A COUNSELLING INTERNSHIP COMPLETED AT WESTERN MEMORIAL REGIONAL HOSPITAL, CORNER BROOK WITH A REPORT OF A NEED ASSESSMENT STUDY.

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by

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ABSTRACT

This internship report provides a comprehensive report of the professional activities of the intern during a thirteen week internship at Western Memorial Regional Hospital at Corner Brook, May 1981 to August 1981. This report also includes a detailed discussion of the results of the research study conducted during the internship period.

Chapter I provides an introduction to the internship, outline of the report, internship setting, rationale, duration, supervision and objectives of the internship. Chapter II gives a detailed evaluation and analysis of the internship according to the professional goals and objectives for the internship as stated in the internship proposal which was submitted to and approved by the Department of Educational Psychology, Memorial University, April 1981. The chapter outlines the opportunities that the intern had to become aware of the many resources available and to utilize these in her helping interventions with her clients. It presents in detail the many professional activities that the intern had the opportunity to become involved with during the internship such as individual counselling, group counselling, testing, parent consultation and so forth. Chapter III gives a final report on the research study, giving an introduction, the rationale, review of related literature and the methodology. Chapter IV provides the

analysis of data with descriptive statistics on the parents and children involved in the study. Also, it presents a table with the specific needs identified by parents in the study in descending order according to percentages, as well these needs identified by the parent are discussed under three headings: A. Universal Needs, B. Disability - Specific Needs, and C. Factors Related to the Differential Expression of Needs. Chapter V concludes the study with a set of recommendations. In particular, the study served to provide some insight into the needs of parents with disabled children and a number of recommendations as to how best these needs may be met. Following Chapter V there is the bibliography and appendix to conclude this report.

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The careful work of my typist--Mrs. Johnston, was much appreciated and essential in the final completion of this report. Last but not least, love to my husband Bob who provided me with the courage to complete this report.

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CHAPTER I

INTRODUCTION

This report is a full-length in-depth description of the internship undertaken by the intern in order to fulfill the requirements of the Master's Degree Programme of the Educational Psychology Department at Memorial University of Newfoundland. The thirteen week internship was undertaken at Western Memorial Regional Hospital, Corner Brook from May 4 to August 5, 1981. The internship proposal was developed, submitted and approved in April 1981 and now will form an integral part of this report. During the course of the internship minor components of the proposal were changed in consultation with the supervisory committee. These changes will be included in this final report of the internship.

Outline of Final Report

The final report begins with an overview of the details of the report. Chapter I will include a description of the internship setting, the rationale of the internship, the objective of the internship, supervision and evaluation.

Chapter II presents a detailed review of the professional activities of the intern during the internship period according to the stated objective of the internship.

Chapter III of this report will present the research project of the internship. Chapter III will, therefore, be presented in this way, introduction, rationale, review of literature, and methodology.

Chapter IV will deal with the analysis of data and conclusions of the research study.

Chapter V concludes the study and internship report with a set of recommendations followed by a bibliography and appendix.

Internship Rationale

The rationale underlying this internship was to provide opportunities for the intern to make practical application of, and to further develop, the skills, concepts and general competencies acquired in the Graduate Program, Department of Educational Psychology, Memorial University of Newfoundland. It was seen as an extension of the practical component already acquired during the graduate program.

It gave the intern the opportunity to experience the actual implementation of the principles and theories of counselling in one setting in the Western Region of the province of Newfoundland. It provided the intern with the experiences to develop and utilize the various skills and capabilities relevant to the field of counselling.

The internship setting, Western Memorial Regional Hospital, Corner Brook, was an excellent location for an internship. It provided ample opportunities to utilize a variety of helping interventions with a wide range of clients.

There were also several opportunities for the intern to become aware of community and institutional resources and to utilize these resources in her helping interventions with her clients. This setting also provided opportunities to obtain a fuller repertoire of skills and competencies which was integrated into the intern's personal helping style. It also offered a greater insight and understanding into the needs, problems and services available for the various age levels being seen at the Western Memorial Regional Hospital, Corner Brook, Newfoundland.

Internship Setting

The internship was undertaken at the Western Memorial Regional Hospital in Corner Brook, Newfoundland, from May to August, 1981.

The Western Memorial Regional Hospital has, as its primary purpose, the delivery of medical services and hospital care. It is located in Corner Brook but it serves the entire West Coast of Newfoundland (approximate population 120,000). Currently, the hospital has 30 acute beds with a separate Special Care Unit with 60 beds, as well as Day Hospital Facilities.

The Western Memorial Regional Hospital offers a diversified program of services for the general public. In particular, the hospital is the site of the following professional programs: the Child Mental Health Service, the Public Health Division, the Psychological Service, the Psychiatry Service, Speech Pathology and many more.

One of the many services offered at the Western Memorial Regional Hospital is the Psychological Service.

The Psychological Service is an autonomous department of the hospital; however, it cooperates in close relationship to other professional services offered at Western Memorial Regional Hospital. The department consists of four psychologists and a stenographer, with the chief psychologist as head of the service.

The Psychological Service has, as its main objective, the provision of a quality generic psychological service to all persons, both within the regional hospital and in the outside community.

The Psychological Service provides the following specific activities - programs:

(1) Assessment
(2) Therapy
(3) Consultation
(4) Education
(5) Research

The Psychological Service accepts referrals of children, adolescents and adults from many facets of the community. Potential referral agents include: physicians, staff nurses, hospital departments, school board supervisors, public health nurses, Department of Social Services, legal agencies and other community agencies.

Each psychologist with the service is primarily responsible for one general category of possible referrals. These categories include:

(1) Psychiatry patients

(2) Child mental health cases

(3) Developmental disabilities - delays

(4) School-related cases

The Psychological Service is a very vital and effective program at Western Memorial Regional Hospital.

Internship Duration

The internship extended over a period of thirteen weeks from May 4, 1981 to August 5, 1981.

Supervisors

The following persons were involved as supervisors of the internship :

Campus Supervisor - Dr. Glen Sheppard, B.Ed. (M.U.N.),
M.Ed., C.A.G.S., Ed. D. (Boston)
Associate Professor, M.U.N.
Coordinator Counsellor, Education
Program, M.U.N., St. John's

Field Supervisor - Mr. Wayne Rideout, B.Sc. (M.U.N.),
M.Ed. (M.U.N.)
Head Psychologist
Western Memorial Regional Hospital
Corner Brook

Committee Member - Dr. Leroy Klas, B.Sc., B.Ed. (Idaho),
M.Ed. (Ohio), Ph.D. (Utah)
Associate Professor (M.U.N.)
Coordinator of Student Selection and
Advising (Faculty of Education, M.U.N.)
St. John's.

Supervision and Evaluation

Supervision and evaluation was the joint responsibility of the intern, the campus supervisor and the field supervisor.

During the course of the period it became apparent that it would not be feasible for campus and field supervisors to travel to St. John's or Corner Brook for evaluation purposes. In an attempt to alleviate this problem, greater use was made of the telemedicine system for continual evaluation of the intern by the two supervisors.

Supervision and evaluation was conducted in the following manner:

(1) Regular weekly meeting of two hours with field supervisor to discuss progress in setting, to critique tapes (audio/video), and to discuss any problems that the intern may have been experiencing at the setting.

(2) The intern travelled to St. John's once during the internship to meet with the campus supervisor.

(3) An audio taped log of internship activities was submitted weekly by the intern to the campus supervisor.

(4) Audio and video tapes of individual and group counselling sessions were submitted to both the campus and field supervisors for evaluation.

(5) There were at least seven conferences of the intern, the field and campus supervisors, utilizing the telemedicine system. This system is an interactive telephone conference network located in fourteen centres in the Province of Newfoundland. It is typically used for a variety of multi-disciplinary activities such as continuing education, special medical consultations, and so forth. The telemedicine facilities located at the Health Science Complex, St. John's, Newfoundland and Western Memorial Regional Hospital, Corner Brook, was used for consultation during the internship.

Schedule of the Telemedicine Conferences

Date	Time
April 28, 1981	4:00 - 5:00
May 12, 1981	4:00 - 5:00
May 26, 1981	4:00 - 5:00
June 23, 1981	4:00 - 5:00
July 10, 1981	1:00 - 3:00
July 7, 1981	4:00 - 5:00
July 21, 1981	4:00 - 5:00

(6) On July 10, 1981 the intern made a formal presentation on the internship and its progress to date, utilizing the telemedicine system. The presentation was made to several other graduate students involved in internships and thesis reports in St. John's.

(7) At midpoint in the internship, the supervisory committee met on the telemedicine system to discuss the progress of the intern and to consider possible adjustments to the internship, its objectives and associated activities.

(8) The Field Supervisor observed the intern in group counselling sessions, case reviews and formal workshops during the internship for evaluation purposes.

(9) Evaluation forms were completed by participants in case conferences during the internship. (See Appendix A for forms.)

(10) Evaluation forms were completed by participants in workshops presented by the intern (see Appendix B for copy of evaluation forms).

Throughout this entire report evaluation of the intern will be noted as it formed an integral and vital component of the internship and its objectives.

Ethical Procedures

The ethical procedures set down by the Canadian Guidance and Counselling Association in Guidelines for Ethical Procedures 1981 were adhered to by the intern in all her activities during the internship (Canadian Guidance and Counselling Association).

Internship Objectives

The following is a list of the general objectives of the internship designed to promote the growth and development of the intern.

General Objective 1. To develop a comprehensive view of the counselling, psychological and community services and resources available at Western Memorial Regional Hospital, Corner Brook, Newfoundland.

General Objective 2. To develop and improve my level of ability to perform effective individual counselling with children and to further develop my knowledge of counselling theories and techniques for younger children.

General Objective 3. To develop and improve my level of ability to perform effective group counselling with children and to acquire further knowledge on group counselling theories and techniques for younger children.

General Objective 4. To provide developmental diagnostic assessment services to developmentally delayed pre-schoolers referred through the following referral sources: The Public Health Department, the Social Services Department, the Direct Home Services Department, the Western Memorial Regional Hospital Staff, the Pediatricians, the Physicians, the Legal Agencies, the Parents and the Public School System.

General Objective 5. To develop my ability to effectively gather and integrate relevant data from diverse sources (i.e. psychometric observation, consultations with significant others) regarding particular developmentally delayed children and to demonstrate appropriate use of such data for assessment of and programming for these children.

General Objective 6. To develop and improve my ability to perform effective counselling with parents and to acquire further knowledge into the needs and concerns of parents.

General Objective 7. To develop and improve my ability to be a consultant with other professionals and to acquire further knowledge on the various components and conceptualizations of the consultant role.

General Objective 8. To become familiar with the techniques and assumptions of need assessments and to develop and conduct an assessment into the needs of parents of developmentally delayed children.

These eight objectives and their associated activities were also partly met in conducting the activities of the intern's research study which involved an assessment of the needs of parents with developmentally delayed children in the Western Memorial Regional Hospital District, Corner Brook, Newfoundland.

CHAPTER II

REVIEW OF INTERNSHIP ACTIVITIES

This review of the internship will critically examine the professional activities engaged in during this period in relation to the objectives which were established for the internship.

OBJECTIVE I involves an orientation period during which the intern became familiar with the counselling, psychological and community resources available at Western Memorial Hospital, Corner Brook. Part of the orientation involved meetings with a number of personnel at Western Memorial Regional Hospital and in the local communities. Table I presents the list of persons seen by the intern during this period.

These orientation meetings were designed for the dual purpose of discussing with the individuals concerned their professional roles and services as well as providing an opportunity to share with them the expectations regarding the internship. In general, the following topics were discussed:

(1) The role of the intern at the Western Memorial Regional Hospital, Corner Brook.

(2) The objectives and associated activities of the internship.

Table I

A Schedule of Persons Seen by Intern During Orientation Period

Name of Persons	Location	Number of Hours	Sessions
Hospital Administrator	WMRH*	1	1
Assistant Hospital Administrator	WMRH	1	1
Director - Child Mental Health Clinic	WMRH	10	5
Director - Social Work Department	WMRH	20	10
Child Social Worker	WMRH	5	10
Home-Care Nurse	WMRH	1	1
Child Psychologist	WMRH	20	10
Public Health Nurses	WMRH	5	5
Public Health Nurses	Stephenville	2	2
Public Health Nurses	Deer Lake	3	3
Medical Health Officer	WMRH	4	4
Psychiatrists	WMRH	2	2
Play Therapists	WMRH	10	5
Child Psychiatrist	WMRH	10	5
Paediatricians (3)	WMRH	3	3
Head Nurse on Paediatric Ward	WMRH	4	4
Head Nurse on Psychiatry Ward	WMRH	1	1
Head Nurse on Adult Day Care Ward	WMRH	1	1
Head Psychologist	WMRH	2	2
Worker - Diabetics Clinic	WMRH	1	1
Direct Home Services Worker	Stephenville	1	1
Direct Home Services Worker	Deer Lake	1	1
Direct Home Services Worker	Corner Brook	3	3
Child Welfare Worker - Department of Social Services	Corner Brook	1	1
Child Welfare Worker - Department of Social Services	Stephenville	1	1
Guidance Counsellors	Corner Brook	2	2
Dr. Allan Kenworthy - Psychological Consultant	WMRH	1	1

* WMRH - Western Memorial Regional Hospital

(3) The programs and services of the Western Memorial Regional Hospital, as well as the outside community agencies.

(4) The research study of the internship

(5) Progress of the internship

(6) and many more related issues.

The orientation also included the intern observing several counselling, diagnostic and play therapy sessions at Western Memorial Regional Hospital. Table II provides a summary of such orientation sessions.

These observations served as orientation and training for the intern. It helped to give the intern a clearer insight into the programs and services available at Western Memorial Regional Hospital, Corner Brook.

OBJECTIVE 2 involves improving my level of ability to perform effective individual counselling with children. In an attempt to fulfill this objective, the intern read the following articles and books on the subject of counselling younger children and play therapy.

Book/Article	Author	Publisher	Date
1) Play Therapy	Virginia Axline	Houghton Mifflin	1947
2) Dibs in Search of Self	Virginia Axline	Houghton Mifflin	1964
3) Paediatric Play Program	Pat Azarnoff & Sharon Flegal		

Book/Article	Author	Publisher	Date
4) Counselling Children with Play Media	Betty Basdell	Holt, Rinehart & Winston, Inc.	1973
5) Recent Trends and Innovations in Play Therapy	Eileen Nickerson	International Journal of Child Psychotherapy Vol. 2, No. 1	1973
6) Counselling Techniques with Youth	Frank Krause	Charles E. Merrill Publishing Company	1972
7) Puppetts and Hospitalized Children	Susan Linn		
8) Bibliotherapy: A Therapeutic Medium for Helping Children	Eileen Nickerson	Xerox College Publishing	1974
9) Therapeutic Communication with Children: Mutual Story Telling Technique	Richard Gardner	Science House	1971
10) Puppetry as a Tool in Child Psychotherapy	Adolf G. Woltman	International Journal of Child Psychotherapy Vol. 1, No. 1	1972

Counselling children on both a long-term and a short-term basis formed a major part of this professional objective of the internship. Table III shows the professional involvement of the intern in counselling children.

The total number of children seen on a short-term basis was somewhat less than what had been intended originally. However, this change was discussed and approved of by the intern's supervisory committee and was judged to be necessary since the intern was spending substantially more time with the parents of young children than was anticipated. Table IV shows the professional involvement of the intern in short-term counselling

Table II

Schedule of Observational Sessions Conducted by the Intern During the Orientation Period

Session	Date
Individual Counselling Session	May 6, 1981
Individual Counselling Session	May 6, 1981
Individual Counselling Session	May 13, 1981
Play Therapy Session	May 13, 1981
Play Therapy Session	May 25, 1981
Diagnostic Assessment Session	May 4, 1981
Diagnostic Assessment Session	May 5, 1981
Diagnostic Assessment Session	May 13, 1981
Diagnostic Assessment Session	May 29, 1981
Diagnostic Assessment Session	June 2, 1981
Parent Consultation Session	May 5, 1981
Case Conference Session	May 15, 1981
Case Conference Session	May 27, 1981
Initial Assessment Session	May 12, 1981
Child Mental Health	May 27, 1981

Table III

Schedule of Long-Term Counselling Sessions with Children During Internship

Name*	Dates of Session	Recording
Mary	May 28, 1981	
Mary	May 29, 1981	
Mary	June 4, 1981	
Mary	July 1, 1981	
Mary	July 3, 1981	audio taped
Mary	July 4, 1981	audio taped
Mary	July 12, 1981	audio taped
Mary	July 28, 1981	
Tom	July 9, 1981	audio taped
Tom	July 10, 1981	
Tom	July 14, 1981	
Tom	July 22, 1981	audio taped
Tom	July 29, 1981	
Wayne	May 19, 1981	
Wayne	May 28, 1981	
Wayne	June 3, 1981	
Wayne	June 17, 1981	audio taped
Wayne	July 28, 1981	audio taped

* the names have been changed to ensure the anonymity of the persons involved in the counselling sessions.

Table IV

Schedule of Short-Term Counselling By Intern

Name*	Number of Sessions
Sharon	2
Phil	3
John	2
Paul	3
Peter	2

* the names have been changed to ensure the anonymity of the persons involved in the counselling sessions.

OBJECTIVE #3 involved the development of the intern's ability to perform effective group counselling with children. In an attempt to fulfill this objective the intern read the following articles and books on the subject of group counselling with children.

	Book/Article	Author	Publisher	Date
1)	Counselling Children in Groups	Merle M. Ohlsen	Holt, Rinehart & Winston	1973
2)	The Adlerian Approach to group counselling	Driekurs	Holt, Rinehart & Winston	1973
3)	Group Counselling: Leadership Functions	Don Dinkmeyer	Depaul University	

	Book/Article	Author	Publisher	Date
4)	Ground Rules for Group Sessions	Eugene T. Gardlin		
5)	Group Procedures with Children: A Developmental Approach	George Gazda	Holt, Rinehart & Winston	1973
6)	Developing Role Playing for School and Counselling Groups	Fritz Bell Robert Moore	Xerox College Publishing	1974
7)	Role Playing: A Therapeutic Adjunct to Group Counselling	Laurence Passmore	Holt, Rinehart & Winston	1973

The intern also attended a two-day workshop on Working with Groups presented by Ms. Joan Pennell, Social Work Professor, Memorial University, St. John's, Newfoundland.

A play therapy group was also organized and led by the intern for a period of one week (four consecutive sessions) during the month of July with two of the sessions being videotaped for supervision and evaluation purposes. Table V gives details on the play therapy group sessions.

The play therapy group consisted of 4 children ages 10 to 14 years and it ran for four consecutive sessions. The overall goal of the play therapy group was to help strengthen the child's ability to express thoughts and feelings and to strengthen the child's ability to cope more effectively with difficulties of life. More specifically, the objectives were:

(1) To provide a supportive/relaxed controlled environment for the children to be themselves and to feel accepted as individuals.

(2) To encourage the children to play out their inner thoughts, feelings, and problems through various play media.

(3) To encourage the children to become aware of their interactions with others and to discuss related problems with others in the group.

(4) To provide appropriate role modeling of effective methods of coping with social situations.

The play therapy group experience was a very valuable one for the intern. However, the group was unable to meet its overall objectives, mostly as a result of a short time limit and the age of the children. The intern's involvement with this group helped her to reach the conclusion that to be effective, there must be an extended time period with younger children. However, the involvement and experience was well worth the frustrations that the group was to the intern during that year. The group experience provided an excellent opportunity for the intern to participate in a group leadership function. It also helped in the realization that play is a tool used to teach children to live with themselves and with others.

A second group was organized by the intern for the paediatric ward in conjunction with the social work department at Western Memorial Regional Hospital, Corner Brook. Table VI gives details on the Paediatric Group Sessions.

Table V

Schedule of Play Therapy Sessions

Session	Date	Recordings
#1 (Introduction)	July 8, 1981	
#2	July 10, 1981	video taped
#3	July 15, 1981	video taped
#4 (Conclusion)	July 17, 1981	

Table VI

Schedule of Paediatric Group Sessions

Session	Date	Recordings
#1	June 23, 1981	
#2	July 1, 1981	Observation by supervisor
#3	July 6, 1981	Videotaped
#4	July 14, 1981	Videotaped
#5	July 24, 1981	
#6	July 28, 1981	

The overall goal of the paediatric group was to strengthen the child's ability to cope with the difficulties of hospitalization. More specifically, the objectives were:

(1) To provide a supportive, controlled environment for the ventilation of feelings and thoughts about hospitalization and related matters.

(2) To minimize misconceptions about illness, treatment methods and hospital procedures.

(3) To minimize feelings of isolation and loss by optimizing supports available within the hospital environment.

(4) To develop productive patterns for dealing with related problem situations.

The programming for the group was flexible because of the variable characteristics of the population being served (children of different ages, skills, interests and mobility) and because the group composition was constantly changing due to admissions and discharges on a daily basis. The group used different techniques such as: group discussion, dolls, art, puppetry, bibliotherapy, mutual story-telling, role playing as media for the indirect, non-threatening expression of children's feelings and concerns. In group sessions with older children and adolescents the emphasis was placed on verbalization as a medium of expression rather than on play and activity.

The paediatric group was deemed a worthwhile and productive group experience. It realized its overall objectives and, in particular, it provided a very supportive experience for the children on the paediatric ward. The group is now presently being continued on a regular basis on the Paediatric ward by the Social Work Department, Western Memorial Regional Hospital, Corner Brook.

Co-leading the paediatric group with a social worker was an excellent opportunity for the sharing of ideas and thoughts with another professional in a related helping area.

General OBJECTIVE #4 focused on the area of developmental diagnostic assessment services for developmentally delayed preschoolers. In preparation to deliver the diagnostic assessment service to developmentally delayed pre-schoolers, the following psychometric instruments were read and evaluated with regards to administration procedures, scoring, write-up and interpretation of the instruments:

(1) The Stanford-Binet Intelligence Scale for Children
(2) The Vineland Social Maturity Scale
(3) The Hooper-Visual Test
(4) The Benton-Visual Test
(5) The McCarthy's Scales for Children
(6) The Denver Developmental Scale
(7) The WPPSI (Wechsler Preschool and Primary Scale of Intelligence)
(8) The Bender Gestalt Test
(9) The Goodenough-Harris Draw-A-Picture Test
(10) The Raven's Test
(11) The ITPA (Illinois Test of Psycholinguistics Abilities)
(12) The Peabody Picture Vocabulary Test
(13) The Junior Eysenck Personality Test
(14) The WISC-R (Wechsler Intelligence Scale for Children - Revised)

In addition, the following articles and books were read to understand more clearly the comprehensive area of developmental disabilities.

Book/Article	Author	Publisher	Date
1) The Parent Portage Program	Boyd, Stauber & Bluma	Cooperative Education Service Agency	1977
2) A Manual for Parents of Children with Developmental Disabilities	Kenney and Payne	Southeast Wyoming Mental Health Centre	1973

Book/Article	Author	Publisher	Date
3) Service Trends for Exceptional People in Newfoundland	Michael Steer		1980
4) Understanding and Working with Parents of Children with Special Needs	Paul, J. L.	Holt, Rinehart & Winston	1981
5) Goal Planning with Developmental Disabled Persons	Houte Scott	Department of Behavioral Science Hershey Pennsylvania	1975

It was also deemed necessary and appropriate to meet and discuss assessment services with a number of personnel at Western Memorial Regional Hospital and in related community agencies. Table VII identifies these personnel and their professional titles.

Involvement with two local committees - the West Coast Paediatric Rehabilitation Team and the Children Referral Team provided enlightened information on services available in the local Corner Brook district. The West Coast Paediatric Rehabilitation Team has, as its primary focus, the referral and appropriate treatment of developmentally delayed children in the district. The Child Referral Team has, as its major concern, the referral and treatment of emotionally and behaviorally disturbed children.

With a clearer understanding of several diagnostic assessment instruments and services for developmentally delayed children the intern administered diagnostic assessments on referred pre-schoolers at the regional public health clinics. The total number of assessments completed was 30. Table VIII

Table VII

List of Professionals Seen by the Intern

Professionals	Location
Medical Health Officer	WMRH*
Direct Home Services Workers	Stephenville Corner Brook Deer Lake
Public Health Nurses	Stephenville Corner Brook Deer Lake
Paediatricians	Corner Brook WMRH
School Guidance Counsellor	Corner Brook Stephenville
Special Services Co-ordinator Integrated School Board	Corner Brook
President - Association for Mentally Handicapped Persons	Corner Brook
Child Welfare Worker - Department of Social Services	Stephenville Corner Brook Deer Lake
Co-ordinator - Interfaith Counselling Center	Corner Brook
Social Workers	WMRH

*WMRH - Western Memorial Regional Hospital shows the location of these clinics.

The diagnostic assessments included a battery of tests such as the Stanford Binet Intelligence Scale for Children, the Bender-Gestalt test, the McCarthy Scales for Children, the Peabody Picture Vocabulary Test, the Goodenough Harris Drawing test and many more. These assessments were scored, interpreted and discussed with parents, nurses and other relevant professional personnel. The interpretation of several assessments with parents developed into parental counselling relationships. Subsequently, in consultation with the supervisory committee, a greater component of the internship was allotted to the area of parental counselling in an endeavor to improve the parental effectiveness with their developmentally delayed child. The parental counselling consisted of both short and long term involvement with 18 out of the 30 parents whose children had been assessed by the intern.

General OBJECTIVE #5 . The professional activities undertaken to meet this objective complemented the intern's involvement with diagnostic assessments of developmentally delayed children and the appropriate interpretation and program planning for the children. The intern participated in a number of case conferences on children as an observer and as a leader of the conference. Evaluations forms completed on two of the case conferences can be seen in Appendix A.

General OBJECTIVE #6. This objective dealt with the important area of parental counselling. In preparation for

Table VIII

Schedule of Diagnostic Assessments Administered by the Intern at the Public Health Regional Clinics

Communities	Number of Children
Curling	5
Summerside	2
Benoit's Cove	4
Lark Harbour	3
Cox's Cove	3
Massey Drive	2
Steady Brook	1
Pasadena	1
Gallant's	0
Stephenville	6
Stephenville Crossing	2
St. George's	1

this objective the intern attempted to become familiar with the various counselling theories, parent education programs, and theoretical perspectives for various interventions with parents. The following are the books and articles read by the intern:

Article/Book	Author	Publisher	Date
Living with Children	Patterson, M.	Research Press	1973
Families	Patterson, M.	Research Press	1979
Parents Are Teachers	Becker, L. D.	Research Press	1971
Behavioral Contracts	Dekisi, D.	Research Press	1975
Parent Effective Training	Gordon, S.	New American Library	1975
Leading Effective Parent Study Group	Dinkmeyer, D.	Elementary School Guidance & Counseling	Dec. 1974
Portage Parent Program	Boyd, Stauber and Bluma	Cooperative Education Service Agency	1977
A Manual for Parents of Children with Developmental Disabilities	Kenny/Payne	Southeast Wyoming Mental Health Clinic	1973
Understanding and Working with Parents of Children with Special Needs	Paul, J. L.	Holt, Rinehart & Winston	1981

The intern also attended two workshops on Counselling Parents. These were the following:

(1) Parent Effectiveness Training sponsored by the Social Work Department, Western Memorial Regional Hospital, Corner Brook.

(2) Counselling Troubled Families sponsored by the Social Work Department, Memorial University, Workshop Leader: Gary Gould.

Counselling with parents of developmentally delayed children became a large component of the internship, in particular, three sets of parents on a long term basis throughout the period.

The aim of the long-term counselling was to improve the communication abilities, effectiveness of the parents as a couple and as parents of their children. The long term counselling proved to be very productive for both parents and the intern. All counselling sessions with one set of parents - Diana and George - were audio taped for evaluation purposes. It is the overall judgement of the intern that this area of parental counselling was a great learning experience and provided insight into the needs and concerns of parents.

General OBJECTIVE #7 involves learning how to become a consultant with other professionals. To become a successful and effective consultant the intern became familiar with various aspects of the consulting process through reading the following books and/or articles.

Article/Book	Author	Publisher	Date
A model for Consultation Training in Canadian Counsellor Education Programs	Rey Carr		
Teacher Consultant - Present Past and Future	Lilly		
How to Put the Consultant to Work in Consulting Teaching	Richard Neil		

Within the hospital structure the Psychology Department is in a high profile position for consultation, which made it possible for the intern to be involved in consultation on a regular basis. In particular, the following persons received consultation.

As well, several educational sessions offered by WMRH proved to be very valuable learning experiences. These included the following:

(1) The Parent Effective Training; Semester Leaders: Joy Clarke, Annette Hardley, Social Workers, Western Memorial Regional Hospital.

(2) Anorexic Neurosis, Dr. Kenworthy, Psychology Department, Department of Education.

(3) Modern Psychiatric Practises - Dr. Patmanidis, Western Memorial Regional Hospital.

(4) Memory and Confusional States - Dr. Patmanidis, Western Memorial Regional Hospital.

Two counselling educational sessions were offered by the intern to the hospital in return for their co-operation. These were on the following topics:

(1) counselling and communication skills

(2) an overview of internship and research component

Presenting these two educational sessions proved to be a very productive experience which helped the intern to understand different health related professionals with different views, concerns and professional backgrounds. It provided an opportunity to observe the different perspectives of related helping agencies within the hospital setting. Evaluation Forms completed on these educational sessions can be seen in Appendix B.

General OBJECTIVE #8 dealt primarily with the area of needs assessments and the intern's research component discussed in detail in a separate section of this report. This involved reading literature in the areas of needs assessment and the area of developmentally delayed children. As well, an interview protocol was devised for the research project itself. This research project consisted of interviewing thirty sets of parents with developmentally delayed children in selected communities in the Western Region of Newfoundland. The overall purpose of this research project was to identify and determine the needs, concerns and problems of parents with developmentally delayed children. Upon completion of the research project the intern has compiled the data, analyzed the results and prepared a final report on the needs of parents with developmentally delayed children. The complete report and its results will be covered in Chapter III of this final report.

General OBJECTIVE #9 was developed in consultation with the intern's supervisory committee. This objective involved the advocate role for clients and required a great deal of special tact and professionalism on the part of the intern. Table X gives an overview of this advocate role.

Table IX

List of Persons Involved with Consultation During the Internship

Person/Group	Location
Psychiatric Social Worker	WMRH*
Play Therapists - Paediatrics	WMRH
Public Health Nurses	Stephenville & WMRH
School Principals	Stephenville
Child Mental Health Service	WMRH
Children Referral Team	Corner Brook
West Coast Paediatric Rehab Team	Corner Brook

* WMRH - Western Memorial Regional Hospital

Table X

List of Agencies - Persons Contacted on Behalf of Clients During Internship

Agencies

(1) The Department of Social Services

(2) Direct Home Services

(3) School Officials

(4) Public Health Nurses

(5) Speech Therapy

(6) Volunteer Services

(7) Social Work Department

(8) The Children Referral Team

(9) The West Coast Paediatric Rehab Team

These nine overall objectives and activities were also met through the activities undertaken as part of the intern's research component, which will be outlined in Chapter III of this report.

Pertaining throughout the entire internship was the issue of supervision and evaluation. It was the joint responsibility of the intern, the campus supervisor, Dr. Glenn Sheppard, and the field supervisor, Mr. Wayne Rideout. The focus of the supervision and evaluation was very positive in outlook with the goal of helping the intern to develop effectively.

In addition to the evaluation procedures outlined in the original proposal, the intern was in very constant and close contact with the field supervisor, which served as an excellent means of supervision and evaluation. One group counselling session was observed by the field supervisor and all written reports and case recordings were analyzed by the supervisor. At the conclusion of the internship a final overall written evaluation of the intern was completed by the field supervisor. This can be found in Appendix C.

One final form of evaluation consists of the intern's statistical record keeping for the Psychology Department. Table XI gives an overview of the total caseload during the internship.

In Appendix D a special psychological services statistical report for the entire internship is enclosed for information on caseload of intern.

Table XI

Schedule of Professional Activities Undertaken During the Internship

Activity	Total Number
Individual Counselling	51
Psychometric Sessions	29
Consultation (Individual and Group)	70
Research Interviews	26
Group Counselling	10

Table XII will show the source of referrals accepted during internship. Total number of referrals was 45.

Table XIII will discuss meetings of the intern.

Conclusion

This chapter has given an overall presentation of the internship and its professional activities. The objectives were highlighted to give a clearer picture of activities during the internship. As well, the supervision and evaluation components were discussed in detail.

Table XII

Source of Referrals Seen During Internship

Source	Total Number
Child Mental Health Clinic	5
Psychology	10
Public Health	30

Table XIII

Schedule of Meetings Attended During Internship

Meeting	Total Number
Special Service	8
Coordination	38
Education	30
Total	49

CHAPTER III

RESEARCH STUDY

Introduction

The research component of this internship was designed to provide an opportunity for the intern to undertake a research study which will be relevant to the internship setting and its programs. It was seen as a means to facilitate the intern's ability to design a research project, select appropriate research instruments, collect, analyze, interpret data and report results.

It helped the intern to become familiar with the techniques and assumptions of need assessments and to develop and conduct an assessment into the needs of parents of developmentally delayed children.

This chapter will present the purpose, rationale, literature review, methodology, data analysis, and results and conclusions of the study.

Purpose

The main purpose of this research study was (1) to assess and identify the needs of parents with developmentally delayed children in selected communities in the Western Regional of the province of Newfoundland and (2) to identify the variables which determine parent needs. The label developmentally delayed child in this study was used to refer to children who deviate from the average or normal child in mental, physical, social and other health characteristics. Such children have been variously labeled in the past as exceptional children, children with special needs or handicapped children.

Several writers (Becker et al., 1980; Chinn et al., 1978; Telford & Sawrey, 1972) recognize that parents of children with disabilities or developmental delays have a number of special needs. According to Skelton (1972), parents identify seven prime areas of concern as most troublesome to them. These were (1) Training and education for the child, (2) Interference with family life, (3) Other family problems interfered with ability to care for child, (4) Physical care and protection for the child, (5) Living situation for the child, (6) Recreation and companionship for child, (7) Problems in community. Becker et al., (1980) list of problems for the parent are: inability to receive a reasonable and understandable diagnosis, lack of information as to services available to the child and the family, psychological and emotional problems, feelings of inferiority and financial difficulties (p. 524). Of course, the needs of such parents are not necessarily static but most likely change over time and are probably affected by a host of variables associated with the child, the nature of the developmental delay and familial factors. For example, the parents of a blind child may need information on programs for their child whereas the parents of an emotionally disturbed child may need personal support and counselling. As well, according to Chinn et al. (1978) the degree of severity of the delay may affect the parents' needs. For example, a learning disabilities handicap may be less traumatic to a family than mental retardation and the prognosis is brighter. Also, parents who have accepted that their child has a disability will be able to identify different concerns than will those parents who are still reluctant to admit to themselves that their child is in some way different and who may still be angry at any such suggestion. This study has attempted to identify these and other significant variables which may serve as determinants of parental needs and concerns.

Several attempts have been made to identify and conceptualize the needs of parents with developmentally delayed children across these variables. Rosen (1955) provides a comprehensive and useful model for reviewing the needs of these parents. He has suggested five stages through which parents of children with disabilities or developmental delays progress from the time they first become aware of their child's problem until they come to accept their child and the disability. These stages are: (1) awareness of a problem, (2) recognition of the basic problem, (3) search for a cause, (4) search for a cure, (5) acceptance of the problem (Rosen, 1955, p. 18). At each stage, he suggests the needs of the parents may include (1) effective communication, which suggests the need for understanding and support and recognition of their basic concerns as parents of a delayed, disabled child; (2) explanation of etiology, which involves the appropriate explanation of the cause of the handicap so as to help parents better understand their child and the disability and to plan for the future; (3) search for a cure, which involves parents in a tireless search for a diagnosis that is acceptable to them, whether it is valid or not; (4) search for help; parents faced with a handicapped child usually feel alone and in need of help from others; (5) maintaining a normal life; the impact of the advent of a child with a disability on the family does disrupt the family. While this is natural, there is a real need to maintain a normal life as much as possible for the sake of the entire family. The emotional stability of the family is a major factor in the overall adjustment and development of the child with the delay or disability; (6) providing for the child's future; parents are concerned about the care and future of the child when they become too old or are no longer living. As well, there appears to be fewer services for the adult with a handicap in today's society.

It is clear that parents of delayed-disabled children have a number of special needs. When these needs are met the adjustment of the child and the entire family is facilitated. In order to meet these needs, it is necessary to first identify and categorize the needs. A modified version of Rossen's model of needs was utilized by this study to identify and categorize the needs of parents with developmentally delayed or disabled children in the selected communities of Curling, Summerside, Benoit's Cove, Lark Harbour, Cox's Cove, Massey Drive, Steady Brook, Pasadena, Gallant's, Stephenville,

Stephenville Crossing on the Western Region of the province of Newfoundland.

Rationale

During the latter part of the 1960's and especially during the 1970's, increased attention has been given to children with special needs and their parents (Dunn, 1963; Kirk, 1979; Lilly, 1979; Wolfenberger, 1971). Major advances in the area of exceptionality have been made through legislation and major reports in the 1970's. The American's Education of all Handicapped Children Act PL 94-142 (U.S. Office of Education, 1977, p. 42478), England's Warnock Report (Warnock, 1978), and Canada's report One Million Children (Commission on Emotional and Learning Disorders in Children, 1970) reflect the increased awareness by society of the area of exceptionality and developmental disabilities.

Results of this increased awareness has involved a movement towards the integration of children with special needs with their normal peers, the notion of early education and involvement of parents in the treatment of the handicapped child. This principle of proximizing the degree of integration of exceptional children has been referred to as mainstreaming or procession of the least restrictive environment (Lilly, 1979). Although mainstreaming has been professionally advocated and is having a profound influence on the manner in which special services are provided, there is not, to date, a strong empirical basis for these practices. Research results seem to be contradictory; Fredericks et al. (1978), Cantrell & Cantrell (1976) report favorable results, while Kaufman et al. (1978), Reynolds and Birch (1977) report unfavorable results.

In the area of special education for children with special needs, there has been an increased focus on the notion of early education - early intervention with the child and his/her parents (Kirk, 1965; Skeels, 1966). According to Karnes (1973):

> One of the most universally accepted propositions in special education has been that the earlier one can apply appropriate treatment responses to the child and the families the more effective special education will be. (p. 171)

This focus on early intervention became evident in the United States through its legislation of two separate bills: <u>The Handicapped Children's Early Education Act</u> (1968) and the <u>Developmental Disabilities Act</u> (1975). These two bills in the United States promoted the earlier referral and treatment of pre-school developmentally delayed children.

Another trend in the area of exceptionality has been the recent upsurge in parent and family involvement in the treatment of the developmentally delayed or disabled child. Many writers (Bricker & Bricker, 1976; Fraiberg, 1975) acknowledge the necessity of parental participation and involvement to facilitate and promote the overall adjustment of the exceptional child and the family.

More recently, there has been an increased awareness and understanding of the families of the special child with particular emphasis on the impact of the child on the family (Chinn et al., 1978; Seligman & Seligman, 1980). It is suggested that the advent of a child with a disability into the family system will have some impact on family integration. Whether or not the event becomes a crisis depends on three basic conditions: (1) the nature of the event, (2) the resources of the family, and (3) how the family defines the event (Chinn & Chinn, 1974, pp. 26-33). As well, it is important to note that the individual child and his disability affects all the members of the family, and their behaviour, in turn, affects the child. Freedman and his co-workers (1957) have described the circularity in an intensive study of fourteen children suffering from a chronic physical disorder.

When working with a child who has special needs or difficulties, it is easy to focus attention so completely on the child that we forget that the child is a member of a family and that the family may be as much a casuality as is the child. While the family's impact on the child with special needs has received attention, there has been less recognition of the effects of the child on the family and the needs of the parents (Becker, et al., 1980; Telford & Sawrey, 1972).

Being a parent of a developmentally delayed child creates a number of special concerns and needs. Over the last few years, several ways of categorizing needs has been proposed by various writers. Kinney and Payne (1973), for instance, identify needs associated with parental reactions such as guilt, marital discord, frustration, utilizing professionals and other parents, institutionalization and schooling. Thomas and Marshall (1977) also recognize that parents of a child with a disability have certain needs and go through certain processes both early and later. These may include: (1) modification of the initial maternal touching at birth (Klaus, Kennell, Plumb and Zueheka, 1970); (2) initial regression and disorganization (Goodman, 1964), and (3) parental reactions such as anger, depression, denial, marital strain and deterioration of religious beliefs (Drotar, Baskiewuz, Irwin, Kennell and Klaus, 1975; Stone, 1973). The Dembinski and Mauser (1974) study showed that parents with learning disabled children needed to receive an honest evaluation of their child's problem and capabilities and to become involved in the child's remediation program.

Other efforts have been made to identify and classify needs of the parents and families of developmentally delayed or disabled children. For example, Telford and Sawrey (1972) suggest that the needs of these parents may include the following:

(1) Need for information concerning the nature and extent of the child's exceptionality.

(2) Need to know probable cause of their child's condition - etiological information.

(3) Need information concerning facilities and services available for the care, treatment and education of these children.

(4) Need to be informed of what the future may hold for the handicapped.

(5) Need to know of the specific programs which are most appropriate to the needs and capabilities of their child.

(6) Need to have someone help them with their attitudes and feelings, fears, guilt, shame.

(7) Need to receive help in reducing emotional vulnerability of the family members.

(8) Need for assistance in behavior management of child at home.

Another model of parental needs has been suggested by Rosen (1955). His model identifies needs in the following categories:

(1) Communication;

(2) Explanation of ethiology (medical-theological);

(3) Search for a cure;

(4) Search for help;

(5) Maintaining a normal family life;

(6) Providing for the child's future.

These conceptualized models of parental needs and concerns reflect the increased recognition that particular attention be directed towards the role of parents and their needs in the development and implementation of programs and services for the delayed-disabled child and his parents (Becker et al., 1980; Stokes, 1976).

Chinn et al. (1978) and Rosen (1955) state that the advent of a child with a delay into the family system has some impact on family integration. The parent is very emotionally involved with the child and faces the child every day and night. There are few, if any, weekends or holidays when the parent can avoid involvement. In fact, the delayed child is a reality for the rest of the parents' lives. The parent is faced with pain, frustration, self doubt and ego shattering experiences which become areas that the parent may be in need of treatment in the form of supportive counselling and assistance. However, in spite of all these experiences, the parents are also very valuable sources of strength and treatment for the developmentally delayed child. If the parents maintain their belief in the self worth of the delayed child and continue to live a reasonably normal life then the parents and the family become a very valuable resource to the child. The emotional stability of the family is a primary factor in the overall adjustment and development of the developmentally delayed child. As professionals, there is need to give the parents support, encouragement and education in accepting the child and preparing for the child's future. This will assist the parents to become very valuable therapeutic agents in the treatment of the child.

Locally, on the Western Region of the province of Newfoundland, the Psychological Services of the Western Memorial Regional Hospital and the Department of Health were proposing to introduce a developmental diagnostic assessment program for developmentally delayed pre-schoolers and their parents. The Western Memorial Regional Hospital advocated the importance of parents becoming active participants in the treatment programs for developmentally delayed children. The overall attitude was that parents are potential therapeutic agents for the child; however, quite often the parents become casualties themselves due to the lack of appropriate programs and services to meet their basic needs and facilitate their therapeutic role. Unless the parents' basic needs can be identified and met, the parents take on the role of being a causality and are unable to progress to the role of a therapeutic agent for their child.

For too long, informal need assessments have been conducted with inferences being made as to the needs of the parents by the professional helpers. Marrs and Helge (1978) feel that:

> typically this relatively informal needs assessment produces a statement from someone in the administrative hierarchy or from the local community to the effect that it seems like something ought to be done regarding ... (p. 145)

Furthermore, they feel that:

> rarely are needs assessed in any structured productive way to assure that those organizations, agencies and individuals who have impact on program and process activities will have input to the goals and objectives of specific programs or projects. (p. 144)

This study consisted of a formal structured interview to obtain information as to the needs of parents with developmentally delayed children in the selected communities on the Western Region of the province of Newfoundland. It was designed to answer the following specific questions concerning the needs of parents:

(1) Are there particular needs-concerns of parents related to the early identification of a child's problem or delay?

(2) What are the needs of parents in searching for help?

(3) Are there special needs of parents related to the accurate explanation of the child's delay and its cause.

(4) What are the needs of parents in receiving information on treatment, remediation and cure of the child's problem?

(5) Are there needs of parents connected with the issue of hospitalization?

(6) What are the parent's needs with regard to home management of a child with a special problem?

(7) What are the needs of parents in maintaining a normal family life?

(8) Are there special needs of parents with regard to support and understanding of their feelings and concerns?

(9) What are the needs of parents as to planning for their child's schooling?

(10) What are the parents' need-concerns toward the future

planning of their child with a special problem?

(11) Are there special needs of parents with regard to the institutionalization issue?

(12) What are the factors that facilitate or hinder the parents' asset to services available in community?

The results of this study provide a source of data to the above questions concerning possible needs of parents with developmentally delayed children. The study involves an interview schedule which is developmental in nature covering the above specific questions.

Answers to the research questions provides valuable information as to needs of parents as causalities and/or therapeutic agents. If the parents' needs can be identified and met, then the parents can become a valuable therapeutic agent for the developmentally delayed child. Telford and Sawrey (1972) suggest that if the entire family is treated, the result will be a better adjusted and better operating family which will encourage and facilitate the developmentally delayed child's potentiality for growth. Overall, if the parent's needs can be met the parents can be helped to move from the role of being a causality to the role of therapeutic agent for their child.

Review of the Literature

During the last three decades, and especially during the 1970's, increased attention has been given to the field of exceptionality and children with special needs and their parents. For example, Cruickshank and Orville (1975) argue that a more positive outlook and attitude on the part of the public towards the handicapped person occurred as a result of many developments such as:

(1) Development of the day school program for exceptional children;
(2) Impact of World Wars I and II;
(3) Development of parent groups;
(4) Research and research techniques;
(5) Growth of teacher education (p. 12).

One of the greater changes was the growing movement to decentralize large institutions, to encourage special classes in the school and to promote the child remaining at home. Kirk (1964), as well as Lilly (1979), estimated that educable mental retarded special class enrollment in the United States increased tenfold between the early 1920's and late 1950's, and the majority of the growth occurred during the last ten years of that period. Lilly (1979) further stated that the development of programs for the visually impaired, hearing impaired, speech impaired, and crippled maintained a steady growth over this period. These changes are also reflected in recent changes in educational provisions for exceptional children in the province of Newfoundland, such as the movement to the provision and growth of special education classes in the schools with an increased emphasis on mainstreaming or provision of the least restrictive environment for the exceptional child.

In the United States, during the period 1950 to 1975, there was an explosion of provisions for the handicapped, spearheaded by state and federal legislation and appropriation. Martin (1976) points out that a national commitment to the right to a free public education for every individual, including every handicapped person, represents a new level of maturity for America. The most significant recent legislation landmark was in the form of the United States' Public Law 94-142, the Education for all Handicapped Children Act. It stated that in order to receive funds under the Act beginning in September, 1978, every school system in the nation would have to make provision for a free appropriate education for every child between the ages of 3 to 18, regardless of how seriously handicapped. According to this law, priority must be given first to education of the handicapped children who are not receiving education at all and second to the most severely handicapped.

In Canada, there has been no broad based federal legislation provision made clearly ensuring the right of exceptional children to receive a proper education, due to the fact that, in Canada, public school education falls exclusively within provincial jurisdiction. However, in all of the provinces of Canada, universally, there are provisions for the orderly development of special education programmes. In Ontario, a most significant legislation landmark was in the form of Bill 82 (May 23, 1980). The Bill states that all children have the right to attend school in the Province of Ontario and to receive the appropriate educational program based on their needs and capabilities. This includes the mandatory provision of special education programs and special education services for exceptional students in the Province of Ontario. As well, in the Province of Newfoundland, December 1979, an amendment was made to the School Act making the school boards responsible for the provision of programs for children with special needs in the regular school. Several other task forces have appeared recently in Newfoundland outlining the provision of services and programs for handicapped children that the provincial government will act on in the future.

One major report in Canada, One Million Children, (Commission on Emotional and Learning Disorders in Children, 1970) made 144 recommendations with regard to special services for exceptional children in Canada. One of the major recommendations was that there be much greater integration of the efforts of governments, not just at different levels, but between departments and far more responsibility for decisions that affect the life of a child be taken by those who are close to the child. The basic philosophy behind the report was that every child should be given the opportunity to develop the normal aspects of life and to become a fully functioning human being. Similarly, in England, there was the Warnock Report (1978), Special Educational Needs: Report of the

Committee of Enquiry into the Education of Handicapped Children and Young People. The overall recommendation of the Warnock Report was that emphasis in special education for the handicapped population be placed on the needs of the particular person at a particular time. Special Education, as outlined in the report, "encompasses the whole range and variety of additional help, wherever it is provided, whether on a full or part-time basis, by which children may be helped to overcome educational difficulties, however they are caused" (p. 47).

One great change that accompanied these significant landmarks in the United States, in Canada, and in Great Britain, was the vocabulary and labels used to describe the child with special problems or difficulties. In the earlier years the designations of handicapped, deviant or atypical were used to describe the child with special problems. Cruickshank and Orville (1975) argues "that these terms imply negative qualities which were and are opposed by parents of the child, by the children themselves, and by adults who are disabled" (p. 9). In recent years, the concern over these connotations has increased and the use of such terms are being discarded and terms such as exceptional child is being adopted. For example, Hobbs' (1975) study, Futures of Children, calls for a minimimum of inappropriate classification, labeling, stigmatization and alienation of children and for the provision of needed services to the child and the family on a continuous developmental basis.

The term 'exceptional child' is an umbrella-like term which encompasses many different groups of children and many different degrees of disability within each category. Kirk and Gallagher (1979) offers the following general definition of the exceptional child:

> the child who deviates from the average or normal child (1) in mental characteristics, (2) in sensory abilities, (3) in neuromotor or physical characteristics, (4) in social behavior, (5) in communication abilities, or (6) in multiple handicaps. Such deviation must be of such an extent that the child requires a modification of school practices, or special educational services, to develop to maximum capacity.
> (p. 3)

In recent times, the medical disciplines have tended to adopt the terms "developmentally delayed-developmentally disabled" to refer to children who have been variously labeled in the past as exceptional children, children with special needs, handicapped children and so forth. The terms developmentally delayed-disabled give a more positive preventive connotation of the child with special difficulties.

The starting point for the evolution of the concept of developmental disabilities can be considered to be the appointment of the President's Panel on Mental Retardation by United States President, John F. Kennedy, in 1961. A broad definition of developmental disabilities, written for legislation, provides only a general outline, so it may be meaningful to differentiate and define the terms developmental delay, developmental deficit and developmental disability. Thompson and O'Quinn (1979) make such a distinction between developmental delay, developmental deficit and developmental disability. They state that whenever an aspect of functioning is not demonstrated by an individual, at an age when the majority of children of similar age demonstrate it, the individual is considered to be exhibiting a developmental delay. If the individual's system is not functioning appropriately, the discrepancy in functioning may reflect a developmental disorder; however, if the system in question is not damaged, the discrepancy between functioning level and expectancy may reflect a developmental delay. If the delay or disorder persists throughout life and hampers the person's adjustment, it can be considered a developmental disability (p. 16).

The whole subject of labeling has been under intense discussion since the 1960's. Hallahan and Kauffman (1978) have stated that "we must be careful not to let labels for handicapping conditions lead to inappropriate restriction on children's exploration of their environment and participation in activities" (p. 421).

Data on behavioral effects of labeling are sparse and not totally trustworthy. Deno (1970) argues that categorical constructs based on presumed child defects is merely a cluttering administrative layer which interferes rather than helps the handicapped child. Gallagher (1972) has pointed out that much of the present support for special education has come about because of the:

> fine mixture of compassion, guilt and social conscience ... established over these many years as a conditioned response to such labels as mentally retarded, learning disabled and emotionally disturbed.

Moss (1973) has noted that a label is useful only insofar as the generalizations made with regard to that label apply to the specific child thus categorized.

The increased concern over legislation for the child with special needs and appropriate labeling of such children has contributed to the overall movement towards normalization by our society. According to Hallahan and Kaufman (1978), normalization "is the philosophical belief that every exceptional child should be provided with an education and living environment as close to normal as possible" (p. 31). The trend towards normalization ranges from mainstreaming to de-institutionalization and increased involvement of parents in the treatment of the child at home.

Mainstreaming, or process of the least restrictive environment, according to Kirk and Gallagher (1979) means:

> that the child should be taken from the regular classroom only when it is not possible to deliver the needed services within the regular classroom, that a special class should be established only when it becomes obvious that a part-time resource room or teacher is not adequate to do the job and that the child should be institutionalized only when all other efforts to provide good education within framework of the local school system have failed (p. 19).

Deno (1970) describes a "cascade system" which is designed to prioritize the array of special education service delivery alternatives available for a child from most to least restrictive. The overall goal for children in special education should always be to prepare each student to move into a less restrictive educational setting (Lilly, 1979).

Mainstreaming or procession of the least restrictive environment has become the focal point of much controversy, with much research results appearing to be contradictory. For example, Frederick et al. (1978) reports favorable results, while Reynolds and Berch (1977) report unfavorable conclusions. In the 1965 study of Goldstein, Mass and Jordon, the point was made that special classes were no worse than regular classes in fostering academic achievement but in special classes there are benefits other than academic achievement. Dunn's (1968) study showed some of the negative effects of labeling children by placement in more restrictive self-contained classroom environments for the borderline retarded child. Blatt (1977) states that no supportable evidence of the advantages of special education classes for the borderline retarded child has been identified. Smith (1976) revealed that principals, regular classroom teachers, and special education teachers are in close agreement on which categories of special education children should be mainstreamed. There was no support for the mainstreaming of trainable retarded, emotional disturbed or behavioral disordered children. Gottlieb and Baker (1975) analyzed the social acceptance of 291 educable mentally retarded children in relation to the amount of time spent in the regular grades. When the children spend 25 per cent of their time in the regular class, they were more socially accepted by their peers than when they spent 75 per cent of their time in the regular class.

One of the real issues involved in mainstreaming is the new responsibilities for the regular teacher. McGinity and Keough (1975) found, in interviews with forty-four teachers, that 88 per cent were of the opinion that they needed to know about the characteristics of exceptional children but only 27 percent felt qualified in the area. Gottlieb and Associates (1976) also have doubts on the ability of the regular class and its teacher to cope with the academic instruction of educable mentally retarded children. Sarason & Sarason (1977) argue that many school systems and regular teachers are not prepared to deal with mainstreaming or are only minimally beginning to meet the extent of mainstreaming. They further suggests that school personnel are perceiving mainstreaming largely in terms of non-retarded, handicapped persons. According to Lilly (1979), if mainstreaming is to succeed, the regular teachers must have course work and practice in the area of special education.

Another trend in the area of exceptionality and special education is the increased focus on the importance and usefulness of early intervention with children and their parents. According to Karnes (1973):

> One of the most universally accepted propositions in special education has been that the earlier one can apply appropriate treatment responses to the child and the families the more effective special education will be (p. 171).

Karnes and Teska (1975) reviewed the growing literature on the effect of intervention programs on young children and reached the following conclusions:

> Can the developmental status of children be changed through deliberate programming? The answer to that from the available research is "yes". It is possible to move groups of children from one-half to one standard deviation higher on measures of intellectual ability. There is substantial evidence that many children will lose the temporary gain in intellectual ability as measured by standard tests, but will keep achievement and motivational gains for a longer period of time. This is substantial evidence to support the general principle, "the earlier the instructional program is begun, the better." While all studies did not show age differentials, those that did invariably showed the younger children in the program to be responding at a greater rate of gain than those who were older. (p. 219)

As far back as 1939, Skeels and Dye describe a study conducted in an institutional environment in which infants were either provided care and stimulation by retarded adolescent girls or were left in unstimulating environment. Skeels follow-up study (1966) found that the experimental children had become productive, contributing members of society, while the other children, for the most part, continued being a costly societal responsibility. Kirk's (1958) classic study showed the value of nursery school experience for young (ages 3 to 6) retarded children over an extended period of time. Bloom (1964) states that "in terms of intelligence measured at age seventeen, about 50 per cent of the development takes place between ages four and eight and about 20 per cent between ages eight and seventeen." Caldwell (1970) had done an excellent job of establishing a rationale for early intervention and cites a sufficient amount of inferential and empirical evidence to support the notion. There appears to be a large amount of support for the popular belief that early detection and intervention are not only possible, but are, in fact, recommended and desirable procedures (Friedlander, Sterrett & Kirk, 1975; Hunt, 1961).

Studies have also shown that there is a characteristic decrease in the developmental quotient of Downs Syndrome children in their early years (Carr, 1970; Centerwall & Centerwall, 1960). Ludlow and Allen (1979) confirms the other studies in that early intensive pre-school stimulation reduced the decline in the developmental quotients of Downs Syndrome children and enabled them to more nearly reach their full potential. Kochanek (1980) presents a review of surveillance programs for infants and young handicapped children conducted by physicians. Results imply that early identification programs should include the following:

(1) screening systems with multiple sources of data upon which decisions can be made;
(2) screening to include assessments of transaction between child and care-givers;
(3) surveillance should be conducted over time rather than a binary outcome procedure.

In the United States, there has been a movement to provide services to preschool handicapped children. This is evident in the passing of bills by the United States Congress, for example: The Handicapped Children's Early Education Act (1968) and the Developmental Disabilities Act (1975). These Acts encourage programs and services for pre-school handicapped children.

The growth of early identification and intervention programs for young handicapped children has been paralleled by an increased involvement of parents in the education of their children. According to George Shepard (1971), family members should no longer be considered incidental to the formal program necessary to remediate and/or develop learning and behavioral skills of the children. One of the most recent steps in the encouragement of parent participation was the certification of the rights of parents as full-fledged and active participants in the programs for their children through the United States Public Law 94-142, the Education for all Handicapped Children Act. As well, there has been un upsurge in the number of parent groups across Canada and the United States; for example, in Canada there is the Canadian Council for Exceptional Children, associations for various other disabilities, and in the United States there are similar groups, such as the Association for Children with Learning Disabilities, National Society for Autistic Children. These groups are beginning to take an active role in the education and planning for their children's futures as exceptional individuals.

The necessity of parental involvement is acknowledged by many professionals working with young children. Fraiberg 1975, Bricker and Bricker, 1976, Bricker and Casuso, 1979, all support the notion that the inclusion of parents in the intervention program is a necessary activity if the child is to make maximum developmental progress. Reviews by Levenstein (1971), Ryan (1974) and by Brofenbrenner (1975), reconfirm the positive roles that parents can play by actively participating in the programs for their children. Hunt (1975) argues that programs designed to modify the parent-child interaction in the home have proven to be effective in producing permanent change in the child. However, the parent participation must be more than merely approving or disapproving an educational plan, it must be arranged so that the parents can contribute their knowledge and also learn from others more formal knowledge.

The Austin Early Childhood Special Education Program, _The Parent Program 1976_, illustrates a method for involving the parents in the child's total program and it stresses providing a wide variety of services for the parents, including support, understanding, and cooperation by professionals. Several other models have been implemented recently to encourage the involvement of parents in the remediation programs for their children. For instance, the Portage Parent Program (Richard D. Boyd, Kathleen A. Stauber and Susan M. Bluma, 1977) stresses involvement of the parents in furthering their child's development. It instructs the parents in more appropriate parenting and child management skills. The Direct Home Services Program of the Department of Social Services, province of Newfoundland, illustrates another effort to involve parents in remediation and treatment programs for their children at home. The Parent

Outreach Program of the St. Louis Association for Retarded Children operates to link parents who are already raising children with disabilities and new parents of disabled infants. It represents a new approach to involving parents in the education of their child.

There seems to be several advantages in educating and working with the exceptional child's parents as primary agents of behavior change and skill building in the home. Wieder and Hicks (1970) evaluated an early intervention program for young cerebral palsied infants and their parents. Results found it to be successful in affecting the adjustment and attitudes of the mothers rather than the fathers. Also, there was significant growth in physical, social, emotional and intellectual areas for the children. Bryant (1971) shows how the parent-child relationship can often impede habilitation and rehabilitation. He suggests that working with parents can help to improve the parent-child relationship and result in better adjustment for the parents and for the child and maximal success of the rehabilitation program. Lovaas et al (1973) argues that the treatment of a developmentally delayed child, without parental training and counseling, can result in limited or transient effects for the child. Brofenbrenner (1975) feels that the ultimate success of any intervention program with young handicapped or culturally deprived children depends on the involvement of the parents in that program.

Villane (1976) explains that parents are likely to be therapeutically powerful because of their emotional relationship to the child and the time they spend with them. It can also be hypothesized that learning in the child's natural environment overcomes to some extent the problem of transfer from school to home. As well, by working with parents, the parents will learn more effective parenting skills which may generalize to other situations and other siblings. Forehand and King (1977) examined the effects of parent behavioral training on children's non-compliant behavior and on parent behavior and attitude change. After treatment and a three month follow-up, children were perceived by mothers to be better adjusted than prior to treatment. An economically disadvantaged toddler, with a developmental lag, was involved in a preventive oriented behavioral intervention program. The results showed increases in child's compliance to parental requests and parental use of praise.

Recently, several programs involving parents in the treatment of their children have been introduced in the area of special education. For example, The Pilot Parent Program (Porter, 1978) is designed to have parents of handicapped children help other parents who have recently learned that their child has a handicap. Diana Bricker and Valerie Casusa (1979) describe a parental involvement program that is an integral component of an early intervention program for preschool moderately and severely handicapped children involving their parents. A transdisciplinary approach to parent involvement by Geneva Woodruff (1980) has been developed to deal with areas of assessment, diagnosis, goal setting, planning, program implementation and evaluation of program and child.

In the early literature on exceptional children there was little mention of the parents of these children, or their feelings and sensibilities; however, in more recent years there has been an increase in literature available on the topic. For example, Banta (1971) argues that:

> if a handicapped child has the right to aspire to the highest level of functioning and achievement possible in the light of his handicaps, and thereby have the most satisfying and productive life possible, his parents and other members of his family have the same rights. (p. 12)

Hewitt (1977) argues that in our diligence to help the child, not only are the rights, feelings and the appreciation of parents passed over, but the enormous task which confronts all parents, namely the task of coping with the needs of the total family, is frequently ignored. Seligman and Seligman (1980) state that an increased awareness and understanding of the families of exceptional children has recently occurred, with particular emphasis on the impact a disabled child has on the family. It becomes obvious that problems which arise from the presence of a handicapped child in the family are as much an appropriate concern of organizations serving the individual child as the problem of treatment of the child.

Many writers have commented on parents' initial reactions to the pressure of having an exceptional child. Villane (1976) states that the birth of a handicapped child strikes at the vital core of the parent. He further explains that from the very beginning the parents may become somewhat frightened and concerned, guilty and anxiety ridden. They may tend to worry about the child's diagnosis, where to go for treatment, the child's slow progress, costs of treatment and educational plans for the child. Love (1970) also argues that the presence of a handicapped child in any family group tends to result in emotional reactions by the parents and the reactions vary in degree and type with the characteristics of the parents. Whether or not the event becomes a crisis depends on three basic conditions: (1) the nature of the event, (2) the resources of the family, and (3) how the family defines the event (Chinn & Chinn, 1974, pp. 26-33).

Seligman and Seligman (1980) point out that in the past parents were usually automatically considered responsible for the child's problem and as emotionally unstable. Their conclusions suggest that looking at the family of a developmentally delayed child as emotionally unstable reflects a jaundiced and negative view of families who happen to have a child with a disability. It is increasingly important to view parents as valuable essential components in the child's treatment instead of considering them unstable. As well, it is important to note that the individual child and his disability affects all the members of the family, their behavior, and, in turn, affects the child. Freedman and his co-workers (1957) have described this circularity in an intensive study of fourteen children suffering from a chronic physical disorder.

An almost infinite variety of initial and later reactions of parents have been described such as: shock, refusal, guilt, bitterness, envy, frustration, confusion and so forth. Kubler-Ross's mourning model (On Death and Dying, 1969) provides a developmental perspective for viewing such reactions of parents. Their reactions progress through stages of denial, anger, bargaining, depression to acceptance.

As far back as 1959, Graliker, Parmelee and Kock interviewed parents in 67 families who had obtained diagnostic services in a clinic and found 40% experienced guilt, shame and rejection as a result of diagnosis; 33% experienced concern over financial cost and why it happened, while 30% experienced concern over reactions of friends. According to Zuk (1962), parents' reactions fall into three major categories: disappointment, anger and guilt. Dalton and Epstein (1963) point out that parents may be depressed about disappointment, guilty about their responsibility and ambivalent and angry about injury done to them and anxious about the future. The Noland (1970) study of the reactions of parents showed that parents feel guilty, tend to blame others for problems, some feel personally defective, sorrow, rebellion against destiny, regret, concern about child's future, and some look for reassurance and information on cause for child's problems. Love (1970) identifies parental reactions such as shock, refusal, guilt, bitterness, envy and rejection. Kinney and Payne (1973) also identify parental reactions, such as guilt, marital discord, and frustration.

Gordon (1976) suggests that the birth of a handicapped child often causes parents to seriously doubt themselves and their worth as procreators and individuals. Searl (1978) talks about the feelings that he experienced as a parent of a retarded child. He refers to the feelings of mortality and death for himself and his child which led to feelings of resentment, guilt and betrayal, also feelings of failure and frustration with his child. He also experienced a sense of bitterness, fear, and anger about society's reaction to the mentally retarded, a great sense of committment and time alloted to a mentally retarded child, which often results in depression and anxiety of the parents. In conclusion, Searl feels that parental reactions do not fit into any one particular pattern that assumes people will "get over it."

The one reaction that appears prevalent among parents of disabled children is that of guilt. Wolfensberger (1971) points out that guilt can be associated with the reaction "Why did it happen to me?" and "What did I do to cause this problem?" Another part of the reaction could be a result of the parents' impulses at times to reject the child. Gordon (1976) suggests that parents of handicapped youth must often deal with thoughts and feelings they find unacceptable or damaging. He further reports that in meetings with groups of parents, the frustration, anger and helplessness has sometimes exploded into admissions of tremendous guilt over these wishes. Guilt feelings are also associated with parents' felt needs for vacations, periods of time to be away from the child.

An associated reaction to guilt is that of frustration. Grebler (1952) saw frustration as a result of social and asthetic stigmentation, lack of services, financial concerns, slow maturation, effects in upholding limits and the feeling that "the stream of the generation is stopped." Olshansky (1962) proposed that some parents experience another psychological reaction identified as chronic sorrow, particularly if the child is severely impaired. Cohen (1962) cautions not to mistake the parents' realistic initial grief reaction as inability to accept the handicap.

It is being increasingly recognized that these parental reactions and feelings can be grouped into stages of adaptation to the child with special problems. Rosen's study (1955) suggests a five stage model through which parents of children with disabilities or delays progress from the time they first become aware of their child's problem until they come to accept their child and the disability. These stages are (1) awareness of a problem, (2) recognition of the basic problem, (3) search for a cause, (4) search for a cure, (5) acceptance of the problem (Rosen, 1955, p. 18). Rosen's (1955) model identifies needs of parents in the following categories: (1) communication, (2) explanation of ethiology (medical-theological), (3) search for a cause, (4) search for help, (5) maintaining a normal family life, (6) providing for the child's future. Grays (1963) and Koegler (1963) view parental development in four stages from guilt to shame, to knowledge and understanding, to acceptance and to help for the child so that he can achieve his potentiality. Robinson and Robinson (1976) describe stages of parental reactions:

> The first stage is characterized by an awareness that a serious problem exists, the second by recognition of the retardation for what it is, the third by a search for a solution, the fourth by a search for a solution, and the fifth by acceptance of the problem, a goal which is seldom fully attained. (p. 43)

Drotar, Baskiewiz, Irwin, Kennell and Klaus (1975) interviewed 20 parents of children with a great variety of congenital malformations, including mongolism, congenital heart disease, cleft palate. Results show that parents seem to struggle with common issues and go through similar stages of reactions. These include: (1) shock, (2) denial, (3) sadness, anger and anxiety, (4) adaptation, (5) reorganization. Seligman and Seligman (1980) also suggest that families go through stages as they adjust to the child and the disability. As well, they argue that it is necessary for professionals who work with parents of disabled children to understand coping mechanisms parents use during different adjustment phases.

According to Love (1970), the relationship between a retarded child and his family is not only more complex and ambivalent than the ordinary one, but also more intense and prolonged (p. 42). Hewitt (1977) argues that as a parent in such a relationship, it is only natural and necessary to consider the parents as having special concerns and needs. Mura Skelton (1972) interviewed 90 parents of retarded children. The parents identified seven prime areas of concern as most troublesome to them. The seven areas were: (1) training and education for the retarded child, (2) the retarded child interfering with family life, (3) other family problems interferred with the ability to care for the retarded child, (4) physical care and protection were sought for the retarded child, (5) a living situation was sought for the child, (6) recreation and companionship, (7) problems in the community. The seven major areas of concern can be grouped under three broad headings:

A) Concern for the welfare of the child;
B) Concern for the welfare of the family;
C) Concern for the welfare of the community.

Telford and Sawrey (1972) provides another model of the needs of parents with developmentally delayed children. These may include the following: (1) need for information concerning the nature and extent of the child's exceptionality; (2) need to know probable cause of their child's condition - etiological information; (3) need for information concerning facilities and services available for the care, treatment and education of these children; (4) need to be informed of what the future may hold for the handicapped; (5) need to know of the specific programs which are most appropriate to the needs and capabilities of their child; (6) need to have someone help them with their attitudes and feelings, fears, guilt, shame; (7) need to receive help in reducing emotional vulnerability of the family members;

(8) need for assistance in behavior management of child at home.

Dor (1974) interviewed 51 families of children with cleft palates and results showed parental concerns in the following areas: (1) care of child at home; (2) age for surgery; (3) duration of treatment; (4) embarrassment before others; (5) mental ability of child; (6) cause of the cleft palate; (7) risk in future pregnancies; (8) chromosomal tests to detect cause of problem. Study also suggested that parental concerns change over time. For instance, the first concerns of these parents were about care, future of child, and embarrassment before others, and their first needs centered on counselling to deal with problem and explanation of the treatment and care of the palate. Later, concerns of these parents centered on the cause of the malformation and the risk for future pregnancies. At this time, the parents felt a need for counselling to deal with feelings of guilt, accusations and family tension. Pannbacker (1977) interviewed 36 parents of children with cleft palates and his results indicated that parents' needs include the following: (1) accurate information about the cleft palate; (2) counselling and guidance to achieve understanding and acceptance.

Deminski & Mauser's study (1974) showed that parents of learning disabled children were requesting an honest evaluation of their child's problem and capabilities, a deemphasis on the use of professional jargon or terminology, an emphasis on immediate relevant advice on vocational outcomes, inclusion of parents in any conferences or meetings and an interdisciplinary approach to work with the child and parent. The Drotar, Baskiewiz, Irwin, Kennell and Klaus (1975) study suggests that parents need paediatric advice and support and counselling during the child's first year of life to enhance the quality of the mother-father-child relationship.

Bassin and Drovetta (1976) further point out that the discovery of a developmentally delayed child is a life shaking experience and parents often look for other parents who are in the same situation or have gone through a similar experience to provide them with hope, encouragement and information. Bechmer (1976) talks about her feelings as a parent of a child with a disability. She identifies feelings of grief, guilt, shame and the need for counselling to help the parent begin to deal with the fact of the disability without the need to blame. She also suggests that becoming part of the professional team in helping the child can overcome some of the feelings of hopelessness and frustration. She also feels there is need for someone to share the work and restriction of taking care of a handicapped child. An important need, according to Bechmer, is to maintain a balanced life, to go out as a couple, to maintain a social and personal life.

Thomas and Marshall (1977) also recognize that parents of a child with a disability have certain needs and go through certain processes. These may include: (1) modification of the initial maternal touching at birth (Klaus, Kennell, Plumb, and Zueheke, 1970); (2) initial regression and disorganization (Goodman, 1964); and (3) parental reactions such as anger, depression, denial, marital strain and deterioration of religious belief (Drota, Baskiewiz, Irwin, Kennell & Klaus, 1975; Stone, 1973). Arlene Swirsky (1977) outlines particular concerns - needs of parents with regard to : (1) the medical personnel and medical diagnosis of the child; (2) Hospitalization of child; (3) education of the child; (4) reaction and adjustment of other siblings in the family; (5) living with yourself and your family; (6) relationship with friends; (7) relationships with individual child. She further suggests that parents should be in touch with their own needs and try to satisfy them because, unless as a parent you are physically and mentally healthy, everything can crumble (p. 47). Becker and Bender and Kawabe (1980) talk about the number of difficult problems that parents of exceptional individuals may face. This list might include: inability to receive a reasonable and understandable diagnosis, lack of information as to services available to the child and the family, psychological and emotional problems related to guilt, feelings of inferiority and financial difficulties.

Needs Assessment

The increasing emphasis on the needs of parents with developmentally delayed children has been facilitated by the utilization of needs assessment studies. In the last few years, the whole area of needs assessments has received increased attention in various fields, such as special education, health and so forth.

Perhaps the best description of needs assessment was made by Coffing and Hutchison (1974):

> Who needs what, as defined by whom? Who refers to the needs of specific individuals such as parents, what refers to the categories of needs about which data are required and defined by whom refers to the necessity for identifying which people should define the needs.

Fear (1978) has offered another definition of needs assessment "as being a systematic process for documenting relevant needs." Carter (1978) further argues that need assessments are an important part of the overall planning process for programs. He states that if programs are designed to enhance quality of life, then it is important to first identify important needs and assign priorities to these needs. Bell (1977) agrees with Carter when he says that programs being anticipated or encouraged must be tied directly to identified human needs (p. 3).

Need assessments, according to Pierce (1976), consist of at least four steps: (1) gathering the data; (2) assessing the data to determine needs; (3) utilizing the data and assessment for the development of a comprehensive program; (4) informing the public about activities. Bell (1977) also talks about the five basic components of need assessments studies. These include the following: (1) constructing need models; (2) translating need models into measurables; (3) measuring procedures; (4) identifying solutions; (5) implementing solutions. Marrs & Helge (1978) also talk about the various major components of the need assessment study, i.e., (1) setting standards; (2) need assessment process; (3) data reporting; (4) use of need assessment data.

The various approaches of need assessments has also been described by Bell (1977). The approaches include: (1) key informant, (2) community forum, (3) service utilization, (4) social indicator, (5) citizen survey. Rookey (1976) presents a need assessment model with four major tasks: (1) goal definition, (2) program assessment, (3) needs identification, and (4) decision making. He further states that his model is a blending of community participation and evaluation and that his need assessment model begins an orderly system of planning and development.

Pierce (1976) feels that to be most realistic, a need assessment must include some indication of what people want now and will want in the future. Unfortunately, the development of new programs usually results from informal need assessment. Typically, this relatively informal need assessment produces a statement from someone to the effect, according to Marrs and Helge (1978), "It seems like something ought to be done regarding ..."

According to Coffing and Hutchison (1974), students, parents, employers, taxpayers and others are demanding that programs meet their needs and they are less willing than in the past to have educators define their needs. He further argues that people's needs are among the basic criteria for designing and for evaluating services. Marrs and Helge (1978) support this notion when they state that "the early ongoing assessment of needs prior to the development of program plans, which are frequently "locked in", is a mandatory prerequisite for optimal adaptive organizational behavior" (p. 144). He feels that programs would be different and better if educators began every new program by conducting a comprehensive assessment to determine actual needs.

An important component of need assessment studies, according to the National Institute of Education (1976), is the centrality of systematic ongoing assessment. Similarly, Marrs and Helge (1978) support the notion of initial, as well as ongoing, continual need assessment as an integral part of any program/project.

Methodology

The following describes the general statement of procedure, definitions, sampling procedures, as well as measurement and statistical methods in analyzing the data of this study.

Procedure

Fear (1978) defines need assessment "as a systematic process for identifying and documenting needs." Various techniques and instruments have been used to systematize such assessment. For example, researchers have used observations, functional assessment inventories, self reports, standardized tests, structured and unstructured interviews and so forth.

Kerlinger (1964) states that:

> the best examples of survey research use the personal interview as the principal method of gathering information. This is accomplished in part by the careful and laborious construction of a schedule or questionnaire. (p. 412)

The structured personal interview used in this need assessment consisted of an interview schedule which had been carefully prepared to obtain information on the needs of the parents. Its questions, wordings and sequences are fixed and structured so as to obtain the following sources of data (Kerlinger, 1964): (1) face sheet (identification) information; (2) consensus type (sociological) information; and, (3) problem information. The primary focus of the interview schedule is on obtaining information concerning the parents' feelings, expectations and needs (consensus-type data).

The interview schedule is constructed according to an open-ended item format. Kerlinger (1964) defines open-ended questions:

> as those that supply a frame of reference for respondents' answers, but put a minimum of restraint on the answers and their expression. While their content is dictated by the research problem, they impose no other restriction on the content and manner of respondent answers. (p. 483)

A special type of open-ended question utilized in the structured interview was the funnel. The funnel question starts with a broad question and narrows down progressively to the important specific point or points. Kahn and Cannell (1957) say that the funnel has the purpose of preventing early questions in a sequence of questions from affecting those that come later and of determining something of the respondent's frame of reference" (p. 349).

Using a structured interview with an open-ended funnel item format has certain advantages and disadvantages. First of all, the advantages are:

(1) The interviewer can stimulate respondent's initial interest.
(2) The interviewer can create a supportive atmosphere for answering.
(3) There is more flexibility in asking questions.
(4) The interviewer can reduce problems associated with the educational level or visual acuity of the respondent.
(5) The interviewer can control the sequence of the questions.

The disadvantages are:

(1) The time needed for administration of the interview.
(2) The possible personal bias of the interviewer in administration of the interview.
(3) It may be uncomfortable for respondent to answer personal questions in front of a stranger (Forcese & Richer, 1973).

In consideration of the advantages and disadvantages of the interview method, it can be regarded as an appropriate tool of research in that it is flexible, adaptable and useful in situations when no other method is possible. For this study, the interview method is most appropriate as it allows for probing and questioning about the parents' needs, feelings and anxieties in such a way that accurate information is received from the parents. It is felt that the data that the study has searched for, such as the parents' personal feelings, concerns was more readily obtained through the use of a structured interview than a questionnaire type format. It is difficult for a person to express these personsl concerns by a yes or no answer. As well, a lot of the data will be obtained more through the informal interview with the parents than with the return of a questionnaire. Based on the nature of the sample, it is recognized that many of the parents may be apprehensive about the study and its purpose and unwilling to complete a mailed questionnaire. With a structured interview there would be opportunity for the parents to test out the purposes of the study and the interviewer. It is also a great possibility that many parents in the sample may be unable to read or write which would interfere with their completion of a questionnaire format. Hopefully the interview format would overcome the problem of possible illiteracy. These statements of support for the interview technique of data collection combine to suggest and justify the utilization of the interview method for this need assessment study. Kerlinger (1964) supports the choice of the interview method and argues that "the interview, when coupled with an adequate schedule of pretested worth, is a potent and indispensible research tool, yielding data that no other research tool can yield" (p. 487).

Further support for the utilization of the interview method comes from Sjoberg (1967) in his view:

> the standardized structured interview offers decided advantages in terms of efficiency, it eliminates needless questions and analysis can be formally built into the design of the interview schedule so that the more formalized the questions, the simpler the coding, computing and tabulation processes. (p. 193)

Several procedures were followed in the construction and implementation of the interview schedule to increase the appropriateness and comprehensiveness of the questions in the schedule. Firstly, the interview schedule was evaluated by experts in the field as to its potential flaws and weaknesses. These experts were the following professional persons: (1) Dr. Norm Garlie, Associate Professor, Educational Psychology Department, Memorial University; (2) Dr. Michael Steer, Special Services Coordinator, Department of Education; (3) Mr. Donald Gallant, Director, Home Services Program; (4) Dr. Norm Hadley, Associate Professor, Memorial University. These experts remarked that the interview schedule was well constructed with minor changes needed in grammatical structure and wording of the schedule. Secondly, the schedule was piloted with a small sample of parents with developmentally delayed children prior to the final construction of the schedule to obtain feedback as to its potential accuracy in obtaining information on parents and their needs. Thirdly, in the implementation of the interview schedule, the interviewer used careful phrasing and asking of questions and skillful handling of the interview to ensure maximum response from the parents. The final procedure to ensure maximum efficiency in the interview method, was to attempt to audio tape record all interviews with parents, solving some of the problems of recording verbatim responses. However, due to refusals from parents to have interviews tape recorded, an alternate method to be employed involved the written recording of verbatim responses. See Appendix E for interview protocol for parents in the study.

Definitions

One of the current controversies is the alleged harmful effects of classifying or categorizing children under various labels. Another difficulty with such labels is that each label has been developed and tends to be used by a particular discipline or helping profession. For example, the medical profession tends to use the term developmentally delayed, developmentally disabled; on the other hand, the education profession tends to use terms like exceptionality, exceptional children or educable mentally retarded children while the rehabilitation profession would most likely use the terms handicapped, disabled to describe children with the special needs.

Kirk (1972) offers a definition of the exceptional child which is often used by the education profession:

> An exceptional child is a child who deviates from the average or normal child (1) in mental characteristics, (2) in sensory abilities, (3) in neuromuscular or physical characteristics, (4) in social or emotional behavior, (5) in communication abilities, (6) in multiple handicaps to such an extent that he requires a modification of school practices or special education services in order to develop to his maximum capacity. (p. 4)

In Public Law 94-142, handicapped children are defined as follows:

> handicapped children means those children ... evaluated as mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired, other health impaired, deaf-blind, multi-handicapped or as having specific learning disabilities, who because of those impairments need special education and related services. (U.S. Office of Education, 1977, p. 42478).

The term developmentally delayed-disabled has been associated with the medical profession and other related health fields. Thompson and O'Quinn (1979) help to differentiate the term into developmental delay, developmental disorder and developmental disability. Developmental disabilities are assessed in relation to the normal development of systems, capabilities and functioning and children with developmental disabilities go through basically the same series, steps and sequences of development as do other children; however, their development occurs at a slower rate than that found in most other children. According to Thompson and O'Quinn (1979),

> whenever an aspect of functioning is not demonstrated by an individual at an age when the majority of children of similar age demonstrate it, the individual is

> considered to be exhibiting a developmental delay or developmental disorder. If the system in question appears to be intact and not damaged, the discrepancy between functioning level and expectancy may reflect a slowness in rate of development (a developmental delay). (p. 16)

A developmental disorder refers to the situation when the system in question is not functioning appropriately and there is a discrepancy in functioning. Any developmental delay or disorder that persists throughout the life and hampers a person's functioning or adjusting can be considered a developmental disability.

For the purposes of this study, the term developmentally delayed children was used to refer to those children variously labeled as exceptional children, handicapped children, developmentally disordered-disabled children and other such labels. Consideration of the various categories and labels leads to the following definition of a developmentally delayed child:

> Any child between the ages of birth to 22 years who deviates from the average or normal child (1) in mental characteristics, (2) in sensory abilities, (3) in neuromuscular or physical characteristics, (4) in social or emotional behavior, (5) in multiple handicaps. The following categories will be included under the term developmentally delayed child. (Kirk, 1972)

(1) Mental Retardation
  a) Educable
  b) Trainable
  c) Custodial

(2) Visual Impairments
  a) Blind
  b) Partially Blind

(3) Hearing Impairments
  a) Deaf
  b) Hard of Hearing

(4) Speech Impairments
    a) Delayed speech
    b) Stuttering
    c) Cleft Palate
    d) Voice disorders

(5) Special Health Conditions
    a) Diabetes
    b) Cystic Fibrosis
    c) Asthma
    d) Clubfoot

(6) Neurological Impairments
    a) Cerebral Palsy
    b) Multiple Sclerosis
    c) Epilepsy
    d) Muscular Dystrophy

(7) Emotional Disturbance
    a) Behavioral Disorders
    b) Severe Emotional Disturbance

(8) Multiple Handicapped
    a) Deaf-Blind
    b) Hearing Impaired Mentally Retarded
    c) Cerebral Palsy with Mental Retardation

This definition was in accordance with the Psychology Department of Western Memorial Regional Hospital, Corner Brook.

It was also recognized that some children with developmental delays may not be living with natural parents but will be living in foster homes, group homes or in institutional settings; therefore, for purposes of this study, the term parent was used to refer to the primary caretaker or adult referred to as a child's guardian.

Sampling

The population for this study was defined as all parents with developmentally delayed children in the selected communities of Curling, Summerside, Benoit's Cove, Lark Harbour, Cox's Cove, Massey Drive, Steady Brook, Pasadena, Gallant's, Stephenville, Stephenville Crossing and St. George's in the Western Region of the Province of Newfoundland.

These communities are all included in the Western Memorial Regional Hospital District. The hospital and all its departments, including psychology, provide a service to persons from these communities. As well, these communities have some similar features in that they are rural home based communities, located within 70 to 80 miles from the Regional Hospital, Corner Brook, with similar concerns and problems.

The provincial registry of handicapped persons, the register lists of children in special classes for educable retarded children and schools for the blind and the deaf, as well as all children seen in the Public Health Clinics, was used to obtain a complete list of the population from which a sample was selected.

The provincial registry of handicapped persons was established in 1973, as an interdepartmental responsibility of the Departments of Health, Education and Social Services. The overall objective of the registry is to ascertain, record and classify persons with handicapping conditions for the province of Newfoundland and Labrador, so as to provide a reliable base for estimating the prevalence, incidence and distribution of specific conditions among the population and to serve as a basis for developing helping services and follow-up. The criteria for registration includes the following: any person aged birth to 21 years of age who has a handicapping condition which would necessitate a significant modification of normal educational approaches within the regular class or placement in a special class or school; who requires continuous medical supervision, as well as requiring special services for the future and who will experience difficulties with open employment in the future.

Multiple sources are used by the Registry to obtain names of persons for their list. The following departments and agencies are used:

(1) Community Health Nurses
(2) Social Workers
(3) Physicians
(4) Canadian National Institute for the Blind
(5) Special Schools and Classes
(6) Special Treatment Clinics
(7) The Dr. Charles A. Janeway Child Health Centre
(8) The Rehabilitation Centre
(9) Hospitals
(10) Division of Statistics and Research, Department of Health

To date, approximately 3,000 handicapped children have been registered. The following is a breakdown of those that have been registered:

1300	Mentally Retarded
1200	Physically Handicapped

331 Hearing Impaired

179 Visually Impaired

Certainly, no list can be taken at face value and it should be examined for any possible bias. The register lists of children in special educable mentally retarded classes and schools for the blind and the deaf were cross-checked with the registry of handicapped persons and all of the children on these lists were found to be on the registry. It is suggested that the milder cases of developmental delays or disabilities may be missed by the registry and parents who have no contact with the Department of Health, Department of Social Services and/or Department of Education may not be identified and registered on the list. The Western Memorial Hospital, especially the Psychological Services, also operate through the same referral sources as does the registry. It is felt that the children with the more obvious and severe delays would be the clientele for the services at Western Memorial Regional Hospital than the milder types of delays and disabilities. As well, the hospital accepts referrals of children with similar types of delays as identified in the registry.

The final source for the sample involved children and their parents being seen at the Community Public Health Clinics in the selected communities on the western region of the province of Newfoundland. These children may represent some of the milder delays and disabilities; however, it is still recognized that this study and its sample is focusing on the more serious delays or disabilities of children.

To obtain a sample of the population, a representative cluster sampling procedure was employed with the registry of handicapped persons. The selected communities of Curling, Summerside, Benoit's Cove, Lark Harbour, Cox's Cove, Massey Drive, Steady Brook, Pasadena, Gallant's are similar to each other in population size, economic status, and geographical proximity so they can be grouped into one cluster. Now the selected communities of Stephenville, Stephenville Crossing and St. George's are similar to each other in the above factors so they can be grouped into another cluster. The two clusters of communities are different from each other in geographical proximity to the Western Memorial Regional Hospital, services available to communities, economic status and development within the community and so forth.

For sampling purposes, the similar communities were grouped together and a random sample was drawn from each cluster in proportion to their representativeness on the provincial registry.

Once the sample had been selected, the public health nurses were responsible for making the initial contact with the selected parents. The initial contact involved informing the parents of the study and arranging an appointment with the parents for the needs assessment interview. It was hoped that both parents would be able to be interviewed for the sample.

However, it was recognized that mothers are usually more available and willing to participate, therefore, it was anticipated that there would be a larger percentage of mothers in the sample.

The sample included parents (large percentage was mothers) of developmentally delayed children in select communities. The parents varied as to socioeconomic class, age group, community and type of disability, etc. One feature common to the sample was that all knew that their child had a disability, however, for different lengths of time.

Validity

Stanley (1964) refers to validity as the extent to which the questions or items of the interview schedule really measure what they are supposed to measure. He further states that the problem of determining the validity of the data obtained in most structured interviews is particularly difficult, because of the lack of suitable criteria against which to compare the data.

The interview schedule of this study was evaluated by the experts in the field to detect invalid and unreliable questions of the schedule. The following questions were posed in the pretest with the experts:

(1) Are the words simple, to the point, and familiar to the subject?

(2) Are the questions written in a straightforward and concise manner?

(3) Do the questions ask about more than one issue at a time?

(4) Are the questions leading?

(5) Do the questions apply to all of the respondents?

(6) Are the answers susceptible to response styles?

(7) Can the questions be rewritten in a shorter form without loss of meaning?

(8) Do the questions read well and will they be understood?

The experts reported that the interview schedule was an appropriate and comprehensive one with changes being made only in the structure and grammar of the interview.

The interview schedule was also piloted with a small sample(s) of parents of developmentally delayed children to either confirm or disprove the following:

(1) Do the subjects understand what the survey is about?

(2) Are the questions clearly worded?

(3) Do the respondents feel comfortable answering the questions?

(4) Which questions seem to embarrass or confuse the respondents?

(5) How long does the interview take?

(6) Is the interviewer having problems with the schedule?

(Clark, 1976, p. 39)

As a result of this pilot it was decided that taping of the interviews would not be practical or beneficial. Therefore, all interviews were recorded by writing out verbatim responses.

Reliability

Stanley (1964) refers to reliability as the consistency of the data irrespective of what they may measure. To ensure reliability of the interview schedule, precautions were taken in the construction and administration of the schedule. The interview schedule was administered in exactly the same way at each time and the questions were as unambiguous as possible as a result of the pre-test with the experts and the small sample of parents. Stanley (1964) also argues that interviewer variability can determine the degree of reliability of structured interviews. In the administration stage of the study, two different professional persons from the fields of health and/or social services received training and became involved in administering the interview schedule to the parents. In particular, these interviewers were one public health nurse and one direct home services worker. They were all presently involved in and aware of developmentally delayed children and their parents. Approximately a total of 6 interviews, 3 per interviewer were conducted by the outside professional persons. These six were randomly assigned to each interviewer.

In an attempt to check on the reliability of the outside interviewers, one interview was taped by the examiner and each interviewer recorded the taped interview on their protocol form to check on the consistency of the interviewer's recording. No inconsistencies were noted following review of each interviewer's protocol recording of the taped interview.

CHAPTER IV

ANALYSIS OF DATA

Descriptive statistics on the parents and children involved in the research study provides an overview of the general characteristics of the sample. These statistics are presented in this chapter utilizing several figures and tables.

The disabilities and the frequency with which they were represented in this study are presented in Figure I. They range from 20% of the sample who are parents of children with moderate to severe retardation to seven disabilities each which constitute 3% of the total.

Figure I represents the major or primary disability of the children. It is important to note that, in addition, there were a variety of associated secondary disabilities as well. For example, a number of the children with cerebral palsy also exhibited some degree of retardation, perceptual disabilities and so forth.

The wide frequency of disabilities of children illustrates the range of needs parents may experience. Throughout this study, parental needs, as reported by parents of disabled children, will be examined from two perspectives. Firstly, there would seem to be a number of needs which were consistently identified by parents, regardless of the nature of the disability. Secondly, some of the needs reported were

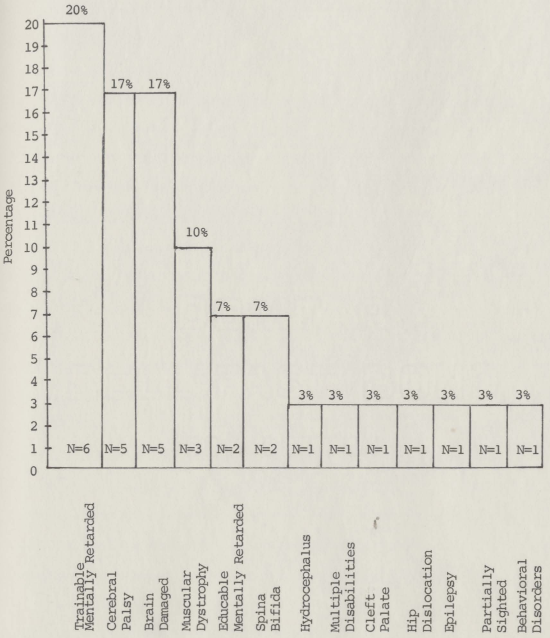

Figure I. Number and Percentage of Children in Study by Category of Disabilities.

identified as being specific to the particular disability. These two need groups will be referred to in this study as universal needs and disability-specific needs. In addition, the needs expressed by parents appear to be affected by various factors such as age of child, severity of disability, education, income and geographical location of parents. These factors, in relation to expressed needs, will also be discussed in this study.

The age and sex of children in this study is represented in Table 14. The data in this table indicate that the majority of the children were of school age (11 to 15 years - 42%) and the second largest group were of pre-school age (under 5 years). In addition, 63% of the sample were male, while only 37% were female.

Not surprisingly, the needs of parents were different, depending on the age of their children. For example, mothers of school age children identified school related concerns such as the provision of special school programs, while mothers of pre-schoolers expressed home-related needs such as information on self-help skills, respit care for parents and so forth.

The number and percentage of children by birth order is represented in Table 15.

The birth order of an exceptional child appears to influence the needs expressed by parents in this study. Typically, parents whose youngest child was disabled reported that this was a detriment or created anxiety with regards to another pregnancy. For example, a mother of a 4 year old

Table XIV

Number and Percentage of Children by Sex and Age

	Under 5 years		5 years to 10 years		11 years to 15 years		16 years to 20 years		Total	
	N	P	N	P	N	P	N	P	N	P
Male	4	13	1	3	9	30	5	16	19	63
Female	4	13	0	0	5	17	2	7	11	37
Total	8	26	1	3	14	42	7	23	30	100

Table XV

Number and Percentage of Children by Birth Order

Youngest		Middle		Oldest		Total	
N	P	N	P	N	P	N	P
19	64	7	23	4	13	30	100

cerebral palsy child stated that ... "After having Mary I was agraid to get pregnant again. I didn't want to have another disabled child."

Several mothers in this study expressed the belief that they were responsible for the child's disability due to the fact that they had the disabled child during menopause. These beliefs appear to be somewhat poorly reality based but a great source of guilt, self blame for the mothers, thus influencing their present attitudes. For instance, some mothers were unwilling to take a second chance in getting pregnant or were unable to "let go" of their disabled child for his/her independence.

Interviews with these mothers clearly pointed to the need for parents to obtain information so as to make realistic and sensible decisions with respect to future pregnancies. The provision of genetic counselling may serve to provide the means to meet these needs of the parents.

The parents and their children are represented from the following communities as shown in Figure II. Two general geographical categories are presented in this study. First, the urban-based communities are in close proximity and easy access to the regional health services in Corner Brook, and secondly, the outside rural-based communities are farther away from health services in Corner Brook (the communities of Stephenville, Stephenville Crossing and St. George's).

Findings indicate that across the communities, regardless of proximity and accessibility to health services, parents

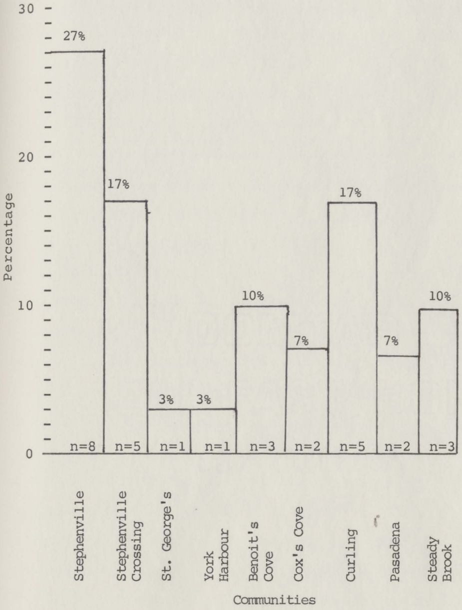

Figure II. Number and Percentage of Disabled Children in the Study by Community.

generally experience several common needs. In particular, parents tend to feel a need for emotional-social support, understand, "someone to talk to." For example, a father of a moderately retarded child in St. George's expresses this need by stating "it would be nice to have someone else around to talk to about my concerns." While a mother of a severely retarded school age boy in Curling identifies her need by suggesting that "having someone else like a social worker around to visit me at home would help me to better cope with my feelings."

Despite this common need for emotional support, there were some substantial differences in the needs expressed by parents in the more rural outside communities, compared to parents in the communities that are closer in proximity to the regional health services. For instance, parents in these more urban communities spoke more frequently of the need for such support services as respit care, genetic counselling, an organization for exceptional children, while rural area parents generally spoke about more basic support services such as adequate hospital facilities, financial assistance for travel, community based school programs and so on.

It appeared that parents from these rural communities had a greater frequency of negative attitudes or resistance towards the suggestion of professional assistance. As one mother from Stephenville Crossing explained, "I don't want to bother anyone because he is my son, so I will take care of him as best I can while I am alive."

Parents of the more urban communities closer to health services in Corner Brook, generally were more accepting of professional help which was illustrated in one mother's comments that: "I think there should be more professional help for parents at home to cope better with their disabled child."

Marital status and the parents' relationship to the child is represented in Table 16. This data describes the population as typically married, natural parents of disabled children. There is only one single parent and one guardian identified, which suggest that it is not practical to generalize these results to the needs of special groups of single parents and/or guardians. Primarily, the needs that are identified are those that represent typical two-parent families living together.

The occupations of the parents are represented in Figure III. Research results show that, although socioeconomic status and educational level of parents are not discrete factors, the results suggest that generally parents of low socioeconomic status, with minimal education, experienced more difficulty articulating their needs and tended to report more basic needs such as financial assistance and the need for appropriate school programs. This is represented by the following statement of an unemployed father of a six-year-old cerebral palsy child. "I need more money to be able to bring Susan back and forth to the doctors." Understandably, parents in the lower socioeconomic status occupations such as fishing,

Table XVI

Number and Percentage of Parents by Marital Status and Relationship to Child

Marital Status	Relationship to Child					
	Parent		Guardian		Total	
	Number	Percentage	Number	Percentage	Number	Percentage
Married	28	94	1	3	29	97
Single	1	3	0	0	1	3

*Footnote: The one guardian in the study was a foster parent.

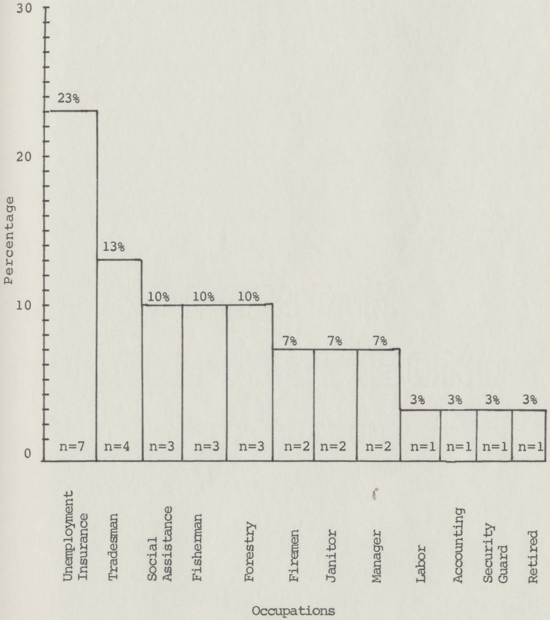

Figure III. Number and Percentage of Occupations of Parents.

labour work and unemployment were more concerned with the additional financial burden of a disabled child in a family.

Also, they appeared to have a negative attitude towards the concept of professional intervention and the concept of respit care, rejecting such a service on the grounds that it was akin to institutionalization. Also, there was a greater frequency of resistance towards the suggestion that they receive home visits from professionals.

In addition, parents of lower socioeconomic status and lower educational level appeared to experience more guilt feelings related to misconceptions on the part of the parents regarding the etiology and nature of the disability. For example, one parent stated that: "Nothing can be done to help Mary--it is God's will," while another parent explained; "I must do this on my own because it is my cross to bear."

The research results show that parents in the higher socioeconomic status, with higher skilled jobs and more education such as accounting, management, were better able to articulate and express their needs. These parents talked about the need for such things as professional literature on the disabilities of their children; learning ways to cope with their disabled child at home; early identification of delays. The higher educated and higher socioeconomic status parents in the study typically expressed the concern for professional involvement and direction as to the prevention and treatment of disabilities.

Table 17 presents the specific needs identified by parents in the study in descending order according to percentages. As indicated earlier, despite differences in disabilities, their severity, age of disabled child and so forth, this study found a substantial number of expressed needs which seem common to all parents of exceptional children in the study. These needs will be referred to as universal needs and will be discussed in the following section:

Section A: Universal Needs

The predominant area of need which all parents spoke to was in the social-emotional area. These needs were expressed in several different ways by the parents. One mother of a 10-year-old severely retarded child commented, "I feel the need to have someone to talk to about my fears and concerns", while another mother of a brain-damaged child commented: "I feel the need to have emotional help during the difficult times such as operations and other crisis."

Several other parents expressed their loneliness in dealing with their child's problem. The parents felt that talking to other parents with exceptional children would help them to handle their fears and worries more effectively. This is illustrated in the words of one mother of a 3½ year old severely retarded child: "I experienced a hard time the last 3½ years and not having someone to talk to about my feelings made it worse. I feel there should be someone there to listen and show concern about me and my child."

Table XVII

Needs of Parents in Descending Order of Importance

Need	Percentage
Social-Emotional Support	98
Respit Care	97
Provision for Child's Future	90
Schooling for Child	83
Proper and Early Diagnosis of Problem and Treatment	78
Self-Help Skills	77
Community Based Programs	75
Early Information on Child's Problem	67
Learning Ways to Cope	67
Financial Assistance	67
Help in Handling Child's Delay	50
Child Management Skills	50
Literature on Treatment	50
Group Home	50
Parent Association	50
Home Based Program for Adults	50
Early Intervention	33
Support and Advice from Professionals	27
Place to Stay While in Hospital	27
Better Facilities and Services	25
Sexual Awareness Program	23
Sheltered Workshop	21
Better and Clearer Use of Language	7
Pre-School Program	7

This type of need was expressed by a large majority of parents across all disabilities and regardless of age or economic circumstance. Such a need suggests the importance of organizing an association for parents of exceptional children. Such an organization would serve a number of functions. It could serve to bring parents in contact with each other so as to facilitate the development of a supportive and caring network as parents struggle to come to terms with their feelings regarding their disabled child. Also, such an organization could serve as a clearing house for helpful information regarding different disabilities and services available, as well as an agency for parental advocacy.

Another universal need experienced by a large majority of parents in this study was that of respit care. The parents generally spoke of their concern for being able to have "time out" from their disabled child and feeling confident that the child was properly cared for at home. In the words of one mother of a brain-damaged child: "Having a professional person come into my house and care for my child while I go shopping or visiting would be a wonderful thing." Another mother of a severely retarded child explained that: "I can't go anywhere unless I know that Johnny will be properly cared for by a professional person who understands handicapped children."

Even though many of the parents in the more rural communities who were in lower-income jobs and had less education, expressed the concern that constant care of their disabled child was stressful, the suggestion that respit care might be helpful was met with some resistance. It appeared that many of these parents experience personal responsibility for the cause of their child's disability (i.e., maternal age) and therefore exhibit greater reluctance to allow "outsiders" to share in the care of their child. The comment of a mother of a 11-year-old child with epilepsy, illustrates this point: "I don't want any strangers coming into my house to take care of Mary. I can do it myself, all they will tell me is how I am doing things wrong."

A third universal need expressed by parents surrounds the concern for proper and early diagnosis of the child's problem and its treatment. Several parents articulated this need by requesting that early information on the child's problem be available, while others requested help in handling their child's delay. Still others felt intervention from professionals at an early age was very much needed.

Regardless of the type, severity of the disability, age of the child, the education, socioeconomic status of the parents, the need for proper and early diagnosis of the child's problem was an expressed concern. However, parents from higher socioeconomic status, with more education and higher skilled jobs, were more able to articulate this need and to make the recommendation that professionals, especially the family physician, should be better trained to deal with various disabilities, as this is usually the first professional person the parents have contact with concerning their disabled child. These parents were able to suggest the utilization of hospital workshops as a means of training for the family physician to better handle the various disabilities of children. The lower socioeconomic status parents, with less education and lower-income jobs, were more concerned with basic information such as the need for better and clearer use of professional language and jargon, as well as management assistance once the child is at home.

Another universal need of parents was worry or anxiety regarding their child's future. As one mother of a severely retarded child put it: "What is going to happen to Jane after I die?" Another mother of a cerebral palsy child stated: "How is David going to manage in a world made for <u>normal</u> adults?" A father of a moderately retarded boy observed: "There is nothing available for mentally handicapped adults--What is going to happen to him?"

Once again the parents of higher education and higher income jobs were able to articulate their need for special services such as group homes, sheltered workshops for disabled adults, while parents of less education and lower income jobs were resistant to the need for such professional adult services. Some of these parents, although accepting of their disabled child, nevertheless had doubts about their child's potential for future development and appeared to expect less of their child. In addition, several of the parents seemed to resist sharing their responsibility for the child with others, especially with professionals.

Comments from parents which point to these attitudes, include the following: "My son will stay with me until I die, then someone else in the family will take care of him." "Mary is unable to do more at this time. I don't want to hurt her by pushing her to do new things."

The final universal need, expressed by parents in this study, was centered on schooling. Many of the parents felt that there were no available programs suited to the needs of their child. Generally parents were very strong in their belief that schooling is an important phase of any child's life. However, schooling was seen as potentially very difficult for an exceptional child. While all parents expressed this need for schooling, it was not surprising that parents of severely handicapped children were anxious concerning the prospect of their child leaving home to attend a special school if none was available at home. At the same time, parents of mildly handicapped children were concerned with the possibility of social rejection and the potential for the children being emotionally hurt if placed in an integrated environment. Even with this concern, parents of mildly handicapped children appear to be supportive of integration in the regular school.

Section B: Disability-Specific Needs

In addition to those universal needs, this study found that many needs were specifically related to the child's disability. Parents of children with severe or multiple disabilities such as moderate to severe mental retardation or cerebral palsy with associated disabilities tended to be concerned about both immediate and long-term needs. While parents of children with milder disabilities such as mild to moderate mental retardation, developmental delays expressed less critical and more short term needs; for example, the need for financial assistance, better and clearer use of professional language and so on.

As well, the particular type of disability of a child tended to influence the expressed needs of parents. To illustrate, here are examples from parents with children of different disabilities:

A mother of a blind child spoke of the need for special provision in the regular classroom in order for her child to function effectively, while a mother of a brain-damaged child discussed the need for emotional help to provide her with guidance when dealing with her child.

Another mother of a child having hip dislocation reported that her major or primary concern was in the area of hospitalization as her child spent extended periods in the hospital. She explains: "It is difficult for me ... I have nowhere to stay when my daughter is in the hospital; as well, it is very expensive to be travelling back and forth to St. John's for her operations."

Not surprisingly, a parent of a child with mild mental retardation would not be worried about the issue of hospitalization but very anxious about management skills at home. As one mother of a mildly retarded child comments: "Raising John is not the same as my other children. It requires more patience and understanding. It is a challenge every day."

The need for self-help skills was a primary issue for parents with children having more severe disabilities such as cerebral palsy and moderate to severe mental retardation than those parents having children with milder disabilities such as cleft palate, hip dislocation and partial sight. The help requested was identified as more professional advice and direction as to teaching their children basic life-skills in preparation for coping in the world. The parents felt this sort of help was not available at this time but was an essential service if parents are to be better able to provide adequate training to their exceptional children.

Section C: Factors Related to the Differential Expression of Needs

As mentioned earlier, the needs expressed by parents appear affected by such factors as the age of the child, severity of disability, education, income and geographical location of parents.

As was expected, parents of lower socioeconomic status with lower income jobs and less education generally spoke of more basic concrete needs such as financial assistance, better and clearer use of professional language, a place to stay during the child's time in hospital, while parents of higher socioeconomic status, with higher income jobs and better education, spoke of such needs as learning ways to cope personally, support and advice from professionals, preschool programs and so on.

As well, the geographical location of the parents tended to affect type of expressed needs in this study. Parents of the more rural communities further away from the regional health services in Corner Brook expressed needs such as better facilities and services on the west coast and community based programs in the local areas. The needs of parents in the more urban areas closer to the regional health services included such areas as the establishment of additional services such as a parent association, group homes and sheltered workshops.

Expressed needs of parents did differ in relationship to type and severity of child's disability. Parents of children with moderate to severe disabilities expressed more long-term critical needs such as home management of their children, lifeskills training, the child's future; on the other hand, parents of mildly disabled children spoke of more immediate short-term needs.

In addition, the age of the child influenced types of needs expressed in this study. Understandably, a parent of a school age exceptional child was more concerned with the provision of proper schooling for the child, just as a parent of an older exceptional child was more worried about the child's future as an adult, sexual awareness programs for exceptional adults and so forth. As well, parents of preschoolers generally were supportive of the concept of preschool education for their disabled children.

Conclusions

Generally, it was found by this study, as discussed in this chapter, that the predominant area of universal need, which all parents spoke to, was in the area of social-emotional help. Parents, despite various differences, all expressed the need for a network of support services such as social-emotional help, respit care, early diagnosis of problem, provision of self-help and home management skills and training. However, the study did find that some of the expressed needs were varied according to a variety of factors such as age of child, type and severity of the disability, education, income and geographical location of the parents.

It is suggested that even though this study did not set out to give recommendations as to how best to meet the needs of parents, several observations and recommendations will be reported on in Chapter V. These observations and recommendations are based on the writer's insight into the expressed needs of parents in this study, as well as parent's own perceptions of what should be done to effectively meet their needs. In addition, Chapter V will present an overall summary and reactions to the internship itself.

It is important to note, as this study identified the needs of only 30 parents in selected communities on the west coast of the province, that it is advised that the results should be cautiously interpreted when applied generally to other parents in different regions of the province.

CHAPTER V

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

This internship and research study was conducted at Western Memorial Regional Hospital in Corner Brook during the summer semester--May to August, 1981. The individual objectives and associated activties specified in the internship proposal and found in Chapter I of this report, was accomplished by the intern under adequate and sufficient campus and field supervision and evaluation.

Writing a comprehensive and complete summary of the internship has been a very difficult and challenging task. Because this internship is essentially a comprehensive professional experience, it is virtually impossible to capture in a written report the on-going daily involvement of the intern in a variety of professional activities. It is also particularly difficult to articulate the contribution of this valuable experience to professional growth and development.

Nevertheless, this internship can be termed a great success with the intern being particularly well accepted by all the hospital staff and by being actively involved in the programs at the hospital. The intern had the opportunity to gain extensive experience in the areas of individual and group counseling, educational assessments, program development, implementation and the research component.

The intern also had the opportunity to receive excellent supervision and evaluation by two supervisors--one field, Mr. Wayne Rideout, and one campus, Dr. Glen Sheppard. Close contact was maintained with both supervisors, meeting with the field supervisor at least once a week and making extensive and continuous utilization of the telemedicine system to maintain contact with the campus supervisor. The telemedicine system is described in Chapter I of this report. In addition, taping of counselling sessions allowed for valuable feedback from both supervisors and enabled on-going evaluation of the intern's counselling.

The intern also had the opportunity to participate during the internship in a research study looking into the needs and concerns of parents with developmentally delayed-disabled children in the western region of the province of Newfoundland and Labrador. The study was designed primarily to identify the expressed needs of parents with developmentally delayed-disabled children.

Although this study identifies a variety of needs of parents with exceptional children, it does not necessarily provide answers as to how best to meet these needs. Nevertheless, many parents did mention rather specific services for which they feel would meet their needs effectively, and, as well, it is possible to draw some implications from these findings as to how some of these concerns expressed could be handled. The following recommendations, therefore, represent some of the more obvious implications drawn from this study:

1. The establishment of a parent association for parents of exceptional children on the west coast of the province with its headquarters in Corner Brook and branch offices in the local areas. Such an organization would be heterogeneous in nature as it is impractical to organize separate groups for each particular type of disability. Such an organization would serve a number of functions. It could serve as a network of social-personal support, a clearing house of information and an agency for advocacy for parents of exceptional children.

2. The establishment of a respit care service to parents of exceptional children on the west coast. Such a service would have to be coordinated and operated by professional persons in order for it to be successful. However, in organizing a service such as respit care, special consideration must be given to the issues such as possible non-acceptance by parents of lower education and socioeconomic status. The implementation of such a service must be done in such a way as to overcome this possible resistance.

3. The establishment of group homes and sheltered workshops in Corner Brook as well as in local areas on the west coast. These services would help to provide adult programs for exceptional individuals that are not presently available on the west coast.

4. The establishment of a children's rehabilitation center on the west coast, in particular in Corner Brook. The

rehabilitation center would give the west coast a complete center of services for exceptional children and their parents. At this time, parents must travel to St. John's, which, at times, can be inconvenient, in order to have contact with various professionals and experts.

5. The Department of Social Services to re-assess their eligibility requirements for financial assistance for parents with exceptional children. The appropriate government departments need to consider the additional financial burden that an exceptional child can bring into a home. It appears to be a financial stress on even the middle-income families to cover the cost of special medication, equipment, therapy and trips to hospitals in St. John's or Corner Brook, for an exceptional child.

6. The organization of physician inservice education on the needs and concerns of parents with exceptional children. As the family physician is usually the first contact for a parent, this professional person needs to be aware of the various disabilities, how to handle parents emotionally and to have knowledge of possible referral agencies for the parents to obtain educational as well as supportive help (i.e., parent associations).

7. For all professional persons who deal with exceptional children to reassess their own involvement with disabled children and their parents. As professionals, they

must start to recognize and identify the intense needs that parents of exceptional children experience, especially in the social-emotional area.

8. The establishment of pre-school programs for disabled children on the west coast. The pre-school program would help to better prepare exceptional children for regular school. As well, it would provide parents with another source of help and advice as to the proper care and management of their disabled pre-schoolers.

9. The establishment of a children's advocacy agency which would be concerned with working on the improvement of programs and services for exceptional children and their parents. Such an agency could work in close affiliation with the association for parents of exceptional children as per recommendation one.

Overall, the internship and the research study was a very valuable experience. In particular, it helped the intern to become aware of the counselling services and programs available at Western Memorial Regional Hospital in Corner Brook. It also served as a practical experience that contributed to personal and professional growth as a counsellor for a variety of agency settings.

The research component served to provide some insight into the needs of parents with disabled children. The study was able to identify 24 needs of parents with delayed-disabled children on the west coast of the province. It also highlighted the factors that appear to influence the types of needs expressed by parents. As well, this study presents a number of recommendations as to how to best meet the needs and concerns expressed by parents in this study. These recommendations are based on the writer's insight into the expressed needs of parents in this study, as well as parents' own comments of what should be done to meet their needs. As this study's sample consisted of only 30 parents in selected communities, it is advised that the results be cautiously interpreted when applied to other parents in other regions of the province.

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APPENDICES

APPENDIX A

Evaluation Forms on Case Conferences

EVALUATION FORM

CASE CONFERENCE/REVIEW

1. Did the background information presented give a concise summary of the client's background relevant for the presenting problem?

2. Did the behavioral observation present a specific description of the client and his/her behavior?

3. Were the interventions attempted apporpriate for the client and the referring problem?

4. Are the recommendations and plans of action realistic and useful?

5. Did the general conclusions/impressions relate to findings, both test and nontest?

6. Did the presenter deliver a clear and comprehensive overview of the case?

7. Was the presentor properly prepared and ready for the case conference?

8. Additional Comments:

Critiqued by: ______________________ Date: ____________

APPENDIX B

Evaluation Forms on Educational Sessions

"WORKSHOP ON COUNSELLING-COMMUNICATION SKILLS"

JULY 6th, 1981

AGENDA

I INTRODUCTION

II OVERVIEW OF DEVELOPMENTAL HELPING MODEL

  (a) Pre-Helping Phase
  (b) Stage I: Responding/Self Exploration
  (c) Stage II: Integrative Understanding/ Dynamic Self Understanding
  (d) Stage III: Facilitating Action/Acting

III EXERCISE IN COUNSELLING SKILLS

IV DISCUSSION

V EVALUATION

"WORKSHOP ON COUNSELLING-COMMUNICATION SKILLS July 6th, 1981"

Evaluation Form

1. Did the presentation provide a comprehensive overview of the Developmental Helping Model?

2. Did the presentation offer details on particular counselling skills in an effective and clear manner?

3. Was the presentation relevant to your work as a social worker/psychologist?

4. Did the small-group exercise serve to illustrate practical use of the workshop material presented?

5. Was the workshop leader well prepared and clear in the presentation?

6. Did the workshop leader facilitate and handle group discussion effectively?

7. Overall comments on workshop and/or workshop leader?

8. Additional Comments:

APPENDIX C

Evaluation of Intern by Field Supervisor

Psychological Services,
August 4th, 1981.

r. Glenn Sheppard,
epartment of Educational Psychology,
emorial University of Nfld.,
t. John's, Nfld.

ear Glenn:

As discussed previously, I am writing to review Marina's internship. would like to address two general areas: the objectives which were utlined in Marina's original proposal; and the benefit derived by sychological Services from Marina's internship.

Marina has been very conscientious in completing the activities isted for each objective. Such activities were reviewed as much as ossible by myself either through direct observation or through review f taped sessions and written reports and letters. I was able to observe irectly Marina in group session with a group of hospitalized children. bservation was also made of Marina in case conference settings and in ettings where she was making educational presentations. Taped client essions and group sessions were reviewed periodically during the nternship.

Marina's skills in therapy, in case presentation, and in educational ctivities were of very high quality. She has provided an excellent ervice which has been of great benefit to her clients and to those who ill be attempting to follow up with them. There is no need to make pecific comments concerning her intervention in therapy sessions other han to note that she has demonstrated an empathetic astuteness and n ability to help her clients progress.

.....................(2)

This in very general terms gives some indication of Marina's accomplishments during her internship. With regard to the benefit derived by Psychological Services, this has been at least two-fold. Firstly, Marina has made a very positive impression on all with whom she has worked. Such a positive image could only help to present this department in a favorable light. Marina has been a great public relations agent. Secondly, you might know that we have obtained the services of an additional Psychologist who will commence work here in late August. This Psychologist will be providing a developmental service designed to identify developmental problems and provide remedial advice as possible. Marina has done much of the ground work that will provide a good basis for the new worker.

We have been very pleased to have Marina with us for the summer. She has been a credit to herself, to the Educational sychology Department, and to Psychological Services. I look orward to making further internship arrangements in the future.

Thank you for your cooperation and assistance throughout this nternship. Have a good summer. I look forward to seeing you soon.

Sincerely,

Wayne

Wayne A. Rideout,
Chief Psychologist.

AR:pc

APPENDIX D

Psychological Services Statistical Report for Internship

STAFF	PER BUDGET		ACTUAL		L.T.O. (%)		DAYS UNDERSTAFFED	

TOTAL DAYS	WORKING FOR MONTH	DAYS SICK	DAYS EDUC. LEAVE	DAYS VACATION	DAYS HOLIDAYS	ACTUAL WORKING DAYS FOR MONTH	SICKNESS RATIO %

	THIS MONTH			THIS YEAR	LAST YEAR
	May	June	July	TO DATE	TO DATE
Clients Registered Beginning of Month..	0	4	15		
New Referrals Seen (IP + OP)= (__+ __)	4	13	11		
Repeat Referrals Seen (IP + OP) = (__+__)	0	0	0		
Total Caseload	4	17	26		
Files Closed	0	2	26		
Clients Registered End of Month	4	15	0		
Contacts: Initial (CMHC __, Other __).	4	13	11		
Followup (CMHC __, Other __).	3	15	20		
Consultation (CMHC __, Other __).	0	74	26		
Clients missed or cancelled	0	0	0		
Department cancelled appointment	0	0	0		
*Not rescheduled	0	0	0		
Waiting List Beginning of Month	0	0	0		
New and Repeat Referrals Received	4	13	11		
Total	4	13	11		
New and Repeat Referrals Seen	4	13	11		
Waiting List End of Month	0	0	0		
Number Waiting > 30 Days	0	0	0		
NEW AND REPEAT REFERRALS SEEN <u>BY SOURCE</u>:					
Department of Western Memorial Regional Hospital	0	0	0		
Other Hospital/Health Institution	0	0	0		
Public Health	0	11	9		
Paediatricians	0	0	2		
Psychiatrists	0	0	0		
Other Physicians	2	2	0		
Lawyers	0	0	0		
School Boards/Department of Education.	0	0	0		
Department of Social Services	0	0	0		
Comm. Prog. for Mentally Retarded	0	0	0		
Community/Family Centre	0	0	0		
Department of Justice	0	0	0		
Child Mental Health	2	0	0		
Other: List Each __________	0	0	0		

	THIS MONTH May	THIS MONTH June	THIS MONTH July	THIS YEAR TO DATE	LAST YEAR TO DATE
BY PROBLEM:					
1. Social Interpersonal	0	0	0		
2. Personal Decision Making	0	0	0		
3. Personal Emotional (Adult)	0	0	0		
4. Situational Stress	0	0	0		
5. Alcohol/Drug Abuse	0	0	0		
6. Developmental Problem	0	11	9		
7. Child Behavioral	1	0	0		
8. Child Emotional	3	2	2		
9. List Each _______	0	0	0		
_______					
_______					
BY COMMUNITY:					
Corner Brook/Bay of Islands	3	8	7		
Other	1	5	4		
BY AGE:					
0 - 4	1	1	3		
5 - 12	1	10	8		
13 - 16	2	2	0		
17+	0	0	0		
BY UNIT IF IP					
Paediatrics	1	2	0		
Psychiatry	0	0	0		
Special Care	0	0	0		
Medicine	0	0	0		
Surgery	0	0	0		
Other	0	0	0		

5.
Other Meetings

	Hospital This Month M	Hospital This Month J	Hospital This Month J	Hospital Year to Date	Community This Month	Community Year to Date
Special Services	5	3	0			
Coordination	31	2	5			
Educational	13	5	2			
Other	0	0	0			
	49	10	7			

REV. 1250-030 (Jan. 8th, 1980)

APPENDIX E

Interview Schedule for Parents

INTERVIEW SCHEDULE FOR PARENTS

I IDENTIFICATION DATA

1. Child's Name ______________________________________ (01)

2. Sex ___ Male (02)
___ Female (03)

3. Birthdate ____ (04)

4. Birthplace ____ (05)

5. School Grade _______________________________________ (06)

6. Parents ___ Married (07) ___ Divorced (08)
___ Separated (09) ___ Deceased (10)
___ Other (11)

7. Relationship to Child ___ Parent (12)
___ Guardian (13)
___ Grandparent (14)
___ Other Relative (15)
___ Foster Parent (16)
___ Other (17)

8. Occupation ____
___ Low (18) ___ Middle (19)
___ High (20) ___ Unknown (21)

9. Number of Siblings ______ (22)
___ Male (23) ___ Female (24)

(a) If no siblings, then delete section VIII, questions (a) and (b) and (c).

10. Birth Order of Particular Child ____________________ (25)

11. Current Address ____________________________________ (26)

12. Child's Delay or Disability

Mental Retardation

___ Educable Mentally Retarded (27)
___ Trainable Mentally Retarded (28)
___ Custodial Mentally Retarded (29)

Visual Impairments

___ Blind (30)
___ Partially Sighted (31)
___ Other Specify (32) ________________________

Hearing Impairments

___ Deaf (33)
___ Hard of Hearing (34)
___ Other Specify (35) ________________________

Speech Impairments

___ Delayed Speech (36)
___ Stuttering (37)
___ Cleft Palate (38)
___ Voice disorders (39)
___ Other Specify (40) ________________________

Special Health Conditions

___ Diabetes (41)
___ Cystic Fibrosis (42)
___ Asthma (43)
___ Club Foot (44)
___ Other Specify (45) ________________________

Neurological Impairments

___ Cerebral Palsy (46)
___ Multiple Schlerosis (47)
___ Epilepsy (48)
___ Muscular Dystrophy (49)
___ Other Specify (50) ______________________

Emotional Disturbance

___ Behavioral Disorders (51)
___ Severe Emotional Disturbance (52)
___ Other Specify (53) _______________

Multiply Handicapped

___ Deaf-Blind (54)
___ Hearing Impaired Mentally Retarded (55)
___ Cerebral Palsy with Mental Retardation (56)
___ Other Specify (57)

Orthopedic Handicaps

___ Limb Deficiencies (58)
___ Other Specify (59) ______________________________

Others (60) ____

____

II EARLY IDENTIFICATION OF CHILD'S PROBLEM

13. Recognizing that your child has a special problem and is to some extent different from other children varies somewhat from person to person and from disability to disability. How did you first become aware of your child's problem? _____

____

____

____

____

(a) Who first suspected the problem? ______________

____

____

____

____

(b) What made you (or others) suspicious of a possible problem? ______________________________

____

____

____

____

13. (c) How did you feel about it at that time? ____

____

____

____

____

(d) What were some of the things you thought about at that time? ____________________

____

____

____

____

(e) Did you have any personal thoughts about the possible causes of (child's name) problem? ____________________

____

____

____

____

(f) Who did you see about that problem? ______

____

____

____

____

(g) Who was the most helpful to you at that time? ____________________

____

____

____

____

(h) Who was the least helpful to you at that time? ____________________

____

____

____

13. (i) What were some of the most difficult things about being aware of (child's name) problem?

____

____

____

____

III SEARCH FOR HELP

14. Parents have different ways to cope with the realization that their child has special needs. Once you were aware of (child's name) problem, did you search for help? ___ Yes ___ No

(If yes)

(a) Who did you see for help? __________________

____

____

____

____

(b) Where did you go for help? ________________

____

____

____

____

(c) What types of information did you receive?

____

____

____

____

14. (d) Were you satisfied with the diagnosis given by the person you consulted?

(e) What were the things you wanted to find out about?

(If no)

(a) Why would that be?

(b) Was there anything else you did at that time instead of look for help?

(c) How did you feel at that time?

IV EXPLANATION OF CAUSE AND DELAY PROBLEM

15. How much time elapsed between your first suspicion that (child's name) was delayed and until it was confirmed by a professional? ____________________

(a) How many professional(s) did you visit before you felt confident you knew the nature of (child's name) problem? ____________________

(b) Who were these professional(s)? ____________

(c) How did you know about these professionals?

(d) What things were most important at that time?

15. (e) What would you like to see done differently about obtaining information on your child's problem? ______

(f) What suggestions would you make to assist other parents who might be having similar experiences? ______

(g) Did you understand what you were told by the professionals? ______

(h) Were you satisfied with the diagnosis? ______

V INFORMATION ON TREATMENT, REMEDIATION AND CURE OF THE CHILD'S PROBLEM

16. After becoming aware of their child's difficulties, parents start to search for information on treatment for their child. What information was most important to you at this time? ______

16. (a) Did you receive information on care, treatment of (child's name)?

(If no)

(b) What would you like to see done about this?

(c) What information would be helpful?

(If yes)

(b) Who did you speak to concerning this information?

(c) What kinds of information did you receive?

(d) Who gave you the best advice for care, treatment of (child's name)?

16. (e) In what way was this the best advice? ________

____

____

____

____

VI HOSPITALIZATION

17. Quite often, the child with special needs has to be admitted to the hospital for extended periods of time. Was this so with you and your child?

___ Yes ___ No

(a) Were the reasons for the hospitalization explained? ________________

____

____

____

____

(b) Who was responsible for taking the child to the hospital? ________________

____

____

____

____

(c) Was care of your home a problem while you had to be away? ________________

____

____

____

____

17. (d) What were some of the difficulties associated with hospitalization?

(e) Did the hospital staff keep you informed about what was happening to (child's name) during his/her stay at the hospital?

(f) Was it explained to (child's name) as well?

VII HOME MANAGEMENT CONCERNS

18. Raising a child with special problems can be more challenging than raising a child without these difficulties. Do you agree or disagree?

(a) What were some of the things that made raising (child's name) challenging?

18. (b) How did you feel about raising a child with special problems at home?

(c) In what ways could raising a child with special problems at home be made easier and happier?

(d) How could someone be helpful at this time?

(e) What would you want to find out about at this time on managing (child's name) at home?

(f) Did raising a child with special needs create any financial difficulties?

VIII FAMILY UNIT CONCERNS

19. The child with special needs may have some impact on a family and its members. What kind of changes have you noticed in your family since becoming aware of your child's problems? ________________

____

____

____

____

(a) What were some of the reactions of your other children towards (child's name) and his/her problems? ________________________

____

____

____

____

(b) How was the child's delay problem explained to other siblings? ____________________

____

____

____

____

(c) Has the relationship between you and your other children changed as a result of (child's name) and his/her difficulties? ____________

____

____

____

____

(d) How about the relationship between you and your spouse? ________________________

____

____

____

____

19. (e) How about the amount of social and personal contacts with other parents, adults in the community?

(f) How did you feel about the community (other people) becoming aware of your disabled child?

(g) How did you feel about the effects on your family financially?

IX UNDERSTANDING AND SUPPORT

20. It is not uncommon for parents of children with special difficulties to feel that they are alone with their problems and to undergo many different feelings or concerns. What kinds of feelings did you experience, being the parent of a child with special needs?

(a) Who did you talk to about these concerns?

20. (b) Were you satisfied with their support? ____________________

(If Yes)

(c) What was the nature of the support (educational -social-counselling-personal) ____________________

(If No)

(c) What kinds of help would you like to have received? ____________________

(d) Did you have any contacts with other parents of children with special problems? ____________________

(If Yes)

(e) How often did you see these parents? ____________________

20. (f) What was the nature of your contacts?
(educational-social-personal-counselling)

(If No)

(e) What would you like to see done about it?

(f) What particular services would you like parents to offer to each other?

X SCHOOLING FOR CHILD

21. Planning for the future of a child with special needs usually involves obtaining appropriate schooling to fit child's special needs. How did you find out about special school programs or special schools for your child?

(a) Were there any special programs or schools suitable for (child's name) needs?

21. (b) What type of program or school? ____________

(c) Who helped you to find the appropriate special programs or schools? ____________

(d) Are you generally satisfied with the special programs or schools? ____________

(If No)

(e) What do you feel should be done about them?

(If Yes)

(e) What parts of the program or school are pleasing to you? ____________

21. (f) What are some of the biggest concerns about (child's name) schooling?

XI LIFE SPAN SERVICES

22. Another part of planning for your child's future involves plans for the after-school years. How do you feel about the future of your child and yourself?

(a) What are your feelings about (child's name) future?

(b) Are you aware of any services for the adult person who has special needs?

(If Yes)

22. (c) Are you satisfied with the type of service?

(d) Are you willing to have (child's name) a participant in the program? ____________________

(If No)

(c) What do you think should be done about it?

(d) What is your greatest worry for the future?

XII INSTITUTIONALIZATION

23. At some point in time, the parents of a developmentally delayed-disabled child may consider the option of institutionalization for their child. Have you considered this option for your child?

(If Yes)

23\. (a) Who helped you make a decision? ______________

(b) What were some of your feelings about institutionalization? ______________

(c) What things did you think about when considering institutionalizing (child's name)? ______________

(If No)

(a) What aspects of institutionalization would you be against? ______________

(b) What other options have you considered for (child's name)? ______________

(c) Does your community have the appropriate programs for (child's name) to help him/her at home?

XIII OTHER CONCERNS

24. If you had the opportunity to have three things that would improve the quality of your own life and your child's life, what would they be?

(a) What would you consider to be ideal with regard to services for yourself and your developmentally delayed child?

(b) What are some of your other concerns for your child and yourself that we have not talked about yet today?