interesting results were found. Fathers (DDC) were more likely than their spouses to indicate that their occupation role was detracting from their quality of life (Fisher's Exact Test  $p=0.044$ ). Only one mother (DDC) selected this domain as detracting from her quality of life, whereas nearly 50% of the fathers (DDC) had selected this domain. A similar finding was true when mothers of children with a developmental disability were compared with mothers of ND children (Fisher's Exact Test  $p=0.019$ ). Fifty percent of the time mothers of ND children stated that occupational role lead to dissatisfaction with their quality of life, whereas none of the mothers (DDC) reported this concern.

When parents in both groups were asked to list 3 of the 15 domains upon which their children had a positive effect, there were several statistically significant results. More fathers of ND children than their spouses selected

Table 10  
 Number of Parents of (A) Children With and  
 (B) Without Developmental Disabilities Identifying  
 QOL Domains Making Them Satisfied with their QOL  
 At the Present Time

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
#1 Passive Recreation	0	1	4	0
#2 Active Recreation	2	5	2	3
#3 Socializing	2	1	2	1
#4 Occupational Role	2	3	4	11
#5 Material Well-Being	3	2	2	0
#6 Health and Personal Safety	1	6	5	7
#7 Relationship with Spouse	10	11	9	11
#8 Having and Raising Children	13	14	9	13
#9 Relations with Other Relatives	3	0	1	1
#10 Relations with Friends	3	1	0	0
#11 Activities Related to Helping or Encouraging Other People	2	0	0	0
#12 Activities Relating to Local or National Governments	1	0	1	0
#13 Intellectual Development	1	2	0	1
#14 Personal Understanding and Planning	1	1	0	2
#15 Creativity and Personal Expression	1	1	0	1

Table 11  
 Number of Parents of (A) Children With and  
 (B) Without Developmental Disabilities Identifying QOL  
 Domains As Detracting From Their Satisfaction  
 With Their QOL At the Present Time

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
#1 Passive Recreation	3	2	2	2
#2 Active Recreation	6	2	4	1
#3 Socializing	2	2	0	4
#4 Occupational Role	1	8	6	5
#5 Material Well-Being	2	4	2	6
#6 Health and Personal Safety	3	1	0	0
#7 Relationship with Spouse	2	1	1	1
#8 Having and Raising Children	1	1	2	1
#9 Relations with Other Relatives	3	2	3	3
#10 Relations with Friends	2	0	3	4
#11 Activities Related to Helping or Encouraging Other People	1	2	0	1
#12 Activities Relating to Local or National Governments	2	4	3	9
#13 Intellectual Development	6	2	2	2
#14 Personal Understanding and Planning	0	4	1	1
#15 Creativity and Personal Expression	3	5	1	4

Table 12  
 Number of Parents of (A) Children With and  
 (B) Children Without Developmental Disabilities  
 Identifying QOL Domains  
 That Were Affected Positively by Their Children

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
#1 Passive Recreation	1	0	0	4
#2 Active Recreation	2	6	2	13
#3 Socializing	3	9	1	2
#4 Occupational Role	0	0	1	2
#5 Material Well-Being	1	0	0	1
#6 Health and Personal Safety	1	1	3	1
#7 Relationship with Spouse	5	6	4	2
#8 Having and Raising Children	5	5	6	4
#9 Relations with Other Relatives	4	3	1	4
#10 Relations with Friends	4	4	3	3
#11 Activities Related to Helping or Encouraging Other People	5	2	4	5
#12 Activities Relating to Local or National Governments	2	0	0	1
#13 Intellectual Development	2	0	1	1
#14 Personal Understanding and Planning	7	7	6	3
#15 Creativity and Personal Expression	2	4	1	2



Table 13  
 Number of Parents of (A) Children With and  
 (B) Children Without Developmental Disabilities  
 Identifying QOL Domains  
 That Were Affected Negatively by Their Children

	Mothers		Fathers	
	(A)	(B)	(A)	(B)
#1 Passive Recreation	3	1	0	4
#2 Active Recreation	8	5	6	2
#3 Socializing	8	4	7	5
#4 Occupational Role	6	6	3	2
#5 Material Well-Being	2	5	2	5
#6 Health and Personal Safety	1	1	2	0
#7 Relationship with Spouse	2	2	4	4
#8 Having and Raising Children	0	0	0	0
#9 Relations with Other Relatives	1	0	1	0
#10 Relations with Friends	0	1	2	4
#11 Activities Related to Helping or Encouraging Other People	2	0	0	1
#12 Activities Relating to Local or National Governments	1	1	0	0
#13 Intellectual Development	3	3	4	3
#14 Personal Understanding and Planning	0	2	0	1
#15 Creativity and Personal Expression	3	2	0	1

“Participation in Active Recreation “ as a domain in their lives upon which their children had a positive effect (Fisher’s Exact Test  $p=0.046$ ). Similarly, far more fathers (NDC) than fathers (DDC) selected “Participation in Active Recreation” as having been positively influenced by the presence of children (Fisher’s Exact Test  $p=0.002$ ).

Further, mothers of a ND child were far more likely than fathers (NDC) to have reported “Socializing” as having been positively influenced by the presence of children (Fisher’s Exact Test  $p=0.016$ ). When mothers (DDC) were compared to mothers (NDC), fewer mothers (DDC) reported their children as having a positive effect on their “Socializing” (Fisher’s Exact Test  $p=0.002$ ).

There were no statistically significant results when parents were asked to list three domains upon which their children have had a negative impact.

## Chapter 5

### **Discussion**

The results from the questionnaires are discussed in detail in this chapter. They illuminate both the positive and negative impacts of a child with a developmental disability on his/her parent's quality of life. The overall information has broad based implications for parents, professionals, practitioners, and legislators, as well as future research.

The analysis of the information provided by parents of children with and without a developmental disability was examined in the context of the literature, including theoretical models of family functioning. Further, the qualitative, anecdotal answers given by parents provide additional insight into interpreting the statistical analysis. The exploration of present findings provide support for theoretical models of quality of life particularly in relation to family functioning, and the effects of the child with a developmental disability on his/her family and environment.

As this study was exploratory in nature, no formal directional hypotheses were put forward. Several issues were investigated. First, unlike the majority of previous studies, fathers of children with and without a developmental disability were included as research subjects. The objective was to illuminate issues between mothers and fathers that may not have been previously explored. Including fathers in the study also provided the opportunity to reveal issues that may be particularly relevant to fathers of a child with a developmental disability.

Second, it appears to have been appropriate to use a quality of life approach involving psycho-social indicators, rather than more traditional and objective outcome measures such as indices of depression, anxiety or stress. Quality of life, as a complex indicator, encompasses positive as well as negative aspects of life. For example, the use of positive indicators of quality of life provided material which would not be elicited by traditional techniques and allowed people to access positive as well as negative aspects of their lives. This study was also directed at exploring the family's quality of life from a subjective view-point from both parents separately. Additionally, the questionnaire focused upon gathering information on specific domains of life.

One of the most important outcomes of this exploration is the recognition of each parent's perception of his/her quality of life. An individual's subjective viewpoint provides information that would not have been collected using objective measurement. Further, it seems likely that parents recognize the strengths and weaknesses in their families. This suggests that the family is in the best position to help themselves, though guidance and interpretation may be necessary. Thus this type of information can be a major influence on service provision or counselling. These are the advantages to the using of a quality of life perspective.

Issues that appeared to surface in this study for parents of a child with a developmental disability included a lack of sufficient financial resources, a lack of adequate time, a lack of education, a need for the support of relatives and need for adequate child care. These did not appear to be issues for parents in

families without a child with a developmental disability. Additionally, positive aspects of the lives of parents who had a developmentally disabled child also became evident in this study. Areas that a child with a developmental disability had positively influenced included the parents relationship with their spouse, the importance accorded to family and children, and the support received from friends and relatives.

Both mothers (DDC) and fathers (DDC) appeared to perceive their situation differently than did parents (NDC). Possibly parents of a child with a developmental disability tended to reframe their situation cognitively and emotionally. Rather than seeing the presence of a child with a developmental disability as a stressor or a problem, as family outsiders might, parents (DDC) tended to perceive their lives as "normal" or "typical". Statements such as *"this is 'normal' for us"*, *"that is an average day for us"* or *"that's life for us"* were commonly spoken amongst all of the families (DDC). Although there is no information on the number of families who made statements like this. The implication is, perhaps, that they had adjusted to the situation. This may be one explanation for the cohesiveness of families in this study. It may be hypothesized that these families functioned effectively because they had the ability to adapt their perceptions of life to accommodate the differences that a child with a developmental disability may have brought. This hypothesis will be explored in a discussion of the statistical results.

Another explanation for the parent's (DDC) view that their lives are no different than the lives of other parents may represent a "do-or-die" situation. In

other words, either parents (DDC) adapted very well to the presence of their child with a disability and stayed together for a long time, or the presence of a child with a developmental disability quickly destroyed the family fabric. Since this study only focused upon intact families it only represents the views of those parents who lived together and may show how they have adapted to the situation in a positive fashion. Hence the negative effects of a child with a developmental disability, which others anticipate, may not necessarily be found within this group. Therefore, it would be important that any future research in this area include both intact and separated families.

It should be noted that statistical results were only considered significant if a p-value was less than or equal to 0.05. This means that a significance obtained had a one-in-twenty chance of being explained by coincidence. Therefore, before any conclusions are drawn, it must be accepted that on one of twenty occasions the result may be attributed to being a statistical artifact, and not due to real differences between groups.

### **Demographics**

One of the differences between parents of ND children and children with a developmental disability is linked to the number of families who participated in the study. Fifty-one families of children with a developmental disability were approached and only 15 families returned questionnaires, compared with 17 families of ND children that returned questionnaires out of the 25 approached. Possibly, families (DDC) are less willing to participate in research studies, although, the reasons for this can only be speculated. Children with a

developmental disability are possibly an overly researched group, and hence families may be unwilling to fill out "*another questionnaire*". In fact, several families indicated that they had previously participated in research, although no formal information on this was collected. This may be partly a function of the geographical area from which the subjects were solicited, namely an urban area with a large university and medical school where many departments encourage community based research. The second explanation is that parents (DDC) may be so busy caring for the needs of a child with a developmental disability their time available for completing questionnaires is limited. In other words, on a list of family priorities, participating in research is far down the list.

Another possible explanation relates to fathers of children with developmental disabilities. Few previous studies have gathered information from fathers of a child with a developmental disability. Historically they are far less likely to attend clinics or interviews than mothers, though both are invited and encouraged. Therefore, it may be the fathers who were unwilling to become involved. This contention is supported by comments from several families that declined to participate in the study because the father was unwilling to participate.

Data pertaining to demographics also revealed differences between families (See Table 1). First of all, parents of a child with a developmental disability, on average, had more children than parents of a ND child. There may be several reasons for this. First of all, the study only focused upon intact families. Parents (DDC) who adapted well to the presence of a child with a

developmental disability remained intact and, therefore, had the opportunity to have more children. Whereas families who adapted poorly to the presence of children with a developmental disability may have been more likely to separate and would have been excluded from the study. This is consistent with the “do-or-die” scenario suggested earlier, and may have resulted in selection bias in favour of larger families. Again, this also suggests that any further research should involve both intact and separated parent couples.

The contention that families (DDC) were larger because they remained intact is also supported by looking at the average age of children of the family (see Table 1). The average age of children with a developmental disability in this study was 7.5 years, however, the average age of all the children in families (DDC) was 6.6 years. Thus, children with a developmental disability tended to be the elder children in the family, which is consistent with the argument presented above. The results are also consistent with the arguments of both Turnbull and Turnbull (1986) ‘Family System Conceptual Framework’ and Mitchell (1986,) ‘Factors That Influence a Families Reaction to a Member with a Handicap’. Both reports indicate that family size is directly related to positive family functioning with moderately larger size families (3 to 5 children) functioning more effectively.

Additionally, intact families (DDC) may have been the families who enjoyed the parenting role and wished for more children. Parents (DDC) may also have wished to compensate for the birth of a child with a developmental disability by having a subsequent “normal” child. These are all possibilities for



exploration in future studies.

Families with a child with a developmental disability had a significantly lower income than families with a ND child. There may also be many reasons for this, and they are possibly associated with the way a family functions. Each of the factors that impact on a family are not independent, and most authors argue for interactive causation (eg. Mitchell, 1986, and Turnbull and Turnbull, 1986). Families (DDC) compared with those without a child with a disability, may have had a lower household income because (a) work was less valued than other aspects of life; (b) mothers on average had less education; (c) mothers were more likely to stay home with the children; (d) families were less likely to make family life decisions based on economic or job opportunity factors. Such values may have developed because other priorities benefited the child with a developmental disability to a greater degree in terms of parent perception.

The reasons for the family of a child with a developmental disability receiving a lower household income is perhaps explained in a more concrete manner if visualized in the context of Turnbull and Turnbull's (1986) family model. It is suggested by these authors that the outputs of family function are economic and educational. Further, these outputs are mediated by family interaction, cohesiveness and adaptability, the families resources including the child's exceptionality, and the stage of development of the family in terms of the life-cycle. The family has made economic, educational, and vocational choices based on the needs of the child with a disability, the family's interaction, and

where the child is in the life-cycle.

Further support for this model is provided by other statistical results from this study. For example, fathers (NDC) rated the importance of work as higher than fathers (DDC). This result may indicate that the output of a model for family functioning, namely a father's occupation, was influenced by the presence of child with a developmental disability. The fathers (DDC) were perhaps less satisfied with work because they had made choices pertaining to their child with a developmental disability that influenced their occupation. This result is discussed in detail later in the chapter.

Statistically, mothers (DDC) had less education than mothers (NDC). There are at least two possible explanations. Either the mothers (DDC) had less education in the first place or a choice was made based on the presence of a child with a developmental disability. Mothers (DDC) may have placed greater importance on caring for their family rather than going to school. This tenet is supported by the statistical results for the domains of Intellectual Development and Occupational Role. Mothers (DDC) were more likely than mothers (NDC) to report that their needs were not being met in the domain of Intellectual Development. Apparently, mothers (DDC) would have liked to have furthered their education, but instead decided to care for their child with a developmental disability. However, compared to both mothers (NDC) and fathers (DDC), mothers (DDC) did not rate their occupational role as detracting from their quality of life. In other words, mothers (DDC) found staying home acceptable, or it was an alternative they had adapted to as a result of having a

child with a developmental disability.

### **#1 Passive Recreation**

Several significant differences existed between mothers and fathers of children with a developmental disability and mothers and fathers of ND children for the general domain, 'Passive Recreation'. Overall, the data indicated several trends. First, that parents (DDC) felt that their needs were not being met in this area; second, parents of a ND child had rated this area as very important in their lives; and finally there were differences between mothers and fathers in both groups.

The question regarding sleep provided several interesting results. Mothers of children with developmental disabilities were significantly more likely than their husbands and other mothers to report that their needs were not being met. As reported by Simeonsson and Simeonsson (1981) families with a child with a developmental disability are more likely to face sleep interruptions beyond the infancy period. A child with a developmental disability is more likely to not only wake at night, but to cause parents night-time worries about wandering. This is reflected in six quotes by parents of children with a developmental disability.

One mother (DDC) reported: *"My son can often wake during the night . I can never sleep in ...", "A good night sleep is extremely rare! At least one of our children is always up at night or sick. More often than not it is our special needs son",* and another stated *"Handicapped son often wakes at night and squeals, laughs. Wakes us up."*

This is also mirrored by three fathers (DDC). One stated: *"Our younger children, and particularly our special needs child have erratic sleeping habits. T. wakes up early every in the morning"*, another noted that his child *"Wakes up often during night"*, and a third reported *"Kids constantly wake us up early mornings, disabled son's sleep habits erratic."*

Parents of ND children made no comments regarding a lack of sleep or nocturnal wakings by their children.

It is also important to note that although both mothers and fathers of children with a developmental disability made comments pertaining to the sleep habits of the child, only the mothers reported that their own needs were not being met in this domain. It may be possible that the mothers were shouldering the majority of the burden of attending to the child's night time needs. It is interesting that mothers with a child with a developmental disability may have taken on a traditional caretaking role. This raises the question whether families with particular views of parenting are more likely to survive having a child with a developmental disability; a question that should be followed-up in further research. It seems possible that a family (DDC) where the mother accepts the role of traditional mother is more likely to survive.

The interaction of variables such as lack of sleep, the parent's energy level and motivation, and the relationship between the parents, possibly has broad implications for policy-makers. Cunningham (1988) has suggested that it is not the presence of a child with a developmental disability that leads to familial stress, but an unmet need for services. One reason that families may

adapt well to the presence of a child with a developmental disability could be related to the amount of in-home support that a family receives. A family that receives more support may face less sleep interruptions, and hence, have more energy and greater motivation. Increased support may also improve the relationship between parental couples. The couple would be better rested, less prone to upset and have more time to spend together, which in turn may be reflected in improved marital relations. It is important to note that support may be provided in many different ways. It may be very formal such as respite or special daycare, or it may be provided very informally through family or friends.

The present study provides some evidence for the contention that the support provided to a family, whether formal or not, is related to the family's ability to adapt to the stressors in their lives. In this study, parents of a child with a developmental disability presented several issues which indicate their need for support in various areas of their lives and how those needs were met. For example, many parents (DDC) stated that their social lives were not affected by the presence of a child with a developmental disability, because they have adequate and effective baby-sitting. Further, support from the extended family, in terms of child care, was described as very important. Mothers also stated that their husbands provided both emotional support and help with household tasks. Areas that parents (DDC) identified as difficult because they lacked support included: sleeping, camping, and vacationing. However, not every family described the same areas of their lives as needing support. All of the above results will be discussed in detail later in the document.

It was clear that each family in this study needed different levels of support in the various aspects of their lives. For example, not every family described having adequate baby-sitting or the lack of support necessary to go camping. This illustrates the broad variability in perceptions of need for support among different families. This implies that before support can be given to a family, it may be very important to assess each family individually, in terms of their need for support. This illustrates the value in using a subjective perspective quality of life indicator.

It was also reported that parents (DDC) felt that their needs for watching movies or entertainment/sporting events were not being met. It seems reasonable to assume that their needs were not being met because of time constraints related to the presence of a child with a developmental disability. Perhaps, parents (DDC) could not psychologically or physically afford to make any time for such events. This would be consistent with the argument presented above that parents (DDC) have variable needs. One may also contend that the parents were simply too tired to participate in any of these activities. This would be consistent with the results described above pertaining to sleep.

A final specific difference for the domain of passive recreation involved fathers of children with a developmental disability rating music as important in their lives. Neither the literature reviewed nor the anecdotal information provides an explanation for this. It may be argued that parents (DDC) used music as a coping mechanism. Music has many relaxing qualities. Parents of child with a developmental disability may use music as a method of relaxation

to help cope with day-to-day stressors associated with a child with a developmental disability. Families (DDC) may remain intact because they had developed effective coping mechanisms, such as the use of music for relaxation. This suggests the development of effective coping mechanisms may be important in helping the family remain intact. The concept of music as a potential coping strategy for parents of a child with a developmental disability presents an interesting question for further study.

## **#2 Active Recreation**

Several different questions concerning active recreation indicated differences between parents of a child with a developmental disability and a ND child. Primarily, parents (DDC) felt that their needs were not met when compared to parents of ND children. These differences, once again, may be a reflection of a lack of time available. If a great deal of parental time is concerned with care of a child with a developmental disability, time must be taken away from other activities. Perhaps, as indicated in the discussion of the demographics, financial difficulties may also explain the inability of parents (DDC) to participate in active recreation activities. Once again, there may also be an interaction between variables involving finance and recreation. This may have broad implications for parents (DDC), for if they are unable to afford the time or the money for rest and recreation, they are more likely to be stressed or anxious. This may be further support for the "do-or-die" scenario. Additionally, this provides evidence for the argument that each family has different needs for support, and that these needs should be addressed individually.

Another aspect of data comparison which is of interest is that the anecdotal answers to questions were not necessarily consistent with the group comparisons found to be statistically different. For example, a statistical difference was found between fathers of ND children and children with developmental disabilities when asked about cycling. More fathers (DDC) felt that cycling was important. Yet there were few anecdotal responses to explain these differences. However, both mothers and fathers of children with a developmental disability responded liberally when asked about camping, vacations, and travelling. This is interesting because none of the group comparisons involving these areas were found to be statistically different. This may be a reflection of variability among group members and quality of life measures tend to pick this up.

Some of the varied comments made by parents (DDC) for questions regarding camping, vacations, and travelling are listed below.

### Camping

One mother of a child with a developmental disability made stated that: *"Would like to do more but it would be hard. Before we could stay for two weeks, now for only 4 days. Have to watch him all the time. Take your eyes off him for a minute and he'd be up to his neck."*; another reported *"It's difficult to camp with M., however we do occasionally leave him at a group home and go."*; a third mother (DDC) noted *"We do camp, but have to be very watchful of him - he tends to wander and bother people and animals. It can be stressful."*; and a fourth mother (DDC) also noted *"We can only camp when child is cared for by*



*host family. This is once a month. We enjoy it very much because we can do things that a normal family can do."*

One father (DDC) reported: *"Unable to go to certain areas due to handicapped child's limited mobility."*

### Vacation

One mother (DDC) reported: *"Don't get a lot of time alone. Can only leave A. alone with certain people. It hard on the aging grandparents. We were looking forward to camping but grandma died."* Similarly, another mother (DDC) said that *"We do vacation but it can be stressful rather than relaxing with T. along;"*; while another mother (DDC) pointed out that *"Accessible vacation spots with respite possibilities a big problem."*; and a fourth mother (DDC) noted *"We need child-care to go on any kind of vacation. Expensive and worrisome."*

Similarly, one father (DDC) reported: *"Time and money constraints;"* and another father (DDC) noted *"We like vacationing as a family but managing our special needs son in public and unfamiliar situations is challenging and can be stressful. It doesn't usually keep us from vacationing, however, lack of funds is more of a constraint than having T. in our family."*

### Travel

Two mothers (DDC) made statements relating to travel. One reported: *"Difficult to bring son along;"*; and the other noted *"Not enough money."*

However, not everyone selects camping, travelling or other specific activities as important activities to them. Choice operates in relation to people's likes and dislikes. Any assessment of quality of life must take this into account.

It is likely that concerns would be expressed only when the activity was selected as a major component of an individual's lifestyle. Any specific statistical comparison might not show significant differences, because only a few individuals in each group would participate in specific recreation activities. This is consistent with the view that quality of life should be measured subjectively using an individual's perceptions of life quality across a variety of aspects of life (Parmenter, 1988). Further, as discussed in detail below, subjective perception would be an important component of a model describing quality of life in parents with a developmental disability. The adapted questionnaire (Flanagan, 1978) used in this study appears to effectively assess the variability among individual's perceptions across different domains. This variability underscores the need to see families as individual units. Not every family has interests or difficulties in the same areas. Therefore, any service programs need to bear the families idiosyncracies in mind. This is reflected by Turnbull and Turnbull (1986) who stated: "Every family is idiosyncratic, if not unique" (pp. 24). In order to find any significant differences between groups and avoid the lack of difference due to individual taste, it would be necessary to combine all recreation activities.

When this was done in the present study, significant differences were found between groups. For example, a sign test based on all the questions pertaining to active recreation comparing fathers (DDC) and fathers (NDC) indicated that less fathers (DDC) felt their needs were being met for this domain. Further, when fathers (DDC) were asked, which of the 15 quality of life

domains their children influenced, the entire domain of active recreation was identified as positively influencing quality of life. However, as described above, few statistical differences existed for specific recreational activities in this domain.

### **#3 Socializing**

As seen in the review of the literature, there was some evidence to show that a parent's social life was affected by the presence of a child with a developmental disability. It has been reported that parents (DDC) have more trouble getting out of the home, having guests over or finding a baby-sitter (Hewitt, 1970). From this it may have been predicted that parents of a child with a developmental disability would be more likely to have difficulties in the domain of socializing. The statistical analysis, however, revealed no differences between the reports of parents of a ND child and a child with a developmental disability in this area.

There is at least one possible explanation for the lack of difference. A possible explanation pertains to the access parents have to adequate and effective babysitting. Byrne and Cunningham (1988) reported that parents of a child with Down syndrome had few difficulties with socializing, however, for those families who did have difficulty, inadequate babysitting was cited as the reason.

In the present situation, the lack of difference between the two sets of parents may be attributed to the presence of adequate child care for parents (DDC). This is reflected in comments made by parents (DDC). One mother of a

child with a developmental disability stated, *"We have an excellent baby-sitter, who loves and understands T."* Similarly, one father of a developmentally disabled child stated, *"We have excellent baby-sitters who really enjoy our children including our special needs son."* Further, there were no comments made pertaining to inadequate babysitting. It would seem that in this study babysitting was not an issue, and therefore may have enabled parents to socialize adequately.

These results are of particular interest when taken in the context of the literature, which stresses provision of support services where needed. If needs for aid such as baby-sitting are met the difference between parents of a child with and without a disability become much smaller. The provision of community resources lessens difficulties faced by parents (DDC) and improves their quality of life. This gives rise to a practical dilemma. It appears that parents can function well if given adequate support, but the type of support needed may differ substantially from family to family. Recognition of this by agencies, government services and other support agencies is critical. This contention fits well with quality of life models which argue for choice and empowerment. Here it is the parents who need to be in a position to voice their choices, and society needs to be able to help meet those needs if the family is to be effectively supported.

Although specific questions relating to socializing did not reveal differences, asking parents which domains their children had a positive effect upon demonstrated two differences worth noting. Mothers of ND children, more

than fathers, stated that children had a positive effect upon their socializing. Presumably, for mothers as the primary care-giver, the presence of children opened opportunities to meet people of similar ages, who also had children. For example, mothers were able to meet other mothers through church, school, parent associations and daycare. Conversely, fathers may only have the opportunity to meet people through work.

Mothers of ND children were also more likely than mothers of children with a developmental disability to report that their children positively influenced their socializing. Mothers of ND children probably have more opportunity to get out with their children and socialize. Going out and meeting and interacting with people is likely to be more problematic for a mother of a child with a developmental disability than for a mother of a child without a developmental disability. For example, one mother stated that she was hesitant to take her developmentally disabled son to the grocery store. Apparently, her son was quite noisy and disruptive, and had a short attention span. Further, he drooled on the food carousel at the check-out, which did not endear him to other patrons. Other mothers (DDC) told similar stories about the hassles of going out with a child with a developmental disability. One mother was embarrassed to go to the mall because of the noises her son made. Another mother was bothered by her child's inability to "sit for five minutes".

Of the mothers described above, the first mother would benefit from assistance that would allow her to go grocery shopping without the added concerns described. She could be provided with a few hours of daycare so she

could go shopping, or someone else could go to the store for her. However, not every parent has difficulty going to the grocery store, and, hence, providing support to meet that need would be inappropriate. These examples clearly provide evidence that each parent has individual needs for support.

#### **#4 Occupational Role**

Overall there were several differences in this domain. Occupation, much like the results described above, appeared to reflect gender differences. There was a broad range of occupations for mothers and fathers in both groups, however many of the mothers did not work outside the home, and listed “home-maker” as their occupation. This should be later taken into account in any interpretation of statistical results, because many of the differences for this domain appeared to be related to mothers views of their “job”.

Cunningham (1988) has reported that mothers of children with developmental disabilities tend to receive more help with household tasks, particularly from their husband, than other mothers. The present investigation appeared to mirror this result. Comparatively, mothers (DDC) felt they received more support from their spouses than mothers (NDC). This trend may be true because fathers (DDC) need to provide a greater level of care to their child with a developmental disability so that the family may function effectively. This is reflected in statements by three fathers of children with a developmental disability when asked about the role of housework. One said *“I help my wife somewhat. I know she has her hands full keeping up with T. and the other children and she sometimes needs help with routine housework.”*; another

reported *"Help out wife."*; and a third father stated *"Housework to me means painting/decorating as well as day to day duties. It is very hard to keep a clean and tidy house with a child who needs constant attention and only nine hours sleep."* Conversely, only one statement pertaining to housework was made by a father of an ND child: *"Tough to get motivated about housework"*.

The amount of help a husband provides in relation to household duties may help explain why mothers (NDC) were more likely than their spouses to state that their needs were not being met for the overall domain of occupational role. There are at least two possible explanations: 1) not enough help in the home, which would be consistent with the view that mothers (DDC) receive more help from their spouses or 2) having become tied to the home. Mothers (NDC) may be dissatisfied with their role of remaining at home to care for the children, and may wish to work outside the home. It is more likely that the mothers (NDC) did not feel supported in the duties required around the house.

More fathers (NDC), when compared to mothers, felt that "having interesting and challenging work" was important, but that their needs in this area were not being met. It is unclear why fathers (NDC) felt that their needs were not being met. One explanation is that fathers (NDC) placed a great deal of importance on occupation, therefore, they were more likely to be disappointed if their career did not progress as expected. Some support for this contention is produced by the fact that significantly more fathers (NDC) listed their occupation as positively influencing their quality of life (discussed later in the chapter). In a traditional male role, work is often seen as the basis for an

adult male's esteem.

Further details became evident when parents were asked which of the 15 quality of life domains (described in the methodology chapter) made them satisfied with their quality of life. Fathers of ND children were far more likely than mothers to list occupational role as a domain that made them satisfied with their quality of life at the present time. Again, as described above, this appears to be consistent with the view that fathers traditionally work outside the home and find value and esteem from their work. Further, this supports the contention that mothers are unhappy with work roles. It is interesting to note that, for this question, statistical significance was only approached between the two groups of fathers, with more fathers (NDC) reporting that their occupation was one domain that made them satisfied with their quality of life.

When asked which factors made them dissatisfied with their quality of life, fathers (DDC) were far more likely than their spouses to report that work made them dissatisfied. A story told by one of the fathers may help to explain this dissatisfaction. When offered a sizeable promotion to the senior management level of a large oil corporation, that required a transfer, the father turned down the transfer because the family was extremely satisfied with the school program that their child with a developmental disability was attending. In other words, fathers of a child with a developmental disability may place less emphasis on one aspect of their lives so they may support other aspects of life which they considered more critical. The balance of resources available for parents (DDC) may be important to how they adapt. In order to place time and resources into



one aspect of their lives, they must, in turn, take time and resources away from other life areas. This is also consistent with Turnbull and Turnbull's (1986) family functioning model described above. The father's vocational choice was mediated by the needs of the child.

It appears that a family's ability to adapt to the presence of child with a developmental disability may be related to how an individual parent views the role of each parent within the family. It appears that parents (DDC) in this study viewed parental gender roles differently than other parents (NDC). For example, it seems that mothers (DDC) had to become more traditional, by staying home, not pursuing a career and receiving less education. Further, fathers (DDC) appeared to be less traditional than other fathers (NDC). These fathers (DDC) took on more household chores, and valued their occupational role less. Perhaps the ability to view gender roles flexibly, aids a family in adapting effectively to a child with a developmental disability.

Mothers of ND children were far more likely to report dissatisfaction with their occupational role when compared with mothers of children with a developmental disability. In other words, mothers (DDC) appear to have the greatest satisfaction of all four groups for this domain. Although a great deal of further research is necessary, there are at least three possible explanations for this. First of all, both groups of mothers may be responsible for the same duties at home, however, mothers of children with a developmental disability may have a greater sense of accomplishment and usefulness than mothers of ND children. Two statements were made by mothers of ND children. One mother

stated that *"Household chores are dull and repetitive."*, and another pointed out that *"Daily household chores are boring. The demands of children are frustrating."*. Mothers of children with a developmental disability tended to make much more positive statements. Four mothers made statements. One mother indicated *"As with any job, home-making has its mundane tasks. As with anything T.'s presence has made my 'job' more challenging and fulfilling."*; another noted *"I try to do my best."*; a third reported *"I have a mostly understanding and sensitive husband and family (occasionally) who recognize my efforts"*; and a fourth mother (DDC) noted *"My husband appreciates what I do, but my children are very demanding"*. Comments like this perhaps also indicate that mothers (DDC) receive more positive feedback regarding their work at home than other mothers

The second explanation may involve denial as a coping mechanism on the part of mothers (DDC). Although, mothers (DDC) did not list Occupational Role as detracting from their quality of life, some mothers (DDC) made statements to the contrary. Mothers (DDC) made statements such as *"Had to give up my career to care for my son , e.g. all the appointments, surgeries , etc....."* ; or *"I'm not doing what I would really like to job wise, because of my son"*. Yet, when asked which of the fifteen quality of life domains detract from an individual's satisfaction with their quality of life at the present time, only one mother of a child with a developmental disability listed Occupational Role. Conversely, 50 % of mothers (NDC) reported that Occupational Role detracted from their quality of life. Mothers (DDC) may be denying the problems that are

facing them. In other words, mothers (DDC) may actually be disappointed with their 'job', but are denying that this is true. Rather they give the impression that they are satisfied with working at home and with the child with the developmental disability.

The third explanation is that mothers (DDC) have adjusted their perception. They may have reframed their perceptions of occupation to emphasis the positives rather than just the negatives. In other words, they see their life 'as normal'. For example, one mother of a child with a developmental disability stated that *"the house is just as messy when I started but I feel this comes with having small children not a child with a handicap"*. Mothers of children with a developmental disability may see the positives in a situation and not focus on the differences their child with a developmental disability has had upon their lives.

#### **#5 Material Well-Being**

Only one specific result was found for the factor Material Well-Being. When mothers in both groups were asked about personal possessions, more mothers of ND children felt that their needs were not met. It may be speculated that mothers of children with a developmental disability feel that other aspects of life relating to their child with a disability may be more important than personal possessions. Mothers of a child with a developmental disability may have different priorities than mothers (NDC).

The review of the literature indicated that parents of a child with a developmental disability appear to have greater concerns in regards to money.

There were no statistical differences between parents with and without a child with a developmental disability pertaining to finance. However, many anecdotal statements were made by parents of a child with a developmental disability that seemed to indicate that issues existed in regards to money. For example, when asked about having a home one mother (DDC) responded with: *"Not financially feasible."*, and a second mother reported *"I would love to have a home , but money's a problem."*

These financial concerns have been noted in the literature. Miezio (1983) reports that parents face the added anxiety of paying a high price for child care as well as how the child will receive assistance when the parents are no longer able to provide for him/her. Statements made by parents (DDC) in the present study clearly reflect this. Three similar statements were given by three different mothers. One mother reported: *"I worry about T.'s future when we aren't here to provide."*, another noted *"Money's important in this day and age especially looking at private schools to get quality education for D., prescriptions, dental, etc..."*, and a third mother expressed *"My son will need so much in the future, and he will be unable to support himself - very frightening"*. A similar statement was made by a father (DDC), *"I would like to save more money than we do. For retirement and to provide for T. when we are elderly."* No similar statements were made by parents of ND children.

It is interesting to note that no statistical differences were found between parents (DDC) and parents (NDC), but it seems clear that parents of a developmentally disabled child have different concerns. Once again, the

variability in parent's perspective is illustrated. A summary of this individual variability and the need for parents to choose is summarized by one mother (DDC): *"We are a single income family at present as I wish to be home with my children. We have to budget and be careful but we have chosen this lifestyle".*

## **#6 Health and Personal Safety**

There are few statistical differences between groups, however parents of a child with a developmental disability provide qualitatively different and varied responses to questions in this domain. Again this is likely related to the variability in individual's perceptions.

When parents were asked about emotional health, there were qualitative differences between groups in their responses given. One mother of a ND child responded by saying, *"There is no doubt I'm frustrated with the role of parenting but I'm finding ways of dealing with that frustration."* Whereas the statements from three of the mothers of a child with a developmental disability appeared considerably more negative. One mother stated that *"I think I feel the demands of the children, especially T., rest mainly with me - It can be draining at times."*, another noted, *"Again - too much stress"*, and a third mother (DDC) reported *"My emotions are very up and down, more so since D. was born and now that he is approaching school. Some days are extremely hard!"*. These mothers (DDC) appeared to have different concerns than mothers of an ND child, that were not illuminated by asking about the importance of an aspect of life or whether their needs were being met.

As suggested previously, in regards to the domains of passive recreation,

active recreation, and occupational role each parent has individual needs and perception of needs. Further, every individual fulfils his/her needs in a different manner. This implies that if support is to be provided to a parent, it should be the specific support that the parent wants if the support to be most effective. For example, only a few mothers (DDC) made statements pertaining to their emotional health. It is these mothers that may benefit the most from some form of emotional support, possibly including individual or group counselling. However, it would be unnecessary and inappropriate to provide counselling support to all mothers of a child with a developmental disability.

When mothers were asked about mental health, a mother of a ND child stated, *"Stress is a major concern these days for everyone."* However, some mothers of a child with a developmental disability responded differently. One mother stated, *"My husband is very helpful and understanding. I can rely on my faith and church friends, and read bible for help. Family is also supportive."* It is very interesting to note that when asked about mental health the parent responded by describing her coping mechanisms. It seems positive that she recognizes where potential difficulties in her life may be and the best way for her to deal with them. These coping mechanisms are reflected in the Conceptual Family Model described by Turnbull and Turnbull (1986). It is further supported by the list of factors that mediate a parents reaction to a disabled child described by Seligman and Darling (1989).

Another example is given by a mother of a child with a developmental disability, who responded to the question on mental health by saying *"These*

*are some emotional times, that 's life".* This illustrates nicely a parent's ability to reframe a situation so that it may be perceived in a positive light.

Other concerns that face parents of a child with a developmental disability are illustrated by two responses given to a question regarding health care. One mother reported that her family *"Have an excellent understanding doctor"*; and another parent explained that *"Our son can't tolerate excess sugar , and no artificial dyes. He is a very picky eater"*. In other words, parents (DDC) may face extra medical issues (Seligman and Darling, 1989), that other parents may not face.

The difference between parents of a child with a developmental disability and a ND child for this domain may be summarized in a statement given by one father of a child with a developmental disability. He stated that, *"Stress from dealing with a sick handicapped child or in just dealing with the necessary day to day requirements in providing his daily needs can often build up over time."*

As discussed previously, this emphasizes the virtue of asking parents for their personal perspective. By looking for information in this manner we find the variability of individuals. The variability is picked-up by the qualitative anecdotal responses that parents gave to different question. Again this indicates how measures of quality of life can be sensitive to personal variability. Parents (DDC) did not necessarily have the same issues or difficulties with the same aspects of life.

Within this domain parents of a child with a developmental disability have made comments pertaining to the emotional stress of a child with a

developmental disability, the use of church as a support to maintain mental health, and specific medical concerns faced by parents (DDC). It is these individual concerns that have implications for those who provide services to parents of a child with a developmental disability. As discussed previously, it is hoped that policy-makers keep these individual concerns in mind when designing services for families (DDC).

#### **#7 Relationship with Spouse**

There were several significant differences between groups in the general domain 'Relationship with Spouse'. Mothers of a ND child indicated that they did not receive the amount of help with household duties from their spouse that they felt was necessary, whereas NDC fathers indicated that they provided adequate help. The same pattern was true in a comparison between mothers and fathers of children with a developmental disability. However, as discussed above, mothers (DDC) appear to have received more help. For example, one stated, *"My husband helps out more with chores concerning R."* and another said *"Husband is very helpful."* This is consistent with the question pertaining to housework discussed above. This is also consistent with the literature which states that mothers of a child with a developmental disability are involved in most household tasks but that they do receive more help, particularly from fathers (Byrne and Cunningham, 1988), than do mothers in other groups. It is important to note that similar findings are being recorded from different countries in the western world. This result perhaps, reflects the gender difference present in our society where mothers perform the majority of



household duties. This result also provides further support for the contention that parents (DDC) who have adapted well to their child with a developmental disability child, may have adjusted their family behaviour to more traditional male and female roles.

Although there was no statistical difference, three parents (DDC) made statements indicating that they were somewhat dissatisfied with the time they spend with their spouse. One mother (DDC) noted *"We don't spend as much time alone as I would like."*, a second parent explained *"We don't get away as much as we would like by ourselves."* and a third parent felt that *"Very little time is available"*. As discussed previously, this may be another example of the sensitivity of the questionnaire to inter-personal variability within the group. A statistical difference was seen between mothers and fathers of an ND child for the question pertaining to spending time alone with their spouse. More fathers (NDC) than mothers felt that their needs were not being met. This was not true for parents of a child with a developmental disability. It might be expected that parents (DDC) would have less time to spend alone with their spouse, and, hence, that their needs would not be met.

Lastly, more mothers (DDC) than mothers (NDC) were dissatisfied with the way that their companionship needs were met. The dissatisfaction may be related to the time necessary to take care of the special needs of a developmentally disabled child. In other words, if a great deal of time is taken up with child care it would be difficult to find time to dedicate to a relationship.

It is important to note that parents in the study only came from intact

families. As seen in the literature review some authors had reported that the presence of a child with a developmental disability is likely to put stress on the relationship between the parents. Further to this, Friedrich (1979) reports that marital satisfaction was the best predictor of coping in families with a handicapped child. Since only intact marriages were involved in the study, it is less likely that a distressed relationship would be found.

#### **#8 Having and Raising Children**

Only one statistical difference was found for the category "Having and Raising Children". For the overall category, fathers (DDC) rated their overall needs being met as low compared with fathers of ND children. This result is probably explained by fathers (DDC) being dissatisfied with their role in having children, given the special needs of their child. However, very few negative statements were made by DDC parents in regards to their children. One father stated, *"We love and enjoy our children, including our special needs son."* Most of the statements involved the time available to spend with family. One father stated, *"Not always enough time in the day to spend the amount of time I would like to spend with them."*

A great deal of the anecdotal information indicated that mothers (DDC) felt that their needs were not being met when compared to mothers (NDC). This would be consistent with what has been stated in the literature review which indicates that the presences of a developmentally disabled child affects mothers more than fathers (Byrne & Cunningham, 1988). A statistical analysis of questions in this domain did not indicate that differences existed between

mothers and fathers of children with developmental disabilities. However, four mothers (DDC) made a number of statements that indicated their needs were not met. It was reported by one mother that, *"Again - the extra time my son requires detracts from the time I'd be spending with his siblings ."*, a second mother (DDC) explained *"I have been frustrated and sad at times about T.'s development - but try to remain positive. I have the hardest time around children of his chronological age."*, a third mother reported *"A. eats with mouth open" "Drooling bugs mom" "I don't like A. hugging people with drool."*, and, lastly, a fourth mother (DDC) explained *"Wanted to wait until A. was older so he could walk before having another. Would have had 3 by now instead of 2."*

These statements suggest issues that affect the quality of life of a mother of a child with a developmental disability. Further, not every parent faces the same issues within this domain. For example, not every mother has a child that drools. This, again illustrates how important the assessment of inter-personal variability is to any discussion of quality of life.

### **#9 Relationships with Other Relatives**

Again there were only a few statistical differences in this domain, however a great deal of information about individual problems faced by parents (DDC) was found. Parents (DDC) when compared with parents (NDC) indicated that their needs were not met for both the help they were able to give or receive from relatives. The amount of social support available from the extended family is seen as a predictor of the family homogeneity and cohesiveness (Bristell, 1984). Further, Turnbull and Turnbull (1986) and

Mitchell (1986) both indicated extended family size as related to a family's adaptability to the presences of a disabled child. Three parents (DDC) made comments that they depended on their extended family. One father reported "*They are usually the ones that help me.*", another noted "*They are there if we need them.*", and one mother noted "*My family are very supportive*". Parents (DDC) seem more likely to depend on the resources of their extended family and, hence, are more likely to feel that their needs are not being met if they do not receive this support.

This implies that those parents (DDC) that have fewer natural external supports are more likely to face problems. Therefore, it may be best to provide support services to those families that have fewer natural supports. In other words, some families would benefit more than others from services such as day-care during holidays, financial support, babysitting, and help with transportation (Byrne and Cunningham, 1988). Hence, it is more effective to provide greater support to those families for which there would be the greatest benefit. Other areas that families could benefit from include counselling and other professional services, such as behavioural support.

Families (DDC) face concerns related to their extended family not shared by families (NDC). Although, families (DDC) may be accepting and have adapted to the presence of their child with a developmental disability this does not necessarily mean that their relatives have accepted their child's disability. This was commented upon by two of the parents (DDC). One father explained "*My son's paternal grandparents and some aunts and uncles have*

*never come to terms with his disabilities.”* and a mother noted *“Family ignores our child and offers no support at all.”* These views clearly have implications not only in regards the natural supports available from the extended family, but to the emotional well-being of the parents (DDC) and, hence, to their quality of life.

Further, considering the unique time constraints that families of a child with a developmental disability face, it seems likely that they would be dissatisfied with the amount of help they are able to give to extended relatives. One mother made a comment that reflected this. *“Don’t get to help grandparents with garden because they end up watching A.” “Then grandparents have to baby-sit A.”*

These issues that are particularly faced by parents of a child with a developmental disability have far reaching implications. As discussed above, it is possible there is a relationship between success in the family and the amount of support available. However, each family does not necessarily have the same needs, in terms of support. Perhaps the best model of service delivery would be for the parents (DDC) to have the ability to decide how much support they need and in which areas. One family may not need any help because they have a large and supportive extended family, whereas another family may require a great deal of support because their relatives have not accepted the child with a developmental disability. Lastly, the domain of a families relationship with extended relatives provides further evidence for the need for assessing quality of life issues through subjective means.

This is consistent with the view of many authors. Part of the rationale

behind subjective measures of quality of life is that the term refers to the way in which individual's see their own lives (Parmenter, 1988). Parmenter's (1988) model of quality of life for people with disabilities is composed of three components, including an individual's perception of self. It is possible that this component of Parmenter's may be transferred to parents of children with developmental disabilities. With this in mind it seems important that any model of quality of life for parents of individuals with developmental disabilities should include a component that assesses the parent's subjective view point. It is this personal perspective that provides information to service providers, pertaining to each families individual problems and needs.

#### **#10 Relations with Friends**

Fathers (DDC), when compared with the mothers, felt that their needs were not being met for "Having Close Friends". Mothers have the opportunity to establish a network of friends through schools, daycare, and parents groups, whereas fathers are more likely to be at work. For example, one mother stated, *"All my friends are through having children or church."*

Abbey and Andrews (1986) stated that social support is a direct predictor of positive adaptability and other psycho-social factors. In other words, parents (DDC) may not have as strong social support network as NDC parents. This may be supported by comments made by three parents (DDC). One mother noted *"I feel that our friends are very supportive but I can't think of any that I am totally relaxed about T."*, a second explained *"I am somewhat conscious of T.'s behaviour around our friends."*, and a third mother (DDC) responded by saying

*"Only a few (friends) can I call round to see on a spur of the moment due to the house not being A. proof."* It is also interesting to note that no differences were seen between the two groups of parents. In other words, the need for close friends appears to be well met for NDC parents. Once again, these findings provide added support for the contention that an individual's perspective is very important in regards to the amount and type of services they are provided.

Although further in-depth research should be done, it is clear that the amount of support a family receives from governments and agencies would be dependent on the natural support structures in place. This presents a different dilemma. Do parents of a child with a developmental disability have fewer friendship supports because they are unable to get out? If this is the case, the implication is that families may need greater artificial support in order for them to develop the natural supports they may need.

### **#11 Activities Related to Helping and Encouraging Others**

There were several qualitative differences found between groups of parents for this domain. Parents (DDC) appeared no more likely than parents (NDC) to participate in "helping" groups or agencies, however, the choice of groups appeared to be different. NDC parents helped in organizations such as church, school, Shriner's and Mason's. In contrast, parents of a child with a developmental disability were involved in organizations such as parents support and advisory group for children with developmental disabilities and the Canadian Association for William's Syndrome. In other words, they involved themselves with groups involving their child's disability. Parents (DDC) may

meet some of their individual needs by seeking out groups specific to children with developmental disabilities that provide social support networking. This implies once again that to meet the needs of parents (DDC) it may not be necessary to provide formal counselling support if natural support groups exist. How the use of parent groups affects the functioning of families is an interesting research question.

### **#12 Activities Related to Local or National Governments**

More mothers (DDC) than NDC mothers felt that their needs were not being met in terms of keeping informed through the media. Again, time and energy differences between groups may be relevant. As mothers (DDC) have greater time commitments to child care, they would be less able to dedicate energies to other activities. One mother summarized this by saying, *"Not enough time to read, listen to news reports, etc...."*

Due to the nature of receiving services from the government for their developmentally disabled child, parents (DDC) may have a slightly different view of governments by virtue of the need to lobby for services. For example, one mother stated, *"Politics of the school system. Fighting to keep the physiotherapist and the occupational therapist in the school."* In other words, parents (DDC) may be involved with government agencies more than other parents. Further, legislative decisions may have a greater impact on parents of a child with a developmental disability. For example, political decisions in regards to which programs for children with developmental disabilities to fund may directly impact families (DDC). One conclusion of this study is that



programs that provide support to parents (DDC) should be maintained or increased, as they appear to help prevent marital upset. It will also be concluded that the method for service delivery should also be adapted. Decisions regarding how and when support is to be provided should be based on the subjective perspective of each individual family, and , therefore, will be highly varied.

### **#13 Intellectual Development**

Several statistically significant results were found for the domain of Intellectual Development. Several trends appeared that seem to be related to the amount of education that a parent has received. Mothers (DDC) had significantly less education than did NDC mothers. This possibly explains why more mothers (DDC) than NDC mothers reported that their needs were not being met for the question attending school. This is reflected by statements made by two mothers (DDC). One explained "*I would like to go back to school*", and a second mother (DDC) reported "*I plan to return to school in September, but I will be very limited in how many classes I can attend because of finding adequate care for my son.*" Similarly, mothers of a child with a developmental disability rated the importance of "Attending School" higher than did fathers.

Mothers (DDC) also reported that their needs were also not met for the question "Overall Intellectual Development". The results may be attributed to mothers (DDC) having the least education. They may have less education because they felt that it was more important to care for their child with a developmental disability, than to further their education.

This result, again, appears to reflect the balance of time and energy available for each life domain discussed earlier. Mothers (DDC) have only so many resources to allocate to caring for their child with a developmental disability, therefore time and energy can not be devoted to other areas. Mothers (DDC) seem to choose to not go to school.

NDC fathers rated "Attending School" as more important than did fathers (DDC). Similarly, it was also shown that fathers (DDC) were less likely than both mothers (DDC) and NDC fathers to rate all questions related to intellectual development as important. More fathers of ND children than children with a developmental disability rated their needs as being met for questions relating to intellectual development.

Fathers (DDC) felt that education was less important and that their needs were not being met. However, fathers (DDC) do not have significantly less education than NDC fathers. There is at least one possible explanation for this result. Perhaps, fathers (DDC) may, at some time in the future, wish to further their education but this is not a priority at this time. Two fathers (DDC) made comments that reflected this. One stated *"Have already attended and completed a university degree so I don't have a desire for attending school at this time."* and another father reported *"I would like some formal classes at this point but it is not a priority right now."* In other words, DDC fathers have placed priorities on differently life domains. This may also be consistent with the family functioning model (Turnbull and Turnbull, 1986). The result of mediating effects such as the child's disability, and the stage the family is at in the life cycle may

be the inability to continue schooling. This may be the same effect described above in regards to mothers (DDC).

The results of this investigation appear to indicate that the domain of intellectual development presents a number of issues for parents of children with developmental disabilities. The literature review was unclear in revealing whether parents educational status was related to the ability to adjust to the presence of a family member with a handicap. One study by Kendall and Calman (1964) indicated that education was not related to adjustment, however, a more recent study (Byrne and Cunningham, 1988) indicated that it was inversely correlated with stress. This study appears to support the latter. Although stress was not an outcome measure in this exploration, this study indicates that the parent's (DDC) needs for intellectual development were not being met. The unmet need for education is likely to be an issue for parents (DDC) and, hence, may produce difficulties including stress. Therefore, the provision of support services such as daycare or respite care, may allow parents (DDC) to meet their educational needs, reduce any issues pertaining to this domain, and improve their life quality.

#### **#14 Personal Understanding and Planning**

Significantly more fathers (DDC) than NDC fathers rated their needs being met as low for the question "Gaining Purpose for My Life". Further, fathers (DDC) were more likely to report their needs as not being met for the whole domain, when compared with NDC fathers. Lastly, fathers (DDC) were significantly more likely to rate questions pertaining "Personal Understanding

and Planning” as less important than mothers (DDC).

The explanation for these results is unclear. Perhaps, fathers (DDC) may have planned to have a family, and to focus upon a career, but this was interrupted by the birth of a developmentally disabled child. Therefore they were required to reframe their life plans and redevelop a self-concept that involved a care-giving role for a developmentally disabled child. This is supported by one father (DDC) who stated that *“My purpose in life at the moment is to support my family, on a one-day-at-a-time basis”*.

This difference may not appear for mothers (DDC) because the presence of a child with a developmental disability may not have interrupted their life as much as fathers. For example, if mothers had envisioned themselves as caring for a child, their perception has not changed that much to provide care for a child with a developmental disability.

The difference in the perceptions of personal understanding between mothers and fathers has practical implications for the counselling field and other professions. It seems clear that the presence of a child with a developmental disability may have greater effects on the life plans of fathers (DDC) than on those of mothers (DDC). Services need to account for these differences.

### **#15 Creativity and Personal Expression**

No differences were found between groups for this domain.

### **Quality of Life Questions**

Several differences were found between groups of parents reporting a domain as influencing their quality of life. It is interesting that different groups

do not necessarily list the same domains as making them satisfied with their quality of life. For the majority of the domains, no difference was found between groups of parents listing a domain as making them satisfied with their quality of life. As discussed previously, variability appears to be an important component pertaining to the individual life quality of parents (DDC). The questions that asked parents which domains directly influenced their quality of life clearly reflect this variability. This is particularly evident when parents were asked which life domains detracted from their quality of life.

Fathers (DDC) were more likely than both NDC fathers and mothers (DDC) to list "Passive Recreation" as making them satisfied with their quality of life. NDC fathers, more than any other group, were likely to report that "Occupational Role" makes them satisfied with their quality of life at the present time. This is likely explained in terms of life choices fathers (DDC) have made. Fathers (DDC) may have re-evaluated the importance of work in their lives, and now feel that it is more important to focus on recreation. Statements that were made by fathers (DDC) that are not mirrored by any other group. One father (DDC) noted *"Enough time spent on relaxing type of activities"* and another father reported *"I relax when I'm reading"*. Perhaps one of the coping mechanisms used by fathers (DDC) includes relaxing through the use of passive recreations activities.

For the majority of the domains there were no difference between NDC parents and parents (DDC). As seen in Table 10, the majority of parents in both groups had selected the domains (#7) Close Relationship with Spouse and (#8)

Having and Raising Children as making them satisfied with their quality of life at the present time. Further, it is interesting to note that domains such as (#11) Helping and Encouraging Others, (#12) Activities Relating to Local and National Governments, (#14) Personal Understanding and Planning, and (#15) Creativity and Personal Expression were rarely selected by either group. It is interesting that regardless of the presence of a child with a developmental disability, families lives appeared to be satisfied by the same issues.

As seen above, a consistent pattern seemed to emerge when parents were asked to list those domains that contributed to satisfaction. However, asking which domains detracted from their satisfaction, did not result in as clear a pattern (see Table 11). It appears those aspects of life that make a person 'dissatisfied' may be somewhat individual.

Fathers (DDC) were more likely than mothers (DDC) to chose Occupational Role as detracting from their satisfaction with their quality of life. Similarly, NDC mothers were more likely than mothers (DDC) to report that Occupational Role detracts with their satisfaction with their quality of life. This is consistent with the discussion above under the heading Occupational Role. For example, one NDC mother stated *"I would enjoy the satisfaction of a good job"*. As discussed above fathers (DDC) may be likely to be dissatisfied with their occupational role because they had to sacrifice their work to dedicate time to their child with a developmental disability.

Parents were also asked to list the domains upon which their children have had a positive effect. More NDC fathers than any other group selected

Participation in Active Recreation as having been positively influenced by the presence of their children. Fathers are likely to be given the role of taking the children out of the home. This is reflected with statements from two fathers. One stated *"I spend a lot of my spare time playing or going to movies with my kids"*, and the other noted *"Children have allowed me to participate in many recreational activities and to be able to teach skills to them"*. The difference between NDC and DDC fathers is much greater than the difference between NDC fathers and mothers. There are at least two explanations for this result. Fathers (DDC) may be unable to participate in active pursuits due to their child's disability, or they may be simply too tired. This may again reflect the delicate balance of resources, such as time and energy, faced by parents (DDC).

A statistical difference was also seen for the domain "Socializing". NDC mothers were more likely than NDC fathers and mothers (DDC) to report that their children had positively affected their socializing. Mothers of NDC children, as discussed above, may have a broader social network through the schools, church, parent groups and daycare situations. Four mothers made similar comments. One said she has *"Met many people and done many activities as a result of having children"*, similarly another mother reported *"Our children's activities have led us to meet new and interesting people"*, a third mother stated *"My children have ... created a different network of relationships for me through their developmental phases"*, and fourth mother reported *"Have met more people through kids. Have developed many close friends vis a vis kids school"*. Whereas fathers may only meet people through work.

As seen in Table 12, little difference appears across the rest of the domains for the different groups of parents. This may indicate that families (DDC) and NDC families may perceive similar positive effects of their children across the domains. Additionally, this may be a further indication of the variability picked-up by asking for individual perspectives.

When parents were asked to list the domains that their children had a negative effect upon, no statistically significant results appeared (refer to Table 12). Once again DDC and NDC parents appear to be quite similar. It is important to note that there was not one specific dominant area that was said to provided difficulties for parents of children with developmental disabilities. This reinforces the contention that the perception of need is very individual.



## **Conclusions**

A discussion of the results of the analysis of the 61 questionnaires that were returned has lead to several conclusions and recommendations. It was clear that including fathers in the study was invaluable. Fathers (DDC) differed from fathers of a child without a developmental disability in areas such as perceptions of work, family and active recreation. It was also found that fathers of a child with a developmental disability were viewed as a major support for their spouse. Fathers are rarely involved as subjects in research, but it is extremely important that any future research in families of a child with a developmental disability include them.

The study also showed gender differences between parents. The unmet needs of fathers of a child with a developmental disability are not necessarily the same as their spouses. For example, it appears that fathers (DDC) had more needs in the domain of personal understanding and planning, than did their spouses. The required support for fathers is not necessarily the same as that needed by mothers of a child with a developmental disability. The above type of information is relevant to professionals helping families to support their offspring with disabilities. For example, based on the information described above, counsellors may be able to design support that was specific to a father who had issues relating to his child and his own personal understanding.

Byrne and Cunningham (1988) state that widely felt needs for support by parents of a child with a developmental disability include: daycare, babysitting services, financial support and aid with transportation. However, not every

family has the same need for such formalized interventions. For example, one family may need only a few hours of support so they may shop, while another family may need a great deal of respite. Further, there are families that may not require formal support whatsoever. They may have natural supports in their environment such as emotionally supportive friends and family. Other natural supports that may be available to families of a child with a developmental disability include parent support groups and associations. The present investigation appears to indicate that associations for persons with developmental disabilities were utilized by families of a child with developmental disabilities. Practitioners must assess each individual family's need for support, to find the most effective and efficient method of service delivery for that family.

A family's ability to adapt may be related to the perceived roles of mothers and fathers in a family. It appears that parents of a child with a developmental disability may not have the same views as parents of a child without a developmental disability. Fathers (DDC) in this study were more involved in child-care and household duties, while their spouses seemed to have modified their goals for further education or pursuit of a career. These are some of the ways their function as a family appears more traditional. Further study of this aspect is necessary.

It was also concluded that the use of subjective assessment of quality of life provided a great deal of information that would not have been found using strictly objective measures. Asking people for their individual perspectives on

aspects of their life resulted in subjective personal information as well as indicating intra-group variability. In addition, the anecdotal information that was collected had considerable explanatory value, as well as illustrating individual differences between parents. Individual variability is important when studying quality of life, and enhances detail in interpretation of a family's perceived actions and needs. That which may be important to one person's quality of life is not necessarily identical to that which is central to the quality of life of others. For example, it would be inappropriate to make decisions that affect families of a child with a developmental disability simply because they have a shared concern (a child with a developmental disability) with other families. The individual need for support provides an interesting dynamic which must be examined before developing specific interventions for any particular family. It has been long argued that interventions for persons with developmental disabilities should be individualized for their particular needs. This is the basis for concepts such as Individualized Education Plans (IEP) or Individual Program Plans (IPP). The same rationale should be applied to services provided to families of children with developmental disabilities. Individualized service plans could also provide professionals with an effective and efficient method of delivering services to families and meeting their idiosyncratic needs.

As discussed previously, the contention that individual needs should be the cornerstone of support services has implications pertaining to the mode of service delivery to families of a child with a developmental disability. Thus instead of services being provided in a 'top-down' manner with decisions on

types of support being made by government departments, the majority of the decision-making should lie in the hands of those who receive the services. It is the families who receive service that best know what their needs are and how to best meet those needs. Although further research may be necessary to elaborate on this conclusion, it is clear that the findings of this study support the view that an individual's subjective perception is important in determining what is critical to an individual's quality of life, and how to meet those needs in areas where quality of life is wanting.

As discussed previously, Parmenter (1988) put forth a three component model of quality of life for individuals of developmental disabilities. He suggests that one component of quality of life for persons with a developmental disability is a recognition of the individual's perception of self. The present study has suggested that individual variability and perception is directly related to the quality of life of a parent of a child with a developmental disability. This perception is also directly related to perceived needs for support. Therefore, much like Parmenter (1988), any model that describes quality of life for parents of a child with a developmental disability must incorporate individual perceptions. Individual perception would be only one possible component of a model of quality of life for parents with a developmental disability. Further research would be necessary to provide a more wholistic model.

The overall results of this exploration also support a family systems model. The differences between parents (NDC) and parents (DDC) parallel and support Turnbull and Turnbull's (1986) framework for a conceptual family

system. Several factors such as income level, education, marital cohesion, developmental life stage, degree of handicap and social support were all issues that were repeatedly reported by families (DDC) as influencing their lives. Every aspect of a parent's life is intrinsically related to other aspects of their life. For a family, the birth of a child with a developmental disability may affect decisions made in regard to the parents own education or occupation. Such decisions affect family income, with resulting impact on material belongings, or the financial feasibility of recreation opportunities. These are all mediated by factors such as the severity of the child's disability or the amount of support available from family or friends. But the specific way a child impacts upon a family depends on the interests, needs and choices of each individual. This is why it is difficult to predict group outcomes and why individual assessment and interpretation of specific perceptions are necessary.

Many of the issues raised by this study were in the areas of economics, domestic/health care, recreation, socialization, education and vocation. It is important to note that these areas mirror many of the aspects of a family with a child with a developmental disability, as proposed by Turnbull and Turnbull (1986). The results of this study viewed from a family systems framework leads to the conclusion that families have considerable adaptive capacity. A great deal of literature views the child with a developmental disability as a stressor, however, the results presented here make it clear that families can do very well despite the presence of child with a developmental disability. Many families do not see themselves as different, but rather as "normal" for themselves. Indeed

the statistical results showed few differences in the perceptions of a parent's needs between the two family groups. However, one caution is in order. It should be noted that only intact families were examined. Families may have been more likely to remain intact and participate in the study because they received the support needed. Therefore, the support governments and agencies provide to parents (DDC) may be effective in helping the family remain intact, and this suggests that carefully focussed support delivered to parents (DDC) may be financially cost-effective and viable.

Maintaining individual's with developmental disabilities within the community, especially with their own families, has been a focus in recent years for those who design programs for persons with developmental disabilities. The present investigation provides support for the contention that children with developmental disabilities can be supported effectively by families within their community. It has been shown that not all families of a child with a developmental disability become dysfunctional, but that there are many positives associated with such families. However, this conclusion should be presented with one caveat. It appears that support services such as effective baby-sitting, respite and the like, seemed to be considered important and may be necessary for the family to remain viable. Therefore, if community programs involving parents are to be effective, it seems critical, as suggested by this research, that appropriate individualized support services be provided to parents of a child with a developmental disability.

### **Implications for Parents, Practitioners and Policy-makers**

The discussion presented above leads to several conclusions, which may have many broader implications than the scope of this study. It should be noted that a danger exists in providing any generalizations to the larger population based on the small sample size involved in the present study. Further as this investigation was exploratory in nature, practical strategies should only be suggested. If specific suggestions are to be provided further research should be undertaken. However, this exploration may suggest five global implications for practice. They are:

- 1) Parents of a child with a developmental disability have a need for support, whether formal or informal. Formal support may include counselling, psychological services such as behavioural consultations, financial aid, the provision of respite or daycare, or baby-sitting services. Informal support may involve help in terms of child-care, emotional support from family and friends, or information dissemination through parent support groups.
- 2) Any support that is given should recognize needs as perceived by the individual parent. Only each individual parent knows and understands what his/her needs are, and how to meet those needs.
- 3) Subjective assessment, as in quality of life studies, provides personalized information which is critical for interpretation of

needs. Therefore, any assessment of needs must utilize an individual's subjective perception. This may require an in-depth interview. Individualized assessment would have specific implications for the field of counselling. An assessment technique that provides counsellors with areas of need for each individual would be invaluable in designing individualized interventions. Further, practitioners providing community support services to families would be able to address the specific needs of each family.

- 4) Fathers may have a different view of their quality of life than mothers. This must be taken into account when providing service to parents of a child with a developmental disability.
- 5) Families work as a system. Support provided to an individual in the system affects more than just the individual. For example, providing a few hours of daycare to the child may allow the mother or father to make changes in regard to their education or vocation, which in turn, impacts the family economics and so on. This implies that any support may have far reaching effects, which have implications for the quality of life of the family, and the family's health, economic structure and possibly it's viability.

### **Recommendations for Future Study**

The present exploratory study illustrated many issues worth further investigation. Based on the results it would appear that there is a need to



compare intact families of a child with a developmental disability with pairs of parents of a child with a developmental disability who have separated. A number of conclusions from this study lead to hypotheses regarding maintaining the integrity of families of a child with a developmental disability. The results, while possibly relevant to intact families, may only illustrate factors where the family is coping with stress and has turned difficulties into advantages. Successful families may provide practical information or advice for newer families with a child with a developmental disability. It would be interesting to study the differences between families that remained intact with those that separated to determine what enabled some families to remain together. This may either prove or disprove the "do-or-die" hypothesis suggested earlier. Further, it would be important, especially in the disassembled family, to examine the fathers needs.

Similarly, the results of this study clearly illustrate that any future work should include fathers. More studies should be undertaken that explore gender differences between mothers and fathers of a child with a developmental disability. It was clear from the results that issues that present themselves to fathers are often quite different than those that mothers face. As suggested previously, a study of the views towards male and female roles of parents of a child with a developmental disability may also provide some interesting insights.

It seems very important to assess both positive and negative effects of a child with a developmental disability on both parents. Past literature has

focussed primarily upon the negative impacts of a child with a developmental disability and any possible familial dysfunction. However, as the present investigation has suggested, families do not necessarily feel that a child with a developmental disability has negative impacts upon the family, but that there are, in fact, many benefits. An investigation that focusses only upon negative outcomes is likely to uncover information on negative issues. Therefore, it would be worthwhile assessing parent's lives using a quality of life model. Quality of life as an outcome measure is rapidly becoming a valuable tool as it focusses on individual needs and perception of need from a subjective perspective. The questionnaire used in this study appears to be an appropriate tool in examining people's subjective impressions.

This tool could also be used in a similar manner to study differences between many different age groups, or a variety of disabilities amongst children. For example, this questionnaire, or a similar questionnaire, could be used to study the difference between families with children with a variety of disabilities such as cerebral palsy or cystic fibrosis. Further, the age range could be expanded greatly to focus upon adolescent children with developmental disabilities, adult children with developmental disabilities living at home or even the effect of elderly people with developmental disabilities on their families.

### **Limitations of Present Study**

The present study had three primary limitations: 1) a smaller than anticipated sample size; 2) biases in the sampling of both groups; and 3)

differences between the two groups may be explained by differences in education and income levels. Sample size was not problematic because the study was exploratory in nature and the statistics employed were recommended for use with small samples.

Further, sampling biases were unavoidable. The results also indicated that biases may not have been overly influential to the study. Group differences appeared that were similar to those previously described in the literature. This may indicate that biases in the sampling were not critical.

Lastly, it may be argued that group differences may be attributed to income and education. However, it also may be argued that the differences in education and income are related to the presence of a child with a developmental disability within an active and ever-changing family system.

It is important to note that with these limitations, any conclusions need to be drawn with caution. However, the information gained from a study such as this may be invaluable and are essential, since families can not be studied in the closed and controlled confines of the laboratory.

### **Summary**

The purpose of the present study was to explore the effects, both positive and negative, of a child with a developmental disability on his/her parents, in contrast to parents of a child without a developmental disability. Historically, the effects of a child with a developmental disability has been viewed from a largely negative perspective, focusing on issues such as depression or anxiety (Abbey and Andrews, 1986). Unlike these traditional perspectives, the quality

of life model in this study focused on both positive as well as negative aspects of a parents' life. Parents were also asked for their own subjective perspective on aspects of their lives. Lastly, one major purpose of this study was to gather information from fathers, who have, to date, been neglected in the majority of the literature.

The exploration of these areas was fruitful in both uncovering a great deal of statistically significant differences between groups, and providing many varied questions for future study. A discussion of the results clearly indicated the utility of studying fathers and the usefulness of a subjective measure of quality of life.

In conclusion, a parent's quality of life is best assessed from an individual subjective and personal perspective. Intra-group variability that was recorded lead to the conclusion that support should be provided on a case-by-case basis. Finally, it is suggested that supports, such as counselling, respite, day-care or financial aide are an important focus for helping parents of a child with a developmental disability improve or maintain a high quality of life, and, in turn, this has many implications for government and service providers.

### References

- Abbey, A., Abramis, D.J., & Caplan, R.D. (1985). Effects of different sources of social support and social conflict on emotional well-being. Basic and Applied Social Psychology, 6, 111-129.
- Abbey, A. and Andrews, F.M. (1986). Modelling the psychological determinants of life quality. In F. M. Andrews (Ed.), Research on the quality of life (pp.85-116) Ann Arbor, Michigan: Institute for Social Research, The University of Michigan.
- Andrews, F. (1974). Social indicators of perceived life quality. Social Indicators Research, 1, 279-299.
- Bard, M. (1984). Summary of the informal discussion of functional states: Quality of Life. Cancer, 53(10), 2327.
- Bateson, G. (1972). Steps to an ecology of mind. San Francisco: Chandler Publishing Co..
- Beckman, P. J. (1984). A transactional view of stress in families of handicapped children. In M. Lewis (Ed.), Beyond the dyad. (pp. 281-298) New York: Plenum Press.
- Beckman, P.J. (1985). Influence of selected child characteristics on stress in families of handicapped infants. American Journal of Mental Deficiency, 88(2), 150-156.
- Birenbaum, A. (1971). The mentally rtarded child in the home and the family cycle. Journal of Health and Social Behaviour, 12, 55-65.

- Boggs, E. M. (1988). The changing roles of parents - Intergenerational perspectives. In J. L. Matson & A. Marchetti (Eds.), Developmental disabilities: A life-span perspective (pp. 67-87). Toronto:Grune and Stratton.
- Bristol, M.M. (1984). Family resources and successful adaptation to autistic children. In E. Schopler & G. B. Mesibov (Eds.), Issues in autism, Vol. III, The effects of autism on the family (pp.289-310). New York: Plenum.
- Bronfenbrenner, U. (1979). The ecology of human development. Cambridge, MA.: Harvard University Press.
- Brown, R.I. (1988). Quality of life and rehabilitation: An introduction. In R. I. Brown (Ed.), Quality of life for handicapped people. (pp.1-6) New York: Croom Helm.
- Brown, R.I (1989). Changing concepts of disability in developed and developing countries. In R.I. Brown & D. Mitchell. Early intervention studies for young children (pp. 1-18) New York:Chapman and Hall
- Brown, R.I., and Bayer, M.B. (1991). Rehabilitation Personal Questionnaire: A guide to the individuals's quality of life. Calgary: University of Calgary.
- Brown, R. I., Bayer, M.B., MacFarlane, C. (1985). Rehabilitation Program Study, Report to Health and Welfare, Canada (Grant No. 4558-29-4).
- Burden, R.L. (1980). Measuring the effects of stress on the mothers of handicapped infants: Must depression always follow? Child Care, Health, and Development, 6, 111-125.

- Byrne, E.A. and Cunningham C.C. (1985). The effects of mentally handicapped children on families: A conceptual review. Journal of Child Psychology and Psychiatry, 26(6), 847-864.
- Byrne, E. A. & Cunningham, C. C. (1988). Lifestyle and satisfaction in families of children with Down's syndrome. In R.I. Brown (Ed.) Quality of life for handicapped people. (pp.83-110) London:Croom Helm.
- Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine, 38, 330-314.
- Collins-Moore, M.S. (1984) Birth and diagnosis: A family crisis. In M.G. Eisenberg, L.C. Sutkin, & M.A. Jansen (Eds.), Chronic illness and disability through the life span: Effects on self and family (pp. 39-46). New York: Springer.
- Crnic, K, Friedrich, W. & Greenberg, M. (1983). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. American Journal of Mental Deficiency, 88, 125-138.
- Crnic, K.A., Greenberg, M.T., Ragozin, A.S., Robinson, N.M., & Basham, R.B. (1983). Effects of stress and social support on mothers and premature and full-term infants. Child Development, 54, 209-217.
- Cummings, S.T. (1976). The impact of the child's deficiency on the father: A study of fathers of mentally retarded and of chronically ill children. American Journal of Orthopsychiatry, 46(2), 246-255.

- Cummings, S.T., Bayley, B.A. & Rie, H. (1965). Effects of the child's deficiency on the mother: A study of mothers of mentally retarded, chronically ill and neurotic children. American Journal of Orthopsychiatry, 36, 595-608.
- Dean, H. (1988). Multiple instruments for measuring quality of life. In M. Frank-Stromborg (Ed.), Instruments of Clinical Nursing Research (pp97-106). San Mateo, California: Appleton and Lange.
- DeMyer, M.K. (1979). Parents and children in autism. New York: Wiley.
- Denham, M.J. (1983). Assessment of quality of life. In M.J. Denham (Ed.), Care of the long stay elderly patient. London: Croom Helm
- Edgington, E. (1987). Randomization tests (2<sup>nd</sup> ed.). New York: Marcel Dekker, Inc..
- Evans, D.R., Burns, J.E., Robinson, W.E., & Garrett, O.J. (1985). The Quality of Life Questionnaire: A multidimensional measure. American Journal of Community Psychology, 13(3), 305-322.
- Ferrans, C.E. (1990). Quality of life: Conceptual issues. Seminars in Oncological Nursing, 6(4), 248-254.
- Fewell, R. (1986). A handicapped child in the family. In R.R. Fewell & P.F. Vadasy (Eds.), Families of handicapped children, (pp. 3-34). Austin TX.: Pro-Ed.
- Flanagan, J. C. (1978). A research approach to improving our quality of life. American Psychologist, 31, 138-147.
- Flanagan, J.C. (1982). Measurement of quality of life: Current state of the art. Archives of Physical Medical Rehabilitation, 63, 56-59.



- Frank-Stromborg, M. (1984). Selecting an instrument to measure quality of life. Oncology Nursing Forum, 11(5), 88.
- Frank-Stromborg, M. (1988). Single instruments for measuring quality of life. In M. Frank-Stromborg (Ed.), Instruments of Clinical Nursing Research (pp. 79-95). San Mateo, California: Appleton and Lange.
- Friedrich, W.N. (1979). Predictors of the coping behaviour of mothers of handicapped children. Journal of Consulting and Clinical Psychology, 47, 1140-1141.
- Friedrich, W.N. & Friedrich, W.L. (1981). Psychosocial assets of parents of handicapped and nonhandicapped children. American Journal of Mental Deficiency, 85(5), 551-553.
- Friedrich, W.N., Wiltner, L.T., Cohen, D.S. (1985). Coping resources and parenting mentally retarded children. American Journal of Mental Deficiency, 90(2), 130-139.
- Gath, A. (1974). Sibling reactions to mental handicap: A comparison of the brothers and sisters of mongol children. Child Psychology and Psychiatry, 15, 187-198.
- Goode, D. (1988). Quality of life for persons with disabilities: A review and synthesis of the literature. New York: The Mental Retardation Institute and New York Medical College.
- Grossman, H.J. (Ed.) (1983). Classification in mental retardation. Washington: American Association on Mental Deficiency.

- Halpern, A. S., Nave, G., Close, D.W., & Nelson, D. (1986). An empirical analysis of the dimensions of community adjustment for adults with mental retardation. Australian and New Zealand Journal of Developmental Disabilities, 12, 147-157.
- Harris, S.L. (1983). Families of the developmentally disabled: A guide to behavioural intervention. Toronto: Pergamon Press.
- Harris, S.L., Carpenter, L. & Gill, M.J. (1988). The family. In J. L. Matson & A. Marchetti (Eds.), Developmental Disabilities: A life-span perspectives (pp. 47-66). Toronto: Grune and Stratton.
- Havighurst, R.J. (1972). Developmental tasks and education, (3<sup>rd</sup> ed.). New York: David McKay.
- Heisler, V. (1972). A handicapped child in the family: A guide for parents. Grune and Stratton.
- Hewett, S. (1970). The family and the handicapped child. London: Allen and Unwin.
- Holmes, S. & Dickerson, J. (1987). The quality of life: Design and evaluation of a self-assessment instrument for use with cancer patients. International Journal of Nursing Studies, 24(1), 15-24.
- 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.
- Hornby, G. (1989). Parent involvement. In R.I Brown & D. Michell, Early intervention studies for young children.

- ICD-9 (1978). International Classification of Diseases, 9th revision: Clinical modification. Ann Arbor: Commission on Professional and Hospital Activities.
- Irvin, M.A., Kennell, J.H., & Klaus, M.H. (1982). Caring for the parents of an infant with a congenital malformation. In M.H. Klaus & J.H. Kennell (Eds.), Parent-infant bonding (2<sup>nd</sup> ed.). pp.22-125. Baltimore: University Park Press.
- James, T. and Brown, R.I. (1992). Prader-Willi Syndrome. New York: Chapman and Hall Medical.
- Kendall, D.C. & Calman, I.E. (1964). Handicapped children and their families: A survey based on Shroshire and certain other West Midland Counties. Reports to The Carnegie United Kingdom Trust on the problems of 600 handicapped children and their families. Edinburgh: T. & A. Constable Ltd..
- Klein, C. (1977). Coping patterns of parents of deaf-blind children. American Annals of the Deaf, 122, 310-312.
- Landesman, S. (1986). Quality of life and personal life satisfaction: Definition and measurement issues. Mental Retardation, 24(3), 141-143.
- Lonsdale, G. (1978). Family life with a handicapped child: The parents speak. Child: Care, Health and Development, 4, 99-120.
- MacKeith, R. (1973). The feelings and behaviour of parent of handicapped children. Developmental Medicine and Child Neurology, 15, 524-527.

- McKennel, A. C. & Andrews F. M. (1983). Components of perceived life quality. Journal of Community Psychology, 11, 98-110.
- McNemar, Q. (1962). Psychological Statistics (3rd. ed.). New York: John Wiley and Sons, Inc..
- Mercer, J. R. (1973). Labeling the mentally retarded. Berkeley: University of California Press.
- Milbrath, L. W. (1982). A conceptualization and research strategy for the study of ecological aspects of the quality of life, Social Indicators Research, 10, 113-157.
- Miezio, P.M. (1983). Parenting children with disabilities: A professional source for physicians and guide for parents. New York: Marcel Dekker, Inc.
- Minde, K., Hackett, J., Killou, D., & Silver, S. (1972). How they grow up: Forty-one physically handicapped children and their families. American Journal of Psychiatry, 12, 1554-1560.
- Mitchell, D (1985). Guidance needs and counselling of parents of persons with intellectual handicaps. In N.N. Singh and K.M. Wilton (Eds.), Mental retardation in New Zealand (pp.136-156). London: Whitcoulls Publishers.
- Mitchell, D. (1986). A developmental systems approach to planning and evaluation services for persons with handicaps. In R.I. Brown (Ed.), Management and administration of rehabilitation programmes (pp. 126-156). London: Croom Helm.
- Mittler, P. & Mittler, H. (1982). Partnership with parents, Stratford-upon-Avon, National Council for Special Education.

- Mukherjee, R. (1980). On the appraisal of quality of life. In A. Szalai and F. M. Andrews (Eds.), The quality of life. (pp.189-200) London: Sage Publications Ltd..
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. Social Casework, 43, 191-194.
- Pahl, J. & Quine, L. (1984). Families with mentally handicapped children: A study of stress and of service response. Canterbury: Health Services Research Unit, University of Kent.
- Panel on the Quality of American Life. (1980). The quality of American life in the eighties. Washington, DC: U.S. Government Printing Office.
- Paramenter, T. R. (1988). An analysis of the dimensions of quality of life for people with physical disabilities. In R. I. Brown (Ed.), Quality of life for handicapped people. (pp.7-36) London: Croom Helm.
- Parke, R.D. (1981). Fathers. Cambridge, MA.: Harvard University Press.
- Patterson, J.M., & McCubbin, H.I. (1983). Chronic illness: Family stress and coping. In C. R. Figley & H. I. McCubbin (Eds.), Stress and the family. Vol. II: Coping with catastrophe. (pp. 17-25). New York: Brunner/Mazel.
- Paul, J.L. & Beckman-Bell, P. (1981). Parent perspectives. In J.L. Paul (Ed.), Understanding and working with parents of children with special needs. (pp. 119-153). Toronto: Holt, Rinehart, and Winston.
- Paul, J.L. & Porter, P.B. (1981). Parents of handicapped children. In J.L. Paul (Ed.), Understanding and working with parents of children with special needs. (pp.1-22) Toronto:Holt, Rinehart and Winston.

- Rabkin, J.G. & Streuning, E.L. (1976). Life events, stress, and illness. Science, 194(3) 1013-1020.
- Sameroff, A.J. & Chandler, M.J. (1975). Reproductive risk and the continuum of caretaking casualty. In F.D. Horowitz (ed.), Review of Child Development Research (Vol.4) (pp. 75-91). Chicago: University of Chicago Press.
- Sattler, J. (1988). Assessment of children. San Diego: Jerome M. Sattler, Publisher.
- Scheer, L. (1980). Experience with quality of life comparisons. In A. Szalai and F. M. Andrews (Eds.), The quality of life. London: Sage Publications LTD..
- Schipper, H. (1983). Why measure quality of life. Canadian Medical Association Journal, 128, 1367-1370.
- Schneider, M. (1976). The "quality of life" and social indicators research. Public Administration Review, 8, 297-305.
- Seligman, M. & Darling, R.B. (1989). Ordinary families. special children: A systems approach to childhood disability. New York: The Guilford Press.
- Siegel, S. & Castellan, N.J. (1988). Non-parametric statistics for the behavioural sciences. (2nd. ed.). Toronto: McGraw-Hill, Inc..
- Simeonsson, R.J. & Simeonsson, N.E. (1981). Parenting handicapped children: Psychological aspects. In J.L. Paul (Ed.) Understanding and working with parents of children with special needs. (pp.51-88) Toronto: Holt, Rinehart and Winston.

- Singh, N.N. & Wilton, K.M. (1985). Mental retardation: A New Zealand perspective. In N.N. Singh & K.M. Wilton (1985), Mental retardation in New Zealand (pp. 11-18). London: Whitcoulls Publishers.
- Szalai, A. (1980). The meaning of comparative research on the quality of life. In A. Szalai and F. M. Andrews (Eds), The quality of life. (pp.7-24) London: SAGE Publications Ltd..
- Tavormina, J.B., Boll, T.L., Luscomb, R.L. & Taylor, J.R. (1981). Psychosocial effects on parents of raising a physically handicapped child. Journal of Abnormal Child Psychology, 9, 121-131.
- Travis, G. (1976). Chronic illness: Its impact on child and family. Stanford, California: Stanford University Press.
- Turnbull, A.P. & Turnbull III, H.R. (1986). Families, professionals, and exceptionality: A special partnership. Columbus, Ohio: Merrill.
- Turnbull, A.P., Summers, J.A., & Brotherson, M.J. (1986). Family life-cycle: Theoretical and empirical implications and future directions for families with mentally retarded members. Columbus, Ohio: Merrill.
- Weisgerber, R. A. (1991). Quality of life for persons with disabilities. Gaithersburg, Maryland: Aspen Publishers, Inc..
- Wikler, L. (1981). Chronic stresses. Family Relations, April, 19, 121-140.
- Wilken, D. (1979). Caring for the mentally handicapped child. New York: Croom Helm.
- World Health Organization (1980). International classification of impairments, disabilities and handicaps. WHO, Geneva.

- Zautra, A. & Goodhart, D. (1979). Quality of life indicators: A review of the literature. Community Mental Health Review, 4(1), 1-10.
- Zautra, A. & Reich, J. (1983). Life events and perceptions of life quality: Developments in a two-factor approach. Journal of Community Psychology, 11, 121-131.
- Zola, I. K, (1983). Defining Independence. In D. G. Tate & L. M. Chadderdon (Eds.) International perspectives about independent living. (pp. 115-140).Michigan State University: University Centre for International Rehabilitation.



**Appendix A**  
**Quality of Life Questionnaire**

**Quality of Life  
Questionnaire**

**Confidential**

Thank you for agreeing to participate in a study on the Quality of Life in Families with Children with Disabilities. The intent of this study is to determine how the presence of a child with a disability may affect the Quality of Life of those around him/her.

This study has two groups, of which you and your spouse belong to one. The two groups are: families with a child with a mental handicap; and families who have a child with no disabilities. The questions being asked are for you, the parents, about your lives, and are not about your children.

In terms of participation you will be asked to complete the following questionnaire. Each question in the questionnaire will ask you to rate an aspect of your life, on how "important" that aspect of your life is to you, and whether or not needs associated with this aspect of your life, are being met. To make this clear, a sample question has been provided.

**Sample question:**

	Very High	High	Moderate	Low	Very Low
<b>Listening to Music</b>					
Importance:	1	2	3	4	5
Needs Being Met	1	2	3	4	5

If listening to music is very important to you, then you would circle the "1" (Very High), however, if you do not like to listen to music then you would circle the "5" (Very Low). Similarly, if you like listening to music, but you do not have access to a radio or a stereo, then your needs are not being very well met, so you would circle the "5" (Very Low). On the other hand, if you had easy access to music, you would circle the "1" (Very High) because your needs were being well met.

You may also feel the need to justify your response. Therefore, you are also asked to explain your answer. Please, describe why you answered the way you did if you feel it is relevant.

If you have any questions about the questionnaire please ask the researcher, and he will be happy to answer your questions. Please complete the questionnaire, separate from your spouse.

## Demographic Information

Code \_\_\_\_\_

Date \_\_\_\_\_ Are you the Mother \_\_\_ or Father \_\_\_

Number of Children: \_\_\_\_\_

Age and Gender of Each Child:

<u>Age</u>	<u>Gender</u>
_____	_____
_____	_____
_____	_____
_____	_____

Group You Belong to in the Study:

Child (age 6 to 9 Years) with a Mental Handicap \_\_\_\_\_

Child (age 6 to 9 Years) with no Disability \_\_\_\_\_

Gender of Child between the age of 6 and 9 years: Male \_\_\_ Female \_\_\_

His / Her Birthdate: Day \_\_\_\_\_ Month \_\_\_\_\_ Year \_\_\_\_\_

Your Birthdate: Day \_\_\_\_\_ Month \_\_\_\_\_ Year \_\_\_\_\_

Your Occupation: \_\_\_\_\_

Total Household Income :	\$0 - \$10,000	_____
	\$10,001 - \$20,000	_____
	\$20,001 - \$30,000	_____
	\$30,001 - \$40,000	_____
	\$40,001 - \$50,000	_____
	More than \$50,000	_____

Highest Level of Education:

Less than a High School Diploma \_\_\_\_\_

High School Diploma \_\_\_\_\_

Post-Graduate Diploma \_\_\_\_\_

University Degree \_\_\_\_\_

	Very High	High	Moderate	Low	Very Low
<b>1) <u>Passive and Observational Recreational Activities</u></b>					
<b>a) Watching TV</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>b) Listening to Music</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>c) Reading</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>d) Watching Movies</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>e) Watching Entertainment or Sports Events</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>f) Sleeping</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>g) Other</b>					
Specify: _____					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>h) Overall Passive and Recreational Activities</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

**2) Active and Participatory  
Recreational Activities**

	Very High	High	Moderate	Low	Very Low
<b>a) Participating in Sports</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>b) Hunting</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>c) Camping</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>d) Vacation</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very	High	High	Moderate	Low	Very Low
<b>e) Travel and Sightseeing</b>						
Importance:	1	2	3	4	5	
Needs are Being Met:	1	2	3	4	5	
Explain:						
<b>f) Singing.</b>						
Importance:	1	2	3	4	5	
Needs are Being Met:	1	2	3	4	5	
Explain:						
<b>g) Dancing</b>						
Importance:	1	2	3	4	5	
Needs are Being Met:	1	2	3	4	5	
Explain:						
<b>h) Playing an Instrument</b>						
Importance:	1	2	3	4	5	
Needs are Being Met:	1	2	3	4	5	
Explain:						
<b>i) Cycling</b>						
Importance:	1	2	3	4	5	
Needs are Being Met:	1	2	3	4	5	
Explain:						
<b>j) Exercising</b>						
Importance:	1	2	3	4	5	
Needs are Being Met:	1	2	3	4	5	
Explain:						
<b>k) Other</b>						
Specify: _____						
Importance:	1	2	3	4	5	
Needs are Being Met:	1	2	3	4	5	
Explain:						

	Very High	High	Moderate	Low	Very Low
<b>l) Overall Active and Participatory Sports</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>3) <u>Socializing</u></b>					
<b>a) Entertaining at Home</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>b) Attending Parties or Other Social Gatherings</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>c) Meeting New People</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>d) Participation in Socializing Organizations or Clubs</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>e) Other</b>					
Specify: _____					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					



	Very High	High	Moderate	Low	Very Low
<b>f) Overall Socializing</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>4) <u>Occupational Role (Job)</u></b>					
<b>a) Having Interesting and Challenging Work at Home or Job</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>b) Using My Abilities on the Job</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>c) Obtaining Recognition on the Job</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>d) Accomplishing on the Job</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>e) Housework</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>f) Other</b>					
Specify: _____					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>g) Overall Occupational Role</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>5) Material Well-Being:</b>					
<b>a) Good Food</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>b) Having a Home</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>c) Having Personal Possessions</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>d) Having a Motor Vehicle</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>e) Money</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>f) Financial Security</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>g) Other</b>					
Specify: _____					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>h) Overall Material Well-being</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>6) <u>Health and Personal Safety</u></b>					
<b>a) Freedom from Sickness</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>b) Physical Fitness</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>c) Mental Health</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
--	-----------	------	----------	-----	----------

## d) Emotional Health

Importance:	1	2	3	4	5
-------------	---	---	---	---	---

Needs are Being Met:	1	2	3	4	5
----------------------	---	---	---	---	---

Explain:					
----------	--	--	--	--	--

## e) Freedom From Drug and Alcohol Problems

Importance:	1	2	3	4	5
-------------	---	---	---	---	---

Needs are Being Met:	1	2	3	4	5
----------------------	---	---	---	---	---

Explain:					
----------	--	--	--	--	--

## f) Health Care

Importance:	1	2	3	4	5
-------------	---	---	---	---	---

Needs are Being Met:	1	2	3	4	5
----------------------	---	---	---	---	---

Explain:					
----------	--	--	--	--	--

## g) Other

Specify: \_\_\_\_\_

Importance:	1	2	3	4	5
-------------	---	---	---	---	---

Needs are Being Met:	1	2	3	4	5
----------------------	---	---	---	---	---

Explain:					
----------	--	--	--	--	--

## h) Overall Health and Personal Safety

Importance:	1	2	3	4	5
-------------	---	---	---	---	---

Needs are Being Met:	1	2	3	4	5
----------------------	---	---	---	---	---

Explain:					
----------	--	--	--	--	--

	Very High	High	Moderate	Low	Very Low
--	-----------	------	----------	-----	----------

7) Relations with Spouse

## a) Love

Importance:	1	2	3	4	5
-------------	---	---	---	---	---

Needs are Being Met:	1	2	3	4	5
----------------------	---	---	---	---	---

Explain:					
----------	--	--	--	--	--

## b) Companionship

Importance:	1	2	3	4	5
-------------	---	---	---	---	---

Needs are Being Met:	1	2	3	4	5
----------------------	---	---	---	---	---

Explain:					
----------	--	--	--	--	--

	Very High	High	Moderate	Low	Very Low
<b>c) Sex</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>d) Communication</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>e) Help with Household Duties</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>f) Going out with Spouse</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>g) Spending time Alone with Spouse</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>h) Other</b>					
Specify: _____					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>i) Overall Relations with Spouse</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain					

	Very High	High	Moderate	Low	Very Low
<b>8) <u>Having and Raising Children</u></b>					
<b>a) Having Children</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>b) Becoming a Parent</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>c) Watching Child(ren)'s Development</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>d) Spending Time with Child(ren)</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>e) Helping Your Child(ren)</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>f) Teaching Your Child(ren)</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>g) Teaching Your Child(ren) Appropriate Behaviour</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>h) Being Helped In Caring for Your Child(ren)</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>i) Other Specify: _____</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>j) Overall Having and Raising Child(ren)</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>9) <u>Relations with Other Relatives</u> <u>(Eq. Parents, Extended Family)</u></b>					
<b>a) Visiting Relatives</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>b) Helping Them</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>c) Being Supported by Them</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>d) Other</b>					
Specify: _____					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>e) Overall Relations with Other Relatives</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>10) <u>Relations with Friends</u></b>					
<b>a) Having Close Friends</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>b) Sharing Activities</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>c) Being Supported by Them</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					



	Very High	High	Moderate	Low	Very Low
d) Other					
Specify: _____					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

e) Overall Relations with Friends					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

11) Activities Related to Helping or Encouraging Other People (Other than Relatives and Close Friends)

	Very High	High	Moderate	Low	Very Low
--	-----------	------	----------	-----	----------

a) Helping Adults					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

b) Helping Children					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

c) Membership in an Organization That Benefits Others					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

d) Other					
Specify: _____					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
e) Overall Activities related to Helping or Encouraging Others					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

12) Activities Relating to Local or National Governments

a) Keeping Informed Through the Media

	Very High	High	Moderate	Low	Very Low
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

b) Participating by Voting

	Very High	High	Moderate	Low	Very Low
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

c) Having My Political Freedom (eg. Living in Democratic Society)

	Very High	High	Moderate	Low	Very Low
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

d) Having My Religious Freedom

	Very High	High	Moderate	Low	Very Low
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

e) Other

Specify: \_\_\_\_\_

	Very High	High	Moderate	Low	Very Low
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>f) Overall Activities Relating to Local or National Governments</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>13) Intellectual Development</b>					
<b>a) Learning</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>b) Attending School</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>c) Opportunity to Learn About Things I Want to Know About</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>d) Graduating</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>e) Self-Education Outside of School</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
f) Other					
Specify: _____					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

g) Overall Intellectual Development					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
14) <u>Personal Understanding and Planning</u>					
a) Gaining Purpose for My Life					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
b) Insight into My Assets and Limitations					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
c) Developing a Greater Understanding of Myself					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
d) Decisions and Planning of Life Activities					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>e) Religious and Spiritual Activities</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

<b>f) Overall Personal Understanding and Planning</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

	Very High	High	Moderate	Low	Very Low
<b>15) Creativity and Personal Expression</b>					
<b>a) Showing Ingenuity or Originality</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>b) Involvement in the Arts (eg. Music or Art)</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>c) Other Specify</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					
<b>d) Overall Creativity and Personal Expression</b>					
Importance:	1	2	3	4	5
Needs are Being Met:	1	2	3	4	5
Explain:					

16) Stress is viewed as a persons response to his/her environment and threatens his/her ability to cope. With this definition in mind, rate the amount of stress in your life:

<b>Very Stressful</b>	<b>Stressful</b>	<b>Moderately Stressful</b>	<b>Low Stress</b>	<b>No Stress</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

17) Rate the amount of control you have over your own life:

<b>Total Control</b>	<b>A Great Deal of Control</b>	<b>Some Control</b>	<b>Little Control</b>	<b>No Control</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

18) Rate the amount of control other people have over your life:

<b>Total Control</b>	<b>A Great Deal of Control</b>	<b>Some Control</b>	<b>Little Control</b>	<b>No Control</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

19) Social support refers to the amount of affection, help and encouragement, a person gets from his/her relatives and friends. With this in mind, rate the amount of social support in your life:

<b>Very High</b>	<b>High</b>	<b>Moderate</b>	<b>Low</b>	<b>Very Low</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

- 1) Participation in Passive Recreation
- 2) Participation in Active Recreation
- 3) Socializing
- 4) Work
- 5) Material Comforts
- 6) Health and Personal Safety
- 7) Close Relationship with Spouse
- 8) Having and Raising Children
- 9) Relationships with Other Relatives
- 10) Close Friends
- 11) Helping and Encouraging Others
- 12) Participation in Activities Relating to Local or National Government and Public Affairs
- 13) Intellectual Development
- 14) Understanding Yourself
- 15) Creativity and Personal Expression

**Quality of Life** may be defined as the difference between your needs and whether or not those needs are being met. Answer the questions below, keeping this definition in mind.

A) Of the 15 aspects related to your life listed above, name 3 that makes you satisfied with your Quality of Life at the present time. Why? (Their numbers only need to be listed)

B) Of the 15 categories listed above, name 3 that detract from your satisfaction with your Quality of Life at the present time. Why? (Their numbers only need to be listed)

C) Of the 15 categories listed above, select 3 that your child(ren) have had a positive effect on. Why? (Their numbers only need to be listed)

- 1) Participation in Passive Recreation
- 2) Participation in Active Recreation
- 3) Socializing
- 4) Work
- 5) Material Comforts
- 6) Health and Personal Safety
- 7) Close Relationship with Spouse
- 8) Having and Raising Children
- 9) Relationships with Other Relatives
- 10) Close Friends
- 11) Helping and Encouraging Others
- 12) Participation in Activities Relating to Local or National Government and Public Affairs
- 13) Intellectual Development
- 14) Understanding Yourself
- 15) Creativity and Personal Expression

D) Of the 15 categories listed above, select 3 that you child(ren) have had a negative effect on. Why? (Their numbers only need to be listed)

E) List other aspects of your life, not covered by the questionnaire, that may have been affected by the presence of your child(ren). Why?

F) At the present time how would you rate your overall Quality of Life?

Excellent      Very Good      Good      Fair      Poor

Why? Explain:



G) Describe how the presence of a child has affected your overall Quality of Life. Why?

H) If applicable, describe how the presence of a child with a disability has affected your overall quality of life. Why?

The questionnaire is now completed. Thank-you very much for your participation.

## **Appendix B**

### **Introduction Letter and Consent Form**

Leif Rasmussen  
Educational Psychology - Rehabilitation Studies  
Education Tower - 412  
2500 University Dr. NW  
Calgary, AB.  
T2N 1N4

Tel. - 220-6494

Dear Sir/Madam:

I am a graduate student in Rehabilitation Studies under Dr. Roy I. Brown at the University of Calgary. I am looking for volunteers, such as yourself, to participate in a research study. The study is designed to look at the well-being of parents who have a child with a developmental disability. In order to properly assess parent's lifestyles, I need to compare lifestyles to that of parents of normal children, such as yourself. If you and your spouse give your consent to participate, your comments may help other parents who have a child with a developmental disability.

Providence Child Development Centre (PCDC) supports this research and understands that I am asking you if you would consider volunteering.

If you and your spouse agree to participate, you will be asked questions about your feelings and experiences concerning your quality of life. If you agree, we will together arrange a convenient time to complete the questions. In addition, your child will be given a brief reasoning test. The interview should not take longer than one hour of your time.

If you would like to participate you may return the form included to Providence Child Development Centre; or you can contact me directly by calling 220-6494(w) or 283-2928. Participation is voluntary. In no way will your decision (yes or no) affect you or your child in any way.

Thank-you for taking time to read this. I believe that this study will help to plan programmes for parents of children with developmental disabilities and, as a result, will help children with developmental disabilities.

Sincerely,

Leif Rasmussen  
Rehabilitation Studies

### Consent Form

I hereby consent to participate in the research project entitled "Quality of Life in Parents of a Child with a Disability" conducted by Leif Rasmussen, under the supervision of Dr. Roy Brown, of the Rehabilitation Studies Program at the University of Calgary. I understand that the purpose of the present study, in which I have been asked to participate is to investigate the quality of life in parents of children with a developmental disability. I understand that I will be asked to complete a questionnaire concerning my Quality of Life. Additionally, I understand that I may be asked to explain some of my answers. Sometimes answers raise additional questions and I recognize that I may be contacted at a later time and briefly asked a few follow-up questions. It is the intent of this study to provide useful information, both, to parents of children with developmental disabilities, and to practitioners who work with families with a child with a developmental disability.

I understand that my participation is completely voluntary, and I am free to withdraw from the study at any time I choose, without penalty to me or my child.

The study has been described to me, and I understand that there are no risks other than the feelings associated with answering questions about my personal life.

My name will not be attached in any way to the questions or be reported in the results, so that confidentiality may be maintained. The key listing my identity and the group-subject code number will be kept separate from the data in a locked file accessible only to the project director, and it will be physically destroyed at the conclusion of the project.

I understand that the results of this research may be published or reported to government agencies, funding agencies, or scientific groups, but my name will not be associated in any way with any published results.

I also understand that this questionnaire and interview will be conducted in my own home at my convenience. This should require only one visit and will not take any longer than one and a half hours to complete. It is also understood that I am free not to answer any of the questions that I may choose not to.

I understand that if at any time I have questions, I can contact Leif Rasmussen at 220-6494, or his supervisor Dr. Roy Brown at 220-3543.

---

Date

---

Signature

---

Participant's Name (Printed)