

UNIVERSITY OF MANITOBA

AN EVALUATION OF A RESIDENTIAL RESPITE PROGRAM
FOR FAMILIES OF PERSONS WITH DEVELOPMENTAL DISABILITIES:
CLIENT SATISFACTION AND STAFF PERSPECTIVES

A PRACTICUM REPORT SUBMITTED TO
THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF MASTER OF SOCIAL WORK

FACULTY OF SOCIAL WORK

BY

JOSEPHINE A. VERSTRAETE

MAY, 1991

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BY

JOSEPHINE A. VERSTRAETE

A practicum submitted to the Faculty of Graduate Studies
of the University of Manitoba in partial fulfillment of the
requirements of the degree of

MASTER OF SOCIAL WORK

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ABSTRACT

This study focuses on an evaluation of a respite program offered through a major residential and resource facility in Manitoba for families of persons with developmental disabilities.

Parents were asked to participate in the evaluation and to provide feedback on general satisfaction with the quality of the program, satisfaction with specific dimensions of service, and their perceptions of effects and benefits. Both current users and those who no longer use the service participated. Staff and careproviders also provided information on implementation issues and their perceptions of the effects of the program.

Despite the limitations of client/consumer satisfaction research, the approach was effective in pinpointing specific aspects of the service that prevented access or required corrective action.

Generally, the program was highly rated as a support service. The results demonstrated a need to alter some aspects of service and to expand the service, especially for children and adolescents with difficult behaviours, in order to meet the requirements of families.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS

ABSTRACT

INTRODUCTION.....1

Statement of Purpose
Objectives
Definition of Terms
Organization of the Report

CHAPTER 1 LITERATURE REVIEW.....7

1.1 ECOLOGICAL MODEL.....8

Implications for Policy, Service, & Practice
Relevancy and Applicability

1.2 STRESS, COPING, AND ADAPTATION.....13

Stress in Families With Disabled Children
Limitations of Research
The Adaptational Model
The Double ABCX Model
Social Supports as Mediators
Role of Professionals
Summary

1.3 RESPITE CARE/SERVICES.....29

Respite as Part of Family Support
Definition, Scope, and Function
Models of Respite Services
Benefits/Importance of Respite
Respite Needs, Utilization and Satisfaction
Obstacles Affecting Utilization
Respite Evaluation Framework
Policy Considerations & Implications
Summary

CHAPTER 2 PROGRAM EVALUATION.....54

Purpose, Scope, & Foci of Evaluations
Process Evaluation/Program Monitoring
Client/Consumer Satisfaction

	Defining Consumer Satisfaction	
	Issues Related to Sample	
	Internal vs External Evaluations	
	Summary	
CHAPTER 3	EVALUATION DESIGN, METHODS AND PROCEDURES.....	65
	The Practicum Context	
	Administrative Arrangements	
	Target Population	
	Service Components	
	Evaluation Mechanisms	
	Program Promotion	
	Evaluation Procedures	
	The Evaluation Committee	
	Evaluation Goal and Objectives	
	Research Design and Instrumentation	
	Sample Populations	
	Data Collection Procedures	
	Data Analysis	
	Dissemination of Results	
CHAPTER 4	PARENT SATISFACTION AND STAFF PERSPECTIVES (RESULTS)...	83
	Parent Survey	
	Sociodemographic Profile of Families	
	General Satisfaction	
	Accessibility and Availability	
	Effects and Benefits	
	Service Pathways and Support Services	
	Client Characteristics	
	Nursing Survey	
	Implementation of Procedures/Efforts	
	Effects and Benefits	
	Clinical Survey	
	Implementation of Procedures/Efforts	
	Summary	
CHAPTER 5	DISCUSSION AND RECOMMENDATIONS.....	132
CHAPTER 6	PRACTUCUM EVALUATION AND CONCLUSIONS.....	147
	Evaluation of Client Satisfaction	
	The Respite Evaluation Committee	
	Literature Review	
	Limitations of the Study	
BIBLIOGRAPHY.....		154

LIST OF APPENDICES

APPENDIX A	Flow Chart of Respite Activities
APPENDIX B	List of Pre-Evaluation Interviewees
APPENDIX C	Pre-Evaluation Interview Schedule
APPENDIX D	Evaluation Committee Parameters
APPENDIX E	Respite Committee Members
APPENDIX F	Respite Program Document Model Respite Program Reconstructed Model
APPENDIX G	Parent Survey
APPENDIX H	Nursing Survey
APPENDIX I	Clinical Survey
APPENDIX J	Distribution of Effects (Table 4.6.1)
APPENDIX K	Client Characteristics (Figures 4.1-4.8)
APPENDIX L	Breakdown of Number of Admissions
APPENDIX M	Breakdown of Number of Days Spent in Respite
APPENDIX N	Social Work Department Respite Activity Sheets
APPENDIX O	Respite Committee Evaluation Form

LIST OF TABLES AND FIGURES

FIGURE 1.1	Elements Tied to Respite Satisfaction	43
TABLE 4.1	Sociodemographic Profile of Families	85
TABLE 4.2	Satisfaction with the Respite Program	86
TABLE 4.3	Difficulties with Requirements and Regulations	88
TABLE 4.4	Satisfaction with Specific Aspects of Service	91
TABLE 4.5.1	Availability of Respite Service	93
TABLE 4.5.2	Availability of Respite Service	94
TABLE 4.5.3	Availability of Respite (Adjusted Values)	95
TABLE 4.6.1	Parents Perceptions on Effects/Benefits of Respite	
TABLE 4.6.2	Parents Perceptions on Effects/Benefits of Respite	99
TABLE 4.7	Respite Service Pathways	102
TABLE 4.8	Distribution of Those Using or Not Using Respite	104
TABLE 4.9	Alternative Sources of Respite	105
TABLE 4.10	Unit According to Last Admission	109
TABLE 4.11	Difficulties with Requirements/Regulations	111
TABLE 4.12	Comparison & Distribution of Effects/Benefits	117
TABLE 4.13	Staff Comparisons on the Effects of a Ward Environment	120
TABLE 4.14	Staff and Parent Comparisons on the Need for a Separate Unit	122

INTRODUCTION

The deinstitutionalization movement, the emphasis on "normalization", and the enactment of powerful legislation, have influenced a major shift toward a community based service system designed to support families and persons with disabilities (Cohen & Warren, 1985). With the dual concerns of increasing needs and limited resources, it has become essential to have a more accurate understanding of the kinds of services and programs that would increase the likelihood of disabled persons remaining in their homes while at the same time supporting or enhancing the integrity of the individual and family (Sherman & Coccozza, 1984).

Respite has emerged as an important and essential support service for families of persons with disabilities. Increasingly, it has become one of the most prominent issues to be addressed by policy makers, service providers, and researchers (Warren & Cohen 1985; Salisbury & Intagliata, 1986; Rimmerman, 1989).

Respite care generally refers to an array of services that enable families to take a break or have relief from the physical and emotional responsibilities of caring for a disabled person (Salisbury, 1986; Joyce and Singer, 1983; Upshur, 1982; Cohen, 1982). Respite services are widely believed to provide crucial support to families. There is evidence to suggest that respite care can reduce family stress (Wikler, 1981), enhance family functioning (Cohen, 1982), and delay or prevent residential placement (Joyce & Singer, 1983; Bromley & Blancher, 1989; Bruininks,

1979). However, simply having respite services does not always ensure that the desired outcomes will occur.

Despite the growing body of literature and research on respite care in the field of developmental disabilities, there is still much to be learned about the contextual factors as well as the kinds of benefits that facilitate or inhibit the realization of respite service objectives (Intagliata, 1986). Evaluation data that could substantiate differential impacts, enhance effectiveness, or justify the expansion of respite services are limited in both amount and sophistication (Cohen & Warren, 1985; Slater, 1986; Wikler, Hanusa, & Soycheff, 1986, Salisbury & Intagliata, 1986).

The literature suggests that respite care can be best understood or evaluated from the perspective of the families who need and use it (Salisbury & Intagliata, 1986). The premise that "family and child needs must drive the design and development of respite services" is fundamental to ensuring that services achieve their intended purposes (Salisbury, 1986, p. 19).

However, for respite evaluations to be useful, it is vital to engage in a process with the key decision makers to define the important or relevant aspects of the program that require investigation. A major theme in the literature on evaluation is the need for evaluators who produce information to work with decision makers and program managers who need and use the information (Hegarty & Sporn, 1988; Patton, 1986; Rossi & Freeman, 1987).

Statement of Purpose or Intent

The intent of this practicum was to conduct a descriptive or formative evaluation of the Respite Program offered at a residential facility for developmentally disabled children, the St. Amant Centre. The family or consumer perspective will be viewed as central to the evaluation while keeping in mind what has been defined as relevant and important information areas for the organization. Family needs, perceptions, and satisfaction with various dimensions of the Respite Program will be evaluated in order make recommendations that would strengthen or improve service.

There are two sets of objectives for this practicum: The first pertains to the evaluation of the respite program itself, and the second, relates to learning objectives.

Objectives for Program Evaluation:

1. To develop an evaluation design which would recognize family or consumer perceptions and perspectives;
2. To develop an evaluation committee that would engage in the evaluation process to define questions and increase the usefulness and relevancy of the evaluation;
3. To develop measures/survey instruments to collect data and information in order to assess various aspects of the service;
4. To interpret and analyze the data and results;
5. Using the results, to put forth recommendations that would strengthen policy and improve the program.

Learning Objectives:

1. To gain a comprehensive understanding of the impact of developmental delay on the family through a review of the literature;
2. To develop a knowledge base and understanding of respite as it relates to the broader dimension of family support services within an ecological framework;
3. To explore the utility of a consumer satisfaction approach for evaluating respite based on literature and direct application;
4. To develop some degree of competence in program evaluation through design, implementation and analysis of applied research;
5. To become familiar with measures and be able to effectively interpret results of the research data;
6. To develop some degree of computer literacy in order to be able to process and analyze statistics;
7. To develop an ability to work effectively with many levels within the organization;
8. To systematically evaluate the effectiveness of the selected approach to program evaluation.

Definition of Terms

Throughout this study a number of major concepts will be discussed. In order to provide clarity and understanding, these terms have been defined or interpreted as follows:

developmental disability - "refers to a severe, chronic handicap that is characterized by permanent deficits in cognitive and adaptive functioning" (DeWeaver, 1983). Although disabling conditions include mental retardation, epilepsy, cerebral palsy, autism, dyslexia, deafness, blindness, learning disability, or any combination of these impairments that emerges before the age of 22, the focus of this study is the specific condition known by previous terminology as mental retardation.

respite care - an array of services that enable families to take a break from the physical and emotional responsibilities of caring for a disabled person (Salisbury, 1986; Joyce & Singer, 1983; Upshur, 1982; Cohen, 1982).

extent of service - the degree to which programs provide services, usually reflected by data on number of clients served, amount of money spent on services, or adequacy of services in meeting needs (Davidson & Adams, 1989).

scope of service - the range of options provided within a program, or the type of service provided (Davidson & Adams, 1989).

consumer satisfaction survey - the operationalization of consumer satisfaction through a self-report on aspects of program indices such as rates of service utilization, waiting periods, the felt adequacy of the milieu, reactions to the quality of care, to its helpfulness, cost, continuity, availability, and accessibility (Lebow, 1982).

Organization of the Practicum Report

This practicum examines the theoretical basis for respite care and evaluates an existing respite care program. The Introduction provides an overview of the purpose, the objectives, and the definition of terms for this study. Chapter One contains a review of literature relevant to families with disabled children. Chapter Two provides an overview of program evaluation and client satisfaction research. Chapter Three presents the design of the study including a description of the Respite Program at St. Amant Centre, and the data collection and analysis techniques. Chapter Four contains the results of the surveys and interpretation of the findings while Chapter Five presents an analysis and discussion of the findings and recommendations for the program. Finally, Chapter Six provides conclusions, limitations, and an evaluation of the study itself.

CHAPTER 1

REVIEW OF THE LITERATURE

This literature review attempts to integrate and summarize a variety of factors which have an impact on families with developmentally disabled individuals. By delineating the relationship between stress and adaptation and the role of social support, both formal and informal, this review will provide a framework to assist the reader in understanding the significance of respite and the need to evaluate it as a service.

The literature review will be organized into three parts:

Ecological Model. Of particular interest is the ecological model or framework which will act as a conceptual base by which to understand the linkages and interrelationships between the individual, family, and social support systems along with implications for policy and program development.

Stress, Coping and Adaptation. Special attention will be given to the literature in the area of family stress, coping and adaptation as a way of understanding the impact of the developmentally delayed child on the family and the role of social supports, formal and informal, in mitigating the effects of stress.

Respite Care. The third section will concentrate on the area of respite care including its definition, connection with family support services, potential benefits, obstacles affecting utilization, and political considerations and implications.

1.1 THE ECOLOGICAL MODEL

It has been asserted that the absence of a theory or theoretical framework often leads to interventions and services that are piecemeal, disconnected, and frequently ineffective (Beamish, 1988; Dillon, 1985). Increasingly, professionals have recognized that the processes and responses to life events are highly complex and that well-being is affected by both personal and environmental factors. Hence, there is a need to have a perspective from which to understand the connectedness and interrelationships among dimensions (Coulton, 1979; Germain, 1981).

The ecological systems framework or model is one based on the interrelatedness of organisms and the environment (Bubolz & Whiren, 1984). It is holistic in nature relying on a broad array of knowledge and theory from general system theory, biology, anthropology, psychology, and ecology as well as from concepts of demography, public health, organizational, and communication theories (Maluccio, Fein, & Olmstead, 1986).

Ecological thinking is based on a systems perspective which recognizes the interrelationships and feedback processes between systems. However, it differs to the extent that it does not focus on only the ability to change, but rather it is concerned with the individual's ability to actively negotiate and compromise with the social environment (Dehoyos and Jensen, 1985; Beamish, 1988; Bubolz & Whiren, 1984). Families with disabled persons are viewed as microunits of society making adaptations necessary to function in a complex social milieu.

The notion of "person-in-environment fit" plays a central role in ecological thinking. It refers to the "degree of congruence or correspondence between the individual's needs, capabilities, aspirations, and the resources, demands, and opportunities characteristic of the environment" that would enable them to make creative changes or adapt (Coulton, 1979, p. 5).

The ecological model views humans as part of the total environmental system requiring energy to transact other systems. This energy is needed for adaptive and creative behaviour necessary to enable the system to cope with stress and demands. Undue energy demands can create "energy sinks" where adaptive behaviour may no longer be possible posing yet greater stress on the system (Bubolz & Whiren, 1984).

Coping refers to the capability and skills of people to handle stress while stress is understood as the discrepancy between demand and capability (Germain, 1981). Perceived demand and perceived capability, termed "cognitive appraisal" (Germain, 1981), are in fact more critical than the actual demand or capability. The perceived imbalance then leads to a subjective experience of stress resulting in various psychological, physiological or behavioral coping responses. Stress is viewed then as a cyclical and perceptual phenomenon.

Although stress within an ecosystem is natural or even necessary, the presence of a disabled person in the family can place excessive stress on the family unit to the extent that the demands may exhaust total resources and capabilities. In order to cope, the family must either

increase resource, increase their efficiency, or reduce or eliminate the source of stress (Bubolz & Whiren, 1984).

If family resources are depleted, then society is affected as family members are unable to participate in normal activities such as work and education. In this way society has a stake in the well-being and productivity of its citizens and therefore must confront the need for opportunity, resources, and services when energy demands in the family exceed resources available (Bubolz & Whiren, 1984).

Because the ecological model identifies the disturbance or stress in the interaction between individual and the environment, assessment of the problems must focus on the systems involved. Beyond working with the individual or family then, the model suggests that mediating or advocacy efforts are needed to influence elements of the social and physical environments, of organizations, and institutions in order that they are more responsive to coping needs (Germain, 1981; Swap, 1978). Responsiveness may include diverse interventions such as providing information, social supports, or developing innovative programs and services.

Implications for Policy, Services, and Practice

The ecological systems model, according to Bubolz and Whiren (1984), has the following implications for policy, services, and practice:

1. The total family unit must be considered in the development of a plan or program for the disabled person so that decisions are most likely to produce the greatest benefits to all members of the family.

2. Appropriate support and services must be provided in view of the total family unit. As the family attempts to cope with the disabled, other family members may inadvertently be placed at risk.
3. The issue of longevity of the seriously handicapped in relation to parental and family responsibility must be seriously considered in the development of programs and policies especially as some disabled persons will never be able to function independently.
4. The total energy needs of the family must be considered in establishing external systems of support. The resources and supports should meet the demands created by the handicapped person.
5. Easily accessible information, retrieval, and advocacy systems need to be established so families can receive necessary and relevant information on resources, services, and supports.
6. The ecological model promotes communication, coordination, and cooperation between various public, private, and volunteer sectors. The focus should be on the needs of the handicapped person and the family and how the support system can best interface in providing the needed help. In contrast to the interdisciplinary approach, where the emphasis is on the theoretical structure of the dominant discipline within the agency or support system, the emphasis of the ecological model is on the holistic nature of the problems and strengths of the individual or the family.
7. All programs that are designed to place institutionally handicapped persons in the community should be evaluated in relation to energy or resource base available. The value of self-help voluntary groups should

be considered along with publicly supported programs.

8. Information, counselling, economic support, and respite care should be considered for all families including adoptive or foster parents.

9. Public awareness of the psychological, physical, ethical, and economic dimensions of the family systems of the handicapped need to be expanded so that the complexities of care can be better understood. Although factors such as mainstreaming into public schools and easier access to public facilities have made the disabled more visible, the understanding of the complexities of care remains low (Adapted from Bubolz & Whiren, 1984, p. 10-12).

Bubolz and Whiren (1983) point out that the interrelationships and linkages between values, resources, and decisions are fundamental to the ecological model. They further assert that policies, programs, and services for the disabled are directly related to values about "equality of opportunity and access to resources, respect of life and human dignity, work, health and well being, development of human potential, independence and justice" (Bubolz & Whiren, 1984, p. 12).

Relevance and Applicability

The ecological framework has broad relevance and applicability in a range of settings, target populations, and problem areas (Beamish, 1988). The selection of this framework in understanding issues and needs of families with disabled children is consistent with social work emphasis in two primary ways. First, it focuses not only on problems and

stressors, but also on competency, that is, the ability of families to cope with various stressors and stressful life events. Adaptation and growth, rather than dysfunction or pathology, become important dimensions in analysis (Vosler & Proctor, 1990; Beamish, 1988). Secondly, its holistic view incorporates the transactions of the individual, family and social-environmental systems and guides intervention at these different levels (Garnezy, 1987; McCubbin & Figley, 1983; Kaplan, 1983; Vosler & Proctor, 1990). This framework also has relevance and implications to the development of public programs and policies including support services such as respite.

This practicum uses the ecological framework as a reference point or perspective from which to understand the connectedness and the interrelationships among systems.

1.2 STRESS, COPING, AND ADAPTATION

The literature on stress, coping, and adaptation provides an overarching framework by which to understand the significance of respite services and the need to evaluate it as a service. In this section, the nature of stress and its potential sources in families of disabled children will be reviewed. This is followed by a discussion on the recent shift in viewing family adaptation from a purely stress related paradigm to a coping or competency-based paradigm. Two models that incorporate a competency-based framework are discussed. Finally, the role of both formal and informal supports in mitigating the effects of stress concludes

this section.

Stress in Families with Disabled Children

A recurring theme in the literature on families demonstrates the normalcy of stress on the birth of a child (Salisbury & Intagliata, 1986). Research on parenthood suggests that stress is related to the changes in role, differences in expectations, and to role overload (Aldous, 1978; Burr, 1970; Salisbury & Intagliata, 1986; Suelzle & Keenan, 1981).

The birth of a disabled child, however, can represent a major stressful event for the family, one which requires significant adjustment (Trute, 1988). While these families are subject to the same pressures and tensions that every family faces in modern society, they are often faced with a unique set of problems and stressors as they try to respond and adjust to the disabled child (Gallagher, Beckman, & Cross, 1983). In other words, all things being equal, families with mentally retarded children are likely to experience more stress than families with normal children (Wikler, 1981).

Literature suggests that stress can be linked to several factors in families with a disabled person including child characteristics, parent characteristics, marital relationships, sibling relationships, attitudes and values, family structure, socioeconomic circumstances, formal or professional supports, and countervailing social values (Gallagher et al., 1983). Families respond to stress in various ways. Some will even resort to out-of-home placement or institutionalization as a way of coping and

responding to stress (Wikler, 1981).

Understanding the various factors that might influence stress is useful in comprehending the range of behavioral and psychosocial reactions in times of high stress, loss, or change (Dillon, 1985; Beamish, 1988). It is important then, to examine the factors that influence stress in the family of a disabled person, why it may be that some families respond differently than others, and to develop treatment and service strategies accordingly.

Limitations of Research Findings on Stress

The literature suggests that parents, siblings, the disabled child, and the family as a unit are at risk or vulnerable to higher levels of stress than the general population and that certain factors such as child characteristics, parent characteristics and others mentioned above help in understanding the nature of stress and range of reactions. However, the results of studies on stress in families with disabled children have been inconsistent and even contradictory (Crnic, Friedrich, & Greenberg, 1983). Much of this confusion seems related to variations in methodological adequacy, inappropriate control groups, small samples, and measures differing in quality of reliability and validity, and a bias toward expecting pathological outcomes in families of disabled persons (Crnic et al. 1983). The lack of conclusive results can be related to the fact that adaptational processes are so greatly varied that they cannot be easily generalized (Sherman & Coccozza, 1984; Crnic et al., 1983).

Some researchers (Klein-Walker, Gilbert-Epstein, Taylor, Crocker, & Tuttle, 1989), report that little research has been conducted on samples that are nationally representative while most research focuses on one specific condition rather than a range of conditions. Such factors would also limit generalizations to a particular group or sample.

According to Crnic et al. (1983), many studies have been low in ecological validity and generalizability because they focus on a mother-child dyad using a unidirectional rather than transactional model, and they focus on one setting rather than the interrelationships among settings. He suggests that failure to study families in a large context and to include multivariate studies that address basis issues such as age, type and severity of handicap, appearance, health, sibling and family outcome has posed limitations. Crnic et al. (1983) encourage the use of longitudinal and prospective studies to provide more accurate information especially in such areas as marital satisfaction and psychological and emotional outcomes.

Literature on family stress, then, is rather inconclusive although increased stress levels reported seem to be a reasonable observation and seem to validate clinical impressions (Kazak & Marvin, 1984). Although certain factors can provide us with information on the potential areas of stress for families, it hardly explains why some factors influence some families more than others or why some families adjust particularly well to a disabled child despite stressful influences. The dynamics are complex, but high stress does not necessarily lead to dysfunction nor does

it mean that the family is not coping (Kazak & Marvin 1984; Salisbury & Intagliata, 1986; McCubbin & Patterson, 1983; Crnic et al. 1983; Dunst Trivett, & Cross, 1986).

There is an increasing awareness that research must not only be concerned with the nature of these stressors, but must refocus from solely intra-family issues to the interaction with social support networks and the interrelationship of these systems in either the production or mediation of stress (Kazak & Marvin, 1984; Crnic et al. 1983).

According to Crnic et al. (1983), the concept of coping resources has great utility for the study of adaptation in families with disabled children as the families' differential responses to stress are not solely related to child variables. He argues that research must present a more integrated and multidimensional approach to studying the causal or mediational variables and their interactions.

At this juncture, the study of two particular models that incorporate a competency-based multidimensional approach may be pertinent to further understanding the dynamics involved. The first is the Adaptational Model proposed by Crnic et al.(1983). The second is the Double ABCX Model (McCubbin & Patterson 1983; McCubbin & Figley, 1983).

The Adaptational Model of Stress, Coping, and Ecological Systems

The model proposed by Crnic et al. (1983) integrates concepts from three bodies of research: stress, coping, and family ecology. The model attempts to explain a range of family adaptations as a "response to the

child mediated by coping resources available and influenced by the family's ecological environments" rather than just simply a response to a disabled child (Crnic et al. p. 136).

The conceptualization of this model involves the sources of stress plus the mediators of stress. A competency or coping-based framework is considered as an alternative to the pathology-based concept as it emphasizes tasks and strategies involved in living with a disabled child rather than dealing only with the causes and the nature of stress. In addition, social support is recognized as a potentially powerful mediator variable (Crnic, et al., 1983).

Several investigations suggest the importance of focusing on specific ecological factors and contexts that exert influence on coping resources (Farber, 1959; Rowitz, 1974, Schoggen & Schoggen, 1981; Bronfenbrenner, 1979; Crnic et al., 1983). Interactions of the individual and family within immediate settings such as home, school, work (microsystem); the interrelationships between settings (mesosystem); the formal and informal structures such as government, media, neighbourhood (exosystem); and the ideological patterns of culture and subcultures (macrosystem) are among these influences (Bronfenbrenner, 1979).

Crnic et al., (1983) view this model, which incorporates factors involved in stress, adaptation, and ecology, as an explanatory model for family adaptation. Differential family adaptation can be interpreted as being a function of coping resources which moderate effects of perceived stress associated with the presence of a mentally retarded child. Coping

resources are mediated by various ecological systems in which the family interacts.

A few recent studies have begun to incorporate this framework to some extent. For instance, Nihira, Mink, and Meyers (1981), in a study of the interrelationship of home environment and school adjustment, found that "family harmony, the quality of parenting, family cohesiveness, emotional support for learning, and cognitive stimulation available in the home were significantly related to the child's school adjustment" (cited in Crnic et al., 1983, p. 135). This study concluded that coping within the family environment has an influence on the child's adaptation to a separate ecological context.

Dunst, Trivette, and Cross (1986) also used a multivariate approach in a study of 137 parents of physically impaired and developmentally at-risk children to assess the effects of social support from various systems. They found that the interactive effects of social support, both qualitative and quantitative dimensions, have direct and indirect influences on the child, family, and parents. They reported that the use of specialized community resources was significantly related to both the child's diagnosis and satisfaction with support. Where children had low developmental quotients, fewer resources were accessed. Those with more supportive informal networks reported less use of community resources. They concluded that where informal sources of support were effective mediators, more formal services may not be necessary. In terms of formal respite services, this suggests that families who have strong informal

social support networks may not need to utilize formal respite services to the same extent as other families with few informal supports. In addition, the severity of the child's diagnosis and the degree of satisfaction families experience with formal services like respite may affect their utilization of service.

Dunst et al. (1986) also reported that negative effects such as behaviour problems, pessimism, and overprotection were more likely found with increasing age of the child in families where there was minimal support. This was consistent with a fundamental tenet of ecological support theory that social support has differential impacts and effects at different developmental junctures and transitions (Wikler, 1981; Konac & Warren, 1984; Black et al., 1990; Bronfenbrenner, 1979). That is, during the course of development, the effects of support would differ depending on the age of the child (Dunst et al., 1986). Dunst et al. (1986) concluded that social supports seem to be more important to the family as the child becomes older. These researchers also concluded that their study provides support for the adaptational model (Crnic et al., 1983) in that "although the presence of a disabled child often has a detrimental effect on different family members, ecological influences, including social support, can have positive effects on the development and functioning of child and family" (cited in Dunst, p. 415-416).

The Double ABCX Model of Family Adapataation.

McCubbin and Patterson (1983) noted that some families get stronger

and actually thrive while other families grew weak when confronted with the stress of an ill child plus other life events and changes. The Double ABCX Model of family stress (McCubbin & Patterson, 1983; McCubbin & Figley, 1983) helps to explain the variability of responses to chronic stress and provides a way of understanding family responses over time as they try to adapt to multiple stressors. This model has become one of the most prominent conceptual frameworks in contemporary studies of stress in family coping and adaptation (Selzer & Krauss, 1989).

The Double ABCX Model divides the family response to stress into three phases: adjustment, accommodation or restructuring, and consolidation. The ability of the family to cope effectively within each of these phases depends on: a) the interaction of the stressor (demands or precipitating events); b) the perception of the stressor; c) the families' existing resources (psychological, social and material characteristics of the family and community) (McCubbin & Patterson, 1983; Cole, 1986; Beamish, 1988).

"Pile up", a concept central to this model, involves the notion that multiple demands and exchanges occur simultaneously over time. This notion helps conceptualize long term impacts and tasks associated with events. Normative changes such as the birth of another child, as well as strains associated with disability would be included (Kazak & Marvin, 1984; Beamish, 1988). The tasks that are not resolvable become chronic strains which, in a study by McCubbin & Figley (1983), were judged by families to be most problematic. Some studies demonstrate strong positive

correlations between the pile-up of family stresses and the likelihood of out-of-home placement (Cole, 1986).

During the adjustment, the family will attempt to use coping strategies such as avoidance or denial, eliminating the stressor, or accepting the demands and applying short term solutions (Cole, 1986). The degree of successful adjustment through the application of these solutions (outcome) depends on the "goodness-of-fit" between family members and with the interaction with the community including social supports, services, and social institutions. If the family is unable to restore stability within the family system, they may enter into further disruption and or incapacitation. The family may then begin to draw on new resources or forms of support such as respite, support groups or other professional help. They may attempt to arrive at a new conceptualization and broader perspective of needs and resources or they may realize that there is no perfect balance between resources and demands and that family decisions constitute a mutually acceptable set of compromises (Cole 1986).

Trute (1987) integrates the Double ABCX model in a study of 36 well adjusted families living in Manitoba. Trute reported that these well-adjusted families tended to have a positive or neutral cognitive appraisal of having a developmentally delayed child. Generally there was thoughtful and differential use of extended family and friendship network resources. These families actively employed internal as well as external resources to cope with the demands of their situation. Both friends and family provided high levels of emotional support, advice and information, but

family members were the major source of material aid, physical assistance and respite care. Friends on the other hand were more important for social participation. When specific strategies for coping were studied, well adjusted families seemed to turn more strongly to external resources and seemed to be able to acquire various forms of support. In terms of appraisal of the situation, they reported that they were able to directly meet their problems and mobilize internal and external resources. These families demonstrated no significant differences in their use of reframing as a coping strategy or redefining the meaning of stressful events to make them more psychologically manageable. In particular, the parents in this sample functioned as a team to cope and to mobilize resources. Trute also noted that in this particular sample, two parents with a steady source of income predominated. Single parent families and families on social assistance were absent in this sample of success cases.

Trute concluded that this study lends support to McCubbin and Patterson's Double ABCX Model of family adjustment. That is, a family's capacity to adapt and adjust is related to the stressors, the perception of the situation, and the resources available to cope with the demands of the situation. The study corroborated both the importance and the differential use of social supports such as respite in coping and adjustment. In other words, the family's perception of their situation, the stressors involved, and the resources available to them, will have implications on their need for formal respite programs and determine how and when they might use respite programs. The utilization of respite

could be viewed as a solution or coping strategy important to the adjustment process or a preventative measure to avoid "pile-up" effects associated with multiple demands over time. The study also seems to imply that the ability to negotiate with systems to obtain needed resources may also be related to the family adjustment.

Social Supports as Mediators of Stress

Through the development of models such as the Adaptational Model and the Double ABCX Model, social support has been recognized as a powerful mediator of stress and a potential source for understanding why some families might cope better than others. There is a growing recognition that resources in the community and the extended family are frequently correlated with successful outcomes in high risk families (Tracy, 1990; Schilling, Gilchrist, & Schinke, 1984). Social support resources may have the potential to avert the need for placement or to shorten the duration of placement (Maluccio & Whittaker, 1988; Tracy 1990). However, some families lack concrete and emotional supports, the outcome of which is often deleterious.

A number of studies demonstrate the importance of social support in the mediation of stress. For instance, in research concerning maltreating mothers, it was found that these mothers tended to report fewer neighbours, friend, and relatives and expressed more dissatisfaction with the dependability of their social networks (Gaudin & Pollane, 1983; Polansky, Gaudin, Ammons, & Davis, 1985). Social isolation has also been correlated

with maltreatment although the reasons seem complex and related to environmental variables, personal factors, or social stigma and social distance (Garbarino, 1976; Seagull, 1987). A pattern of social contacts characterized by high levels of negative and coercive exchanges termed "insularity" has also been related to a lack of treatment gains in parent training (Wahler & Afton, 1980; Tracy, 1990).

Bristol (1979) found that mothers of autistic children who reported the least stress also had more support from others including spouse, friends, and parents of other handicapped children. Creal (1974) suggests that outside relationships can influence how parents perceive acceptance or rejection, receive encouragement and assistance, as well as criticism for the way they handle various situations.

Garmezy (1987) reported that stressful events and multiple risk factors are cumulative, and suggested that individual, family, and social-environmental factors, along with the number of stressors involved, need to be identified when working with families. Similarly, McCubbin and Figley (1983) and McCubbin and Patterson (1983), focus on the impact of stress "pile up" and note the importance of assessing the specific stressors and the number of stressors involved in order to design appropriate interventions.

Vosler and Proctor (1990), in their study of 226 children and families, studied stressors and competencies and multiple systems levels to predict child behaviour problems. They found that no one system overrides the importance of another and that problems in the family and

larger social environment are critical. Intervention with only the child, with only the family, or with only the social environment would be insufficient. This study demonstrates the importance of assessing stressors, resources, and competencies at all three systems levels.

Generally, both the Adaptational Model and the Double ABCX Model utilize the person-in-environment (ecological) framework to show the importance of understanding critical factors in the assessment of stress and coping and in recognizing the importance of social supports as mediators of stress. Using this framework as a conceptual base, respite care can be viewed as a social support or resource that has potential to moderate the impact of the disabled person in the family. The degree to which formal services such as respite care will be utilized, will also depend on the families perception of their situation and their ability to mobilize resources.

The Role of the Professional in Enhancing Family Coping/Mobilizing Social Support.

The ecological perspective with emphasis on person-environment exchanges suggest that intervention strategies are necessary to respond to families' needs for social support and/or instrumental services (Saulnier, 1982). However, the degree to which a support network may be mobilized to provide ongoing assistance will vary with proximity, quality of previous relationships, and the skill of the family to mobilize their support networks including accessing resources such as respite care (Kazak

& Marvin, 1984).

Families have a range of skills and while many may be highly successful others may not be able to make use of their immediate resources. Professionals may need to be involved in the mobilization and maintenance of an adequate social support system. It may be that some families have a very sparse support system. Depending on the need, the practitioner might need to intervene at various levels including promoting skill development to make use of a normalized support network, providing information on a range of resources available, and/or in providing assistance to establish links or connections with support agencies or support groups. Families may need instrumental help in training or provision of services such as respite care and day care or they may need help to negotiate with the numerous services that may be involved.

Facilitating the use of a social supports is an important dimension of intervention with the individual or family and it is one that is gaining increased attention as evidence points to the necessity and benefits associated with support networks (Kazak & Marvin, 1984). Respite can be a powerful support, but having respite care alone may not be sufficient. Families may need support to mobilize or access the service. As the ecological frameworks suggests, respite should be viewed as part of an overall support system. This will be discussed in the next section of the literature review.

Summary: Coping and Adaptational Frameworks

The competency based or adaptation paradigms, which is the operational and conceptual core of the ecological approach, is valuable in its broad systemic scope and flexibility (Beamish, 1988). These frameworks recognize the interrelationship of the individual, family, and social support systems and the fact that families with disabled children have multidimensional needs which change over time. In addition to some of the more traditional interventions, it allows for multiple interventions or strategies using the informal or formal support networks as enhancers in the context of family adaptation. The practitioner can intervene or target change at various levels where appropriate.

However, there is a limitation in that these models can be fairly prescriptive in terms of their treatment of systems problems while not offering specific methodologies in respect to individual treatment, for instance how to help families work through affective difficulties (Beamish, 1988). It is therefore necessary to build in or supplement practice strategies, such as the use of cognitive appraisal techniques, where appropriate.

In respect to respite programming, both the Double ABCX Model and the Adaptational framework provide a multidimensional base by which to understand respite as a mediator of stress. Respite care can be viewed as a coping strategy important to the adjustment process, or a preventative measure used to circumvent the "pile-up" effect associated with multiple demands over time. The frameworks denote a need for

services such as respite to be responsive to a range of factors and coping abilities of families. Within the context of the both the Adaptational Model and the Double ABCX Model, respite is seen as an important source of support, and a part of a broader social support base that can exert an influence on coping.

As discussed, interventions aimed at building support networks are gaining in importance and seem to have been influenced by the shift to a competency based framework. Social work literature promoting practice principles has advocated for the development of innovative and responsive services and programs that facilitate the release of adaptive capacities of families (Germain, 1981). In the following section, respite will be described and elaborated as a formal support service that has been developed as a response to families who provide long term care to disabled children and adults.

1.3 RESPITE CARE/SERVICES

Respite services are available to families caring for persons in various age groups and with a range of disabilities. However, in keeping with the focus of the practicum, the emphasis is on respite for the developmentally disabled population.

In this section of the literature review, respite care is discussed as part of the overall system of family support service. Definitions and various models of respite care are reviewed. A review of factors influencing the need and utilization of respite services, follows.

Finally, a discussion regarding obstacles to the development and provision of service along with implications for policy will conclude this section.

Respite as Part of Family Support Services

Family support programs are those designed to assist families caring for persons with disabilities. Services may address diverse family needs such as information, specialized services, respite, social networking and/or assistance with direct care (Agosta, Bradley, Rugg, Spence, & Covert, 1985). From a normalization theory perspective, the goals of family support programs should prevent unnecessary out-of-home placement, return persons in institutions to the family/community environment, and augment the caregiving capacities of families (Agosta, et al., 1985).

Salisbury (1986) suggests that the quality of these resources plays an important role in supporting families. Insufficient services can be expected to produce hardships for families facing stressful life situations. As previously noted, research shows that there is a tendency for families to use informal networks before linking with formal community resources (Dunst et al., 1986). However, at times when resources in the informal network system are insufficient or unable to mediate the effects of stress in the family, respite care can be regarded an important source of social support for families. Advocates of respite services for those who are parenting or care for a child with a developmental disability stress the importance of viewing respite as part of the overall family support service system (Salisbury 1990, 1986; Intagliata, 1986; Cohen,

1985; Seltzer & Krauss, 1984; Upshur, 1982).

Definition of Respite, Scope and Function

Respite care is a specific kind of support service designed to assist families in coping with their disabled family member. As stated earlier, respite care generally refers to an array of services that enable families to take a break from the physical and emotional responsibilities for caring for a disabled person (Salisbury, 1986; Joyce & Singer, 1983; Upshur, 1982; Cohen, 1982). Respite has been defined very simply as a temporary relief service for families or primary care providers (Warren & Cohen, 1985; Joyce & Singer, 1983; Salisbury & Intagliata, 1986). A fairly broad definition of respite care as put forward by the United Cerebral Palsy Association (UCPA) and the City University of New York (CUNY) states:

Respite care is one component of a family/caregiver support system that provides temporary relief for primary caregivers. It cannot function in isolation from other support services. It should be recognized that other services provide relief, although it is not their primary function. Respite care should not operate independently of a case management system (Cited in Warren & Cohen, 1985, p. 68).

"Temporary" is understood to mean anything from an hour to three months and it can mean periodically or on a regular basis regardless of whether it is in-home or out-of-home settings (Warren & Cohen, 1985).

Respite services can have what is described as either primary and secondary intent. Primary respite care would correspond to services

designated specifically to provide relief to the family while secondary respite relates to services provided to the disabled child, such as school, day care or work, but provide temporary relief from childcare (Salisbury, 1986; Cohen, 1982). Respite is the outcome of the service which provides relief from caregiving responsibilities (Salisbury, 1986). However, in the case of secondary respite, the relief provided is a side-effect or by-product (Cohen, 1982).

Models of Respite Service

There are two primary models of respite service: in-home or out-of-home respite (Salisbury, 1986; Warren & Cohen, 1985; Levy & Levy, 1986; Cutler, 1986). Some studies point to a strong preference by families for home based services (Upshur, 1982) while others point to a significant minority (40%) preferring out-of-home respite (Warren & Cohen, 1985).

The service may vary in content, for instance, sitter, companion, nurse, recreational worker, homemaker, or a combination of these. The worker may be salaried or volunteer. Fiscal arrangements can involve a sliding scale arrangement, free service, or cooperative arrangements between families (Warren & Cohen, 1985).

Home-based models, which include homemaker services, sitter/companion, or parent/trainer services, have the distinct advantage of having the disabled individual remain in a familiar environment. In addition, specialized equipment does not need to be transported, arrangements for the transportation of the individual is unnecessary, and

the service is relatively low in cost (Cutler, 1986).

The disadvantages of home-based service include the lack of experienced workers and difficulties in arranging services for those who have severe behaviour or medical problems. Also, parents who may define relief as rest or quiet time at home, may feel compelled to leave their own home. Home-based respite may have disadvantages: It may be more costly in some situations as it usually serves one individual rather than a group; liability issues arise; supervision of workers and quality of service is difficult; and it may be hard to get a provider to travel long distances or to certain areas (Cutler, 1986).

Out-of-home respite options include parent cooperatives, services in a respite provider's home, foster homes, group homes, institutions, or respite residences. Often these provide the advantages of having an emergency response entity, better trained and supervised staff, the ability to deal with more severely disabled individuals, and more activities or peer contacts (Cutler, 1986).

A more recent model of respite being promoted is the "respite residence model" (Cutler, 1986; Levy & Levy, 1986). This is a separate residence or home that serves only respite users. Its appeal is in that it is a home-like environment that can serve more than one person at a time; staff are trained and can engage clients in activities; and the program is coordinated by a professional person who is able to assess the needs of the family and of the disabled individual, and who has knowledge of and ability to link and coordinate effectively with community based

agencies. The disadvantage of this model is the cost of a separate or free-standing residence, and the fact that providing service beyond six individuals is deemed restrictive in terms of quality interactions and activities.

In respect to institutions as an out-of-home respite option, there is still much controversy. Some researchers report the perception or belief that the use of institutions for respite is a way of legitimizing their existence (Salisbury & Griggs, 1983; Cutler, 1986). In addition, access, bias against institutions, and relocating the disabled person to a less normative environment remain among the disadvantages of these settings (Levy & Levy, 1986; Cutler, 1986; Upshur, 1982).

On the other hand, many institutions have allocated specific areas to serve a number of low incidence, underserved populations such as autism, Prader Willi Syndrome, or dual and multiple diagnosis. This is significant in so far as research shows that persons with severe medical or behavioral needs are often excluded or have difficulty accessing existing community-based services or trained personnel even though their families would presumably need more respite because of the intensity of the demands (Upshur, 1982; Apolloni & Triest, 1983; Cutler, 1986; Levy & Levy, 1986).

Although there is still much controversy about the continuing use of institutions as restrictive and/or promoting their use as a way of legitimizing their existence, Cutler (1986) puts forth the following notion:

...degrees of restrictiveness are better measured in the context of client and family needs; physical dimensions of the setting; adequacy of staffing patterns, skills, support and supervision; availability of client information; appropriateness of activities for the client; and the feelings of security families have about the program. When both the clients' and families' needs are met, that model of service that meets those needs is the least restrictive (p. 189).

Cohen (1982) concluded that there is no best form of respite care and advocates for a range of respite models because of variations in family preferences or needs and variations in the intensity of service needed by the disabled person. Furthermore, the same family may need different types of services at different stages in the development of the disabled child and family.

Benefits/Importance of Respite

The importance of respite to families cannot be underestimated. In a study by Apolloni and Triest (1983), the most common reason for respite utilization was "sheer relief for overworked family members" (p. 241). In their earlier study (1980), over 80% of parents reported respite to be of considerable importance. Care provision in case of family emergencies and illness, practical needs, appointments, special events, and recreation needs were identified as priorities with families using respite.

Proponents of respite suggest that the most tangible benefits to families is a significant reduction in stress, strain, and burnout; improved well-being and family functioning; and reduction in out-of-home placements (Salisbury, 1990; Rimmerman, 1989; Halpern, 1982; Salisbury &

Intagliata, 1986; Joyce & Singer, 1983; Wikler & Hanusa, 1980). In addition, some parents report that their satisfaction with life, hopefulness about the future, ability to cope and attitude toward their children improved with the use of respite (Cohen, 1982; Upshur, 1982; Seltzer & Krauss, 1984). A number of studies indicate that respite can result in tax savings to the taxpayer even when parents receive liberal supports arguing that respite care, especially for the severely disabled, is only a fraction of the cost incurred for most placement alternatives (Rimmerman, 1989; Cutler, 1986; Apolloni & Triest, 1983).

Joyce and Singer (1983) reported that respite provided parents with relief by merely knowing that a trained person was available; by being able to make plans ahead of time; by being able to stay away from home for longer periods of time; and by feeling less guilty about leaving the child. In this particular study, only a few respondents cited respite as promoting family relationships, enabling them to spend more time with family, or having an energizing effect.

Joyce and Singer (1983) also found that parents who once considered institutionalization believed respite care enabled them to care for their child at home. This finding is consistent with many studies including Apolloni and Triest (1983), who found that almost half (47%) of the parents in their study stated that they would seriously consider out-of-home placement if respite services were not available. However, in a study by Bromley and Blacher (1989), respite care considered by itself, was not a variable that appeared to keep children in their home longer.

Only 36% of their sample viewed respite as an integral part of keeping children at home. The strongest indicators were attachment to child (57%), followed by thoughts that someone else would be raising their child (63%), and guilt (53%). Although a formal assessment of resource utilization was not completed in this study, Bromley and Blancher noted that the decision to place may be a complex combination of resource utilization, parental cognition, and feelings. In other words, the utilization of respite services may only be one of the several factors involved in the decision to place a child.

Respite is also reported to be an important service for ameliorating transitional problems associated with deinstitutionalization (Bruinincks, 1979; Willer, Intagilata, & Wicks, 1981; Apolloni & Triest, 1983). Boggs (1979) suggests that respite may assist young adults with developmental delay to achieve independence from the constant care and supervision of the family. Similarly, Grant and McGrath (1990) report that respite can assist families to entrust their sons or daughters to others and in this way may help parents through a process of "letting go" when it is deemed appropriate for the individual with the disability to leave home to live in the community or when they, as parents, become unable to cope.

Rimmerman (1989), in a study of maternal coping, resources, and stress measured over time, showed that respite services were associated with a significant reduction in maternal stress as well as an enhancement of coping resources. One of the most striking findings was that the impact of respite services on stress reached its positive peak at

differential periods of time. He suggests that change in maternal stress is related to the cyclical nature of coping, perception of the child's progress, or the type and quality of services. Rimmerman suggests that the benefits of respite may be enhanced if supplemented by other family support service such as family counselling, training, or homemaker services.

A major element in stress as reported by parents, particularly mothers, is the need for more time (Bristol & Schopler, 1984). However, in a study by Wikler (1981), mothers tended not to use their time to rest and personal growth, rather, their time was consumed in maintenance functions. Similarly, a study by Salisbury (1990) found that formal respite services were used for family maintenance activities such as work, meetings, social obligations, and errands rather than personal renewal activities. However, one could consider that even having the freedom to run errands and to do housework without dealing with care demands at the same time can alleviate some stress.

Changes in family dynamics seem to occur with the provision of respite, but in some cases it has shown to increase stress. Rodgers (1983), in his study on deaf and blind children, found that a concomitant increase in marital dysfunction and stress occurred with the provision of respite. From a family systems point of view, the husband and wife had ignored their marital conflict and used the disabled child as the focus or "scapegoat". When the child used out-of-home respite, the parents were forced to confront their own relationship. Rodgers concluded that, in

cases such as these, family counselling should supplement respite services.

Generally the development of respite services is seen as mediating stress for parents, particularly the mother who most frequently is the primary caregiver. However, Powell and Ogle (1986) note that siblings experience additional levels of stress when a brother or sister is disabled. They suggest that respite programs serve critical functions for siblings. These include providing time to renew relationships with parents, having time for special activities, and having more time for themselves. Powell & Ogle view respite services as a critical component in providing relief to parents while at the same time supporting the siblings within the context of the family system.

Respite Needs, Utilization, and Satisfaction

In terms of outcome, the ability of respite to buffer or mediate stressful situations is predicated on the family's utilization of the services (Salisbury, 1990). With the rise of community programming, the issue of why and how families use services such as respite becomes crucial for planning and development (Kazak & Marvin, 1984).

Cohen (1982), in a summary of data collected from 357 families over a two year period, found that families with disabled children using respite, when compared to families with disabled not using respite, found that those who utilized respite tended to have a second disabled individual in the home; had a disabled child whose care was extremely

difficult or burdensome, or lacked a network of persons to help. In this particular study, there was a low but significant relationship between the degree of respite utilization and improvement in family functioning with greater improvement being reported with the increased use of respite.

Grant and McGrath (1990), in a survey of 190 families caring for disabled individuals, used a transactional model of stress and adaptation to explain expressed needs for respite. They reported from their multivariate analysis, that the perceived need for service and the factors predisposing families to express a desire for service were linked to five primary domains: a) perceived effects of stress; b) the nature of the dependency especially behaviour problems; c) material or economic circumstances; d) cultural receptivity such as acceptance or rejection by the local community; and e) demographic variables such as age, marital status and gender of the person with the disability. They also reported that this range of factors an indication that professionals need to ensure that families have support at other levels, for instance in trying to reduce challenging behaviour or carrying out training programs rather than merely providing respite. They concluded that the key to provision of service is flexibility and sensitivity to ways families define their needs.

Several other factors need to be considered in assessing needs of the family in the context of service provision and utilization. In particular, there is evidence that the life cycle of children with developmental disabilities as well as the stage in the family life cycle

are important parameters in the study of service utilization (Wikler, 1981; Seltzer & Krauss, 1984; Seulze & Keenan, 1981).

Suelzle and Keenan (1981), in a survey of 330 parents in four different stages (preschool, elementary, teenager, and young adult), determined that parents of younger children utilized more service and support networks. On the other hand, parents of older children were less supported, more isolated, and in need of expanded services. The older child was faced with limited choices in occupational, residential, and educational alternatives. In this study, parents tended to consider or request living alternatives at two particular transitions, the first being the preschool and the second young adulthood, in particular at age twenty one. The life cycle of children tended to be more highly correlated to service utilization than most other demographic characteristics such as occupation, marital status, education, and income. In addition, parents in this study were more resistant to the normalization concept as the discrepancies with the average age rates of development became more apparent. The parents of older children were more likely to plan for more restrictive programs and placement alternatives. This study seemed consistent with literature on family stress which provided evidence that at certain developmental stages and transitions families experienced more stress (Wikler, 1981; Konac & Warren 1984; Black, et al., 1990).

In a study by Lutzer and Brubaker (1985) of younger and older parents of disabled children, differential needs and approaches were identified. Often older parents (over age 56), who had their own health

problems or who were experiencing the stresses of aging, were more interested in services where they would be relatively uninvolved in interactions with their own child, and with social and professional systems. Older parents may increasingly require support due to their own gerontological concerns. On this basis, Lutzer and Brubaker recommend that professionals need to recognize symptoms of diminishing parental support and design interventions at multiple levels.

Black et al. (1990) noted that caregiving by a parent is not normative when the child has reached adulthood and parents are approaching old age. The need for a conceptual model to understand life-span implications of raising a child with a chronic disability and to develop community programs and support services, become important considerations in planning responsive programs.

In a cross-sectional survey (Trute, 1988) of 81 households in Manitoba with disabled children, results showed that as the child aged, the need for regular respite and crisis respite services increased. Trute (1988) identified a number of elements linked to respite satisfaction and subsequent utilization. First, was the frequency with which a family used respite and second, was how helpful they perceived the services. These two factors were directly associated with importance of the respite service to overall family functioning. Overall family functioning, in turn, was the major link to overall satisfaction with respite. Two other variables seemed associate: the age of the disabled child and the number of confidants in the mother's social network. (See Figure 1.1).

Elements Tied to Respite Satisfaction

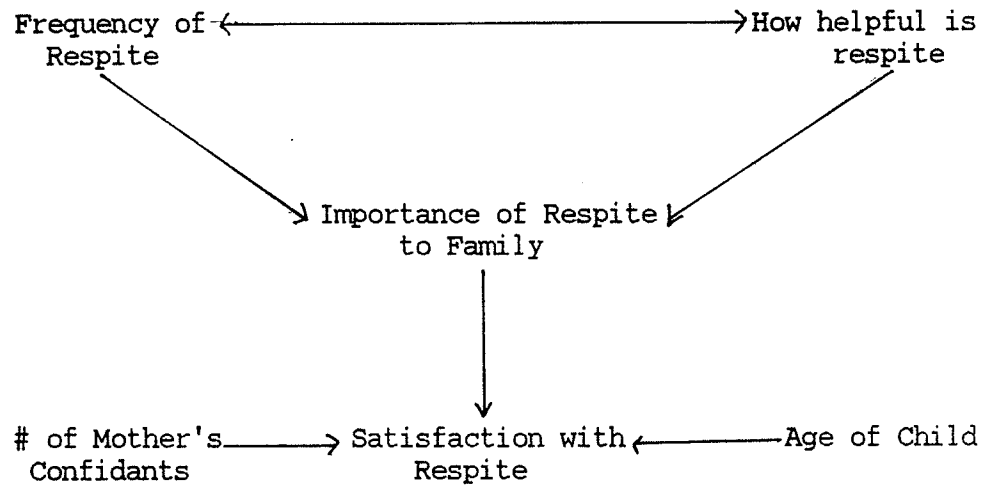


Figure 1.1 (Trute, 1988, p.54)

In the same study, mothers with more support were more satisfied with services received. It was suggested the mothers without adequate supports may have greater needs and/or greater expectations from respite services. Satisfaction with respite tended to decrease as the child aged. Trute concluded that parents' and childrens' needs seem to shift as the child grows and, consistent with studies by Suelzle and Keenan (1981), Lutzer and Brubaker (1985) and Black et al. (1990), suggested that this should be addressed in planning and developing respite.

A study by Salisbury (1990) explored the nature and characteristics associated with individuals seeking respite care, demonstrated need and

utilization. Utilization was based on frequency of use (number of uses per month) and duration (number of days or hours). Those who did use respite tended to represent families with lower incomes, higher stress, and children with more significant disabilities. Mothers of girls tended to use the service more often and tended to use the service to complete obligatory activities rather than for personal renewal. Salisbury concluded on this basis that respite may serve an adjunctive role in family adaptation by helping individuals meet day-to-day demands, but may not be a sufficient contributor to individual well-being.

The results of Salisbury's study (1990) also revealed that there was relatively low utilization (30%) of formal respite services despite financial subsidies, competent providers, high needs, and high expressed interest. This was consistent with low respite utilization findings of Edgar, Reid, and Pious (1988) and Marc and MacDonald (1988). The discrepancy between the level of interest and actual utilization may be due to the fact that families will utilize informal supports first (Unger & Powell, 1980), or it may related to the way the service system is designed, the motivations of the parents, or the contextual variables that affected need for service (Salisbury, 1990). Although those who enroled for this service may have intended to use it, there seems to be link necessary to enhance utilization.

Obstacles Affecting Utilization and Development of Respite Services

The literature on respite utilization provides evidence that it may

not be enough to merely have respite services available (Salisbury, 1990). As discussed above, a number of factors influence the actual use of respite including differential and perception of those needs, demographic variables as well as the life cycle of the child and/or family.

In addition, families may not have information on services. This may be required to promote respite access. Many families of developmentally disabled children have difficulty identifying, gaining access to, and utilizing supports (Wikler, 1981; Salisbury, 1986, Upshur, 1982). These difficulties appear to be related to attitudinal, geographic, economic, and training barriers (Salisbury, 1986).

Apolloni and Triest (1983), in their study of respite services, outline and summarize a number of obstacles blocking the development and provision of respite services:

First, the availability of respite services is inconsistent. Sometimes respite is available for only emergency situations; many services are unable to meet the needs of profoundly handicapped persons.

Second, efforts to plan and evaluate respite services are inconsistent. There is no uniform method of evaluating respite especially in respect to the nature, extent, and quality of the service.

Third, management information systems are inadequate for planning. Objective quality for planning is inhibited by the lack of information on even the most fundamental descriptive data such as the number of clients receiving respite, funds spent, and client functioning.

Fourth, families lack information on respite. Some families were

unaware of respite and those who are aware are often only marginally informed. In addition, some families were uncomfortable with the idea of what they perceive as relinquishing control of their child's well-being and safety to a stranger.

Fifth, no career model exists for respite workers with only limited recognition that the profoundly handicapped, medically fragile, and behaviorally difficult individual required more highly trained workers. The level of payment to respite workers is virtually the same. A high turnover was evident among respite workers (50%/year) (Adapted from Apolloni & Triest, 1983, p.242-243)

In addition, it may be necessary for some families to be "coached" or encouraged to consider respite and by informing them of the potential of respite in assisting families and siblings (Powell & Ogle 1986). Because families are reluctant to leave their children with strangers, they must know where to call, feel that there will be quality service available, and not feel guilty about using the service regardless of the degree of need (Upshur, 1982).

Cohen (1982) suggests that areas of respite service that need improvement revolve around the amount of time available, the quality and skill of the respite worker; and the matter of choice given to parents as to the types of services they can access. She concludes that often only one form of respite is available or promoted and that a continuum of respite care services should be available to families so that models can be matched to needs.

Policy Considerations and Implications

Because respite services are viewed in the context of family support services, it is important to consider obstacles to both family support services in general and to respite services in particular.

Regardless of the research supporting the need for family support services such as respite, Agosta et al. (1985) reported several obstacles in designing and advocating for family support programs.

First, there is a general lack of consensus regarding family responsibility and society's role in what is perceived as a family problem. Some believe that the family is responsible while others believe that monies should be available to meet special needs of families.

Secondly, there are political and economic realities with politicians trying to appease multiple needs and priorities of their constituents on a limited budget.

Thirdly, administrative complexities hinder the establishment of comprehensive family support programs. For instance, questions of what department or service should administer programs, who is entitled to services, and how will funding be allocated or cost-shared are raised. This is evident currently in the Manitoba political environment as the education system looks at trimming its costs for special needs children indicating that their needs are the responsibility of health (Winnipeg Free Press, Feb. 1991). Similarly, the Family Services Minister, reports that the Child and Family Services Act is too broad for the government's available resources and suggests that work expected of social workers in

respect to prevention, education and counselling be left to others (Lett, 1991).

Lastly, Agosta et al. (1985) reported that obstacles to family support programs are complicated by contemporary living. This is particularly evident with the change in the composition of the traditional family and contemporary lifestyles which emphasize women's right to employment, independence and personal growth. At the same time, there is a renewed interest in family based care without the necessary complement of supports to sustain social and familial expectations. Program decisions then, must acknowledge the increase in the female labour force and the increase in the number of single parent families.

Politically and economically, respite represents a key way of responding to the needs of careproviders in the realm of family support programs. Policy should reflect values, standards, and the expressed needs of the family (Warren & Cohen, 1985). In time of fiscal restraint and limited resources, professionals and policy makers must be concerned about who needs respite and how it can be provided to maximize benefits to most families. A fundamental premise is that family and child needs must direct the design and development of respite services in order to ensure that services which are provided actually achieve their intended purpose (Salisbury 1984, 1986). If options do not match their needs, wants, or abilities to use the services, then service outcomes will not reflect the potential of respite. The breadth and depth of the service options should be tailored to the individual, family, and community needs

and abilities (Salisbury, 1986).

Questions as to the efficacy of respite in relation to its stress-reducing potential need to be addressed in overall research on implementation of policy and services. For instance, one must consider whether respite has more stress reducing value if provided for two days per week over 15 weeks versus one 30 day respite period. Also, if a family is unable to get enough service, is this stress producing and actually counteractive to the overall goal of respite, stress reduction (Marc & MacDonald, 1988).

In face of shrinking public monies, family support programs must demonstrate greater utilization levels if they are to wage an argument for development, continuation, or expansion. Furthermore, there is need for comprehensive evaluation to provide critical data to monitor and modify services, to enhance utilization, and to document the value of services (Salisbury, 1990, 1986; Zigler & Black, 1989).

There is evidence also that planners for service must consider special needs such as dealing with disabled adults living with older parents. Because women are the principal caregivers, they would benefit directly from sensitive development of respite care that can assist in domestic, occupational, social, and cultural emancipation (Grant & McGrath, 1990).

More globally, respite represents a departure from the primary thrust of directing services at the disabled person. Rather, it is a service aimed primarily at the welfare of the family. This can create a

new set of complexities and ambiguities (Castellani, 1986). For instance, if the desired outcome is to strengthen families so that they can continue to care for the disabled person, is respite an expansion of a policy for developmental services or does it relate to family policy? Should programs be developed to address the needs of disabled persons or must criteria for access to programs give weight to the needs of parents and siblings?

When the needs of the family become a policy objective, then there is an exponential increase in those served (Castellani, 1986). If the criteria for success of these programs is enhanced coping or family functioning to prevent out of home placements, the assessment tools should be designed not only to identify and measure characteristics of the disabled person but those of the family and the situation. This not only has direct implications for expansion of resources, ie. time, money, and expertise, but also has implications in respect to the coordination of support services for families.

Services are mandated to serve a particular population but the political, economic, and social environment shapes the direction of these services. Families are limited by what is available in their own particular communities, but also by what is mandated or legislated. A family's choice of service may not be consistent with what is made available to them.

The advocacy for increased public funding for respite services is a "political demand for socialization of costs and risks" (Castellani,

1986, p. 300). However, as the government continues to contain spending on social programs, the generally increasing role of private vis-a-vis the public sector in all areas of human service delivery will undoubtedly have a reciprocal effect on the system for the disabled. This in turn has implications on service delivery, access to service, and responsibility for the payment of these services.

Summary of Respite Literature and Services

Policy makers assume that formal support services enable families to continue care because the service improves well-being (Seltzer & Krauss, 1989). The key question regarding respite services is whether availability of respite over substantial periods of time reduces parental stress and/or enhances coping resources. Intagliata (1986), in his review and analysis of outcome research, concluded that existing evidence fails to support assumptions about impact of respite, that studies are generally weak in design and analysis, and that treatment of important issues were inadequate. Rimmerman (1989) reported that few studies have comparison or control group and there is a failure to adopt a longitudinal or repeated measure approach to substantiate findings.

Despite the importance as a support service and the expressed demand for service, studies demonstrate low levels of utilization (Edgar et al., 1988; Marc & MacDonald, 1988; Salisbury, 1990). The "linkage" between families and providers has been identified as an issue especially in terms of how parents access service, what impedes this, and how

information on service availability is presented (Edgar et al., 1988).

Although assumptions about cost effectiveness must be tested through further research, respite appears to be a relatively inexpensive way of extending a needed service to a large proportion of consumers who might otherwise be unable to cope with their disabled individual at home (Grant & McGrath, 1990). However, there is a need to reassert natural opportunities for respite through sporting and recreational activities, clubs, etc., and a need to make these options available to the disabled individual and to provide family with relief (Ogle & Powell, 1986)

Parents need to have sufficient input regarding the nature, quality and content of respite services. Joyce & Singer (1983) posit that an important aspect to evaluate respite service on families is to draw information on their perceptions of the service.

Although many acknowledge that services and policies for children with special health needs must be developed within the family context and be family centred, few reports exist on how parents perceive their own needs (Klein-Walker et al., 1989). A key to implementing and designing services is recognizing the needs of parents as expressed by them rather as perceived and reported by various professionals. Above all, "family and child needs must drive the design and development of respite services...The premise is fundamental to ensuring that the services that are provided help achieve their intended purpose" (Salisbury, 1986, p. 19).

The next chapter will include a section on consumer feedback and consumer satisfaction as a form of service evaluation within the context of program evaluation.

CHAPTER 2

PROGRAM EVALUATION

This chapter presents the theoretical foundation of program evaluation used in this practicum. Aspects of consumer satisfaction research is discussed as a method of evaluation within the context of process evaluation. Finally, a discussion on increasing relevancy and usefulness of program evaluation, completes this section.

Purpose, Scope, and Foci of Program Evaluation

Generally, social programs develop as a response to social concerns. They require an understanding not only of the social and political situations that existed when they were initiated, but also an understanding of change and modifications in situations over time (Rossi & Freeman, 1987).

Spiralling costs of social programs and resource restraints raise serious questions about the extent to which these programs operate effectively and efficiently within fiscal, legal, and operational requirements. Increasingly, policy makers, program managers, and advocacy groups acknowledge the need to evaluate these programs (Rossi & Freeman, 1987).

The scope of an evaluation needs to be considered especially in view of multiple interests, contrasting with limited resources, time, and personnel. Many evaluators suggest limiting the scope of the evaluation to the specific information needs of key stakeholders (Patton, 1986; Rossi

& Freeman, 1987; Pietrzak, Ramler, Renner, Ford, & Gilbert 1990).

Rossi and Freeman (1987) assert that each evaluation must be tailored to the specific program concerned. The scope of the evaluation will depend on the purpose and the stage of the program. The tasks involved differ depending the needs and interests of the stakeholders. Rossi and Freeman refer to three primary foci of evaluation: an analysis related to program conceptualization or design, monitoring and accountability of implementation, or assessment of effectiveness or impact. When the evaluation entails all areas, it is considered to be a comprehensive evaluation.

Others such as Pietrzak et al., (1990) use a systems evaluation model to assess services in three focal areas. An evaluation of inputs involves an analysis of elements relevant to services, clients, or staff. Process evaluations deals specifically with elements related to appropriateness and quality of service. Outcome evaluations address the question of impact or program effectiveness.

Studies can be of two major types, summative or formative. Summative evaluations are concerned with measuring program effectiveness or impact. On the other hand, formative evaluations involve a process of discovery directed at gathering data or information on activities, or outcomes that will help to improve the day to day operation of programs (Rossi & Freeman, 1987). Formative inquiries provide direction for modifying program activities, goals/effects, and the context within which the program operates and can resolve many issues to ensure the more

judicious use of other expensive and time-consuming evaluations (Rutman, 1980).

When the overall purpose and focus of an evaluation is to generate new information and to develop an understanding of what is occurring in the program, it is formative, descriptive, or developmental in nature (Freeman & Rossi, 1987; Intagliata, 1986). This type of evaluation can greatly assist in refining, shaping, or strengthening the program to meet objectives more effectively. To this extent, process evaluation or monitoring of program implementation can be used as a tool to focus relevant evaluation questions.

Process Evaluation or Program Monitoring

Pietrzak et al. (1990) define process evaluation as a method of assessing the internal dynamics and operations of a program. This involves the analysis of the service delivery system and the administrative arrangements that support it. Process evaluations focus on the activities between clients and line staff and interactions which are central to the accomplishment of goals and objectives (Pietrzak et al., 1990). In a general sense, the analysis involves the assessment of the quality of service, provides a record of the program's services and delivery system, and isolates problems or areas for program change.

Rossi and Freeman (1987) define this type of evaluation as program monitoring or the systematic attempt to measure coverage and process, that is the extent to which the program reaches the intended target population

and the extent to which the service that is provided matches what is intended. Monitoring the delivery of services is important as it often concerns decisions about program continuation or expansion (Rossi & Freeman, 1987).

Rossi and Freeman (1987) suggest several sources of data collection including direct observation, service records, and data from program staff. This type of evaluation begins with a description of the programs service delivery system and components. Vital to the evaluation is the existence and examination of program manuals outlining administrative procedures, fiscal and legal accountability, service delivery, qualifications of personnel, and the amount of time that is to be directed to activities in order to assess whether workloads are too heavy or too light. Existing records can provide an account of target coverage as well as staff time and resources expended. Generally, records will vary with the nature of treatment and the resources available.

Rossi & Freeman (1987) conceptualize service delivery and implementation efforts as a combination of pathways and actions. Evaluation of these components is vital in determining whether actual program interventions approximate the intended ones. This requires the examination of possible system delivery errors and access.

Service delivery errors such as insufficient service, the wrong kind of service, or unstandardized service often account for reasons why programs fail to show impact (Rossi & Freeman, 1987). For instance, one cannot show impact if no treatment or not enough of it is delivered.

Specific questions are concerned with how well the services are delivered, whether services are doing what is intended and in a consistent manner, the timing between phases, and the quality of interaction between the service providers and clients (Pietrzak, 1990).

Access, on the other hand, refers to the structural and organizational arrangements that provide opportunities and facilitate participation in a program (Rossi & Freeman, 1987). Evaluation questions address access operations, pathways for potential targets, equity for ethnic and cultural groups and whether there are gaps or "bottlenecks" with the service that prevent accessibility (Rossi & Freeman, 1987; Pietrzak et al., 1990). More specifically, access operations involve strategies or procedures that facilitate the use of service. These may include outreach campaigns, providing transportation, or ensuring that the program's location is convenient. It also can refer to procedures that minimize dropouts. Rossi and Freeman (1987) also view participant satisfaction as part of access. They explain that if a program is viewed by participants as unsatisfactory, then it may fail to draw other families and thereby block their access to the program..

The need to access a program is usually related to a need for particular services. Kettner, Moroney, and Martin (1990) offer insights on various kinds of need. First, is normative need or an existence of a standard or general opinion that a service, such as respite, is needed. Perceived need, or what people think or feel their needs are, is another aspect of need that provides information that can be used in designing a

more responsive service but it tends to be unstable and will fluctuate depending on the situation or will vary with individual standards.

Need can also be assessed in terms of expressed need whereby the actual attempts of individuals to access or obtain a service is recognized. This is critical as it focuses situations where perception is translated into action for those program planners who rely on "demand statistics" to make alterations to their programs. The major drawback is that often a deterrent to seeking service is the absence of service and studies show that those who seek service may only do so if they believe there is a real possibility of receiving it (Kettner, et al., 1990). Finally, relative need is defined and measured as the gap between the level of service in one community compared to a similar community elsewhere. Assessing various aspects of need then, can provide information regarding service gaps which prevent access to service and can be helpful in determining the need for program expansion.

Rossi and Freeman (1987) suggest that in addition to using data and observation techniques, another source that should be considered for monitoring evaluations is information from participants on what is needed and important to them including their satisfaction with the program itself. They view participant or client satisfaction with a program as a key indicator in program monitoring efforts.

Similarly, Pietrzak et al. (1990) asserts that describing the processes or procedures of a program does not in itself constitute an evaluation. In order to judge the merit of the service delivery com-

ponents, the evaluation needs to include criteria such as best practice standards, agency policies, or client satisfaction.

Client/Consumer Satisfaction

Client satisfaction feedback is useful in program evaluation, planning, quality assurance, and clinical care (Lebow, 1982). Surveys are often initiated for specific reasons including scientific investigation, decision making, public relations, or the introduction of an evaluation in a non-threatening way (Lebow, 1982). Increasingly, consumer satisfaction is recognized as an important invaluable as an outcome variable in health service evaluation (Lebow, 1983; Blais, 1990;). In the context of those families who care for disabled persons, this feedback reinforces the view that parents or caregivers should have a voice in services that are made available to their children.

Various forms of data may be salient depending on the particular audience. The information collected can be used to: identify service delivery problems; to assess need for service, acceptability, and willingness to use a program or facility; to evaluate solutions; or to measure impact of service change or innovations (Posavac & Carey, 1980). Consumer evaluations can provide a source of data about the path of entering or barriers to entrance, attitudes, expectation, enabling components, and suggestions for change or improvement (Lebow, 1983). The feedback can also enhance cost efficiency by identifying unwanted or unnecessary aspects of programs. The investigation must aim at questions relevant to the

participants while at the same time, addressing the information needs of the program managers.

Defining Consumer Satisfaction

Consumer satisfaction is a measure that has been used to describe a broad range of research from merely denoting a method of data collection, to studies of patient rated outcome, and reactions to treatment or milieu (Lebow, 1983). Lebow provides both a broad and narrow definition of consumer satisfaction. The narrow definition includes:

all inquiries into the extent to which services satisfy the clients' wants, wishes, or desires for treatment....inquiries into both the felt adequacy of treatment and of the surrounding milieu; specific aspects may include reactions to the quality of care, to its helpfulness, its cost and continuity, the availability and accessibility of the practitioner and the reaction to supporting service (Lebow, 1983, p. 212).

The broader definition according to Lebow involves the more global measures or indices of satisfaction such as Global Improvement Scales (Strupp, Wallach, and Wogan, 1964), Ward Atmosphere Scales (Moos & Houts, 1970), or records of complaints or praise for treatment.

Consumer satisfaction is a measure along the continuum of evaluation research (Lebow, 1982). As in other evaluative studies, delineating the purpose and identifying the audience are important factors especially given the broad range of use and definition (Lebow, 1982).

Issues Related to Sample Selection

A key set of decisions in consumer evaluation involves who will be included in the sample. Although a representative sample is desirable, it is not always possible so the reasons for inclusion and exclusion need to be articulated (Babbie, 1986, Lebow, 1982). An important point stressed by Lebow (1982, 1983) is that early terminators will have formed an opinion which may be significantly different in nature from those participating or from those who have completed the treatment or program.

Also, the point in time that is chosen for the evaluation may affect evaluation as differences occur over time in what the consumer is seeking (Lebow, 1982). For instance, evaluations at an early point of service utilization may be a poor indicator of later satisfaction. Sampling from active cases can provide valuable information but introduces a subtle bias as those clients who terminate after short periods of time may be under-represented. Evaluation at the point of termination or afterward focuses on completed treatment and increases the likelihood of probability of selection. However, difficulties in locating clients and the chance of them responding also can become problematic. In addition, as time from termination increases, distortion of the experience increases thus introducing a further bias. Lebow (1982) suggests that assessing satisfaction at multiple points has its merits.

Internal vs. External Evaluations

Other factors that may influence outcome include whether the survey

is internally or externally generated. One position on this matter is that evaluators are best off when they are independent from influences of project staff. There is the risk that the evaluator who is part of the program staff may be biased and consequently, some individuals may be suspicious of the findings. The other position posits that the work of the evaluator is enhanced by sustained contact with policy and program staff as it provides better understanding of the organization, objectives, and/or activities (Rossi & Freeman, 1987).

Bernstein and Freeman (1975), in their study of evaluation quality, found that internal rather than external evaluations tended to be of higher quality. This was attributed to the fact that internal evaluators were more apt to influence the conduct of intervention efforts. Similarly, Van de Vall and Bolas (1981) found insider evaluations more successful at influencing social policy because insiders communicate more easily and frequently and develop greater consensus over substantive and methodological issues. This however, assumes the competency, interpersonal relation skills, and influence of the evaluator.

Summary

Program evaluations test the efficiency or effectiveness of programs in meeting intended purposes. They can be summative or formative in nature. While summative evaluations are concerned with measuring impact or effectiveness, formative evaluations are concerned with a process of discovery. A formative evaluation can greatly assist in refining,

shaping, or strengthening programs. When the focus of evaluation is on process or monitoring of program activities, it involves the assessment of the quality of service, provides a record of services, and isolates problems. In addition, evaluations that include consumer participation can enlighten program managers and add to the relevancy of the evaluation. Most importantly, their participation in providing feedback is fundamental to ensuring that the services achieve their intended purposes (Salisbury, 1986).

For the purpose of this study, I have chosen a formative approach, more specifically, process evaluation, directed at gathering information on activities that can help improve the day to day operation of the program. Consumer satisfaction is incorporated to add to the relevancy to the evaluation.

CHAPTER 3

EVALUATION METHODS, PROCEDURES, AND DESIGN

The Practicum Context

The site for this practicum was St. Amant Centre, a 260 bed residential and resource facility for mentally and physically disabled children and adults located in a suburb of Manitoba's provincial capital, Winnipeg. In addition to residential services, the Centre offers several outreach services including an integrated Day Care Program; a Community Assessment Program; group homes for adults and children; and the Respite Program. The Centre is administered by the Grey Nuns with the primary sources of funding being the Province of Manitoba through the Department of Family Services.

The St. Amant Respite Program is one of the resource or outreach services that operates from the Centre. It began operation in 1974, about the same time as social and political shifts were being made toward a community based service system designed to support families and persons with developmental disabilities (Cohen & Warren, 1985). The stated goal of the Program is to provide relief, on a regular or emergency basis, to families who care for disabled children or adults; the stated objective is to maintain persons with disabilities in their homes by providing relief to caregivers (Social Work Policy & Procedure Manual).

Three beds on three separate units are officially designated for respite utilization. According to data available (Five Year Plan, 1989-

1994; Social Work Department Annual Reports, 1985-1991), an average of forty-six families per year use this program. Some families have used the program only once while others have used it several times over several years. Table 2.1 shows the distribution and utilization rates for the five year period 1986-1991.

TABLE 2.1

RESPITE ADMISSIONS/UTILIZATION

<u>YEAR</u> <u>(APR.1-MAR.31)</u>	<u># FAMILIES</u> <u>SERVED</u>	<u># OF TIMES</u> <u>ADMITTED</u>	<u># OF DAYS</u> <u>UTILIZED</u>	<u># OF NEW</u> <u>INO/REFERRALS</u>
1986-1987	53	106	1532	*
1987-1988	44	106	1335	*
1988-1989	42	91	861	*
1989-1990	43	133	1166	48
1990-1991	<u>50</u>	<u>148</u>	<u>1444</u>	<u>41</u>
MEAN	46.4	116.8	1267.6	44.5

Note: * statistics not available

While the number of families using the program have remained fairly constant over the last five years, there is a 28% increase in the number of admissions over the same five year period. The increase in the admissions and the bed utilization days may be related in part, to the availability of long term beds for a period of time in the last year which were intermittently used for respite admissions.

Administrative Arrangements

The Respite Program is coordinated by two departments, Social Work and Nursing, each with an assigned coordinator who reports to his/her respective Department Director. At this time, the Director of Nursing (DON) is also the nursing coordinator. Although the administrative structure for the program is not specified, policies, procedures, and standards conforming with the Quality Assurance Program are outlined in the Policy and Procedure Manual for each Department.

In respect to other administrative dimensions, all respite applications are taken to the Admissions and Discharge Committee of the Centre for approval of eligibility. This Committee is chaired by the Executive Director of the Centre and has representation from the administrative, and service delivery levels. As well, a representative from the Department of Family Services participates on the Committee. Social workers advise the families and community workers regarding the decision of the Committee. There is no standardized written format to advise about the decision on eligibility.

There are important legislative dimensions involved in the program. For instance, in the cases of children, a Child and Family Service Worker (CFS) must be involved in the pre-admission process by entering into a Voluntary Placement Agreement (VPA), as legislated by the Child and Family Service Act of Manitoba (1986). The VPA allows parents to maintain guardianship while the child is placed in care at the Centre. The VPA is also a vehicle for fiscal remuneration.

In adult cases, an Order of Supervision, as legislated by the Mental Health Act, is a prerequisite for admission. Under this Order, adults are certified as mentally retarded but unlike long term admissions to the Centre, their cases are not referred to the Public Trustee to have their affairs administered through that office. A Varying Order is required for each admission for the purpose of fiscal remuneration. This particular policy of certifying adults is currently under review.

The Director of Child Special Services for children under age eighteen, and the Director of Psychiatric Services for those eighteen and over, authorize payment for services. There is no direct cost to the families for respite at the Centre providing they reside in the province. Special consideration has been granted to out of province residents with fiscal responsibilities being redirected to that particular region.

Target Population

The program is available to residents of Manitoba diagnosed with a developmental disability. Individuals admitted to the Program are in the mild to profound ranges of mental disability and often have multiple physical handicaps. There are a few cases in the mild range of disability who have been refused admission to the program by the Admissions and Discharge Committee as it was judged to be against the child's benefit to be admitted. The minimum age specification is one year of age. There is no specified upper age limit.

Service Components

Regular Respite. All referrals to the Respite Program are directed through the Social Work Department. A flow chart showing the logical sequence of activities or tasks is located in the Appendix A. The social workers have the primary responsibility for coordinating various aspects of the intake process including: assessing the family situation; liaison with support services; coordinating admission requests; maintaining a record of VPA's and Orders of Supervision, and ensuring annual updates on medical reports and family situations are completed. Although all social workers are involved in or assist with the intake and assessment process, a part time social worker is assigned as the primary coordinator of the respite caseload along with her regular caseload of approximately 145 residents at the Centre.

Nursing also coordinates aspects relating to the direct care or health of the individual ensuring assessment of the care needs, and that all immunization, specimens, and medication orders are received. Social workers and nursing staff may also consult with other St. Amant staff about special aspects of care, for example, about special diets or use of special equipment.

Individuals are admitted to the area that most closely approximates his/her age, developmental level and/or care need. At this time the three respite beds are allocated to three units as follows: 3 West, one bed for adults who are non-ambulant; 3 East, one bed for young small children, usually under age five and who are non-ambulant; 1 East, one bed for young

children and adolescents, usually between six and fifteen years, who are ambulant or non-ambulant. Currently, the Centre is not able to take ambulant adults who present with difficult behaviours.

As part of the admission criteria, individuals are required to be free of contagious diseases, to have up to date immunizations, and to have completed a pre-admission assessment/application for the program.

Families are entitled to use the program as often as needed providing there is time and space available. Some restrictions are specified during periods of high demand. For instance, families are restricted to a two week respite in the summer months in order to allow as many families as possible the opportunity for a summer vacation. Any requests over a two week period are reviewed to ensure adequate programming and activities are available to the individual admitted.

Crisis or emergency respite. A crisis admission is a component of the Respite Program although the Centre is not always able to accommodate emergency situations. Although procedures are not formalized, in situations where a person is not known to the Centre but space is available, a meeting of representatives from the Admission and Discharge Committee is called. Depending on the circumstances, criteria for admission may be waived or addressed once the individual is admitted. It is estimated that only two or three individuals per year will be admitted on this basis although an unknown number of requests are made by community social workers or physicians. If space is not available, the community workers must try other options. Social workers at the Centre are able to

assist by providing names of alternate resources if the community worker is not familiar with services for the developmentally disabled.

Respite "Plus". Although this component of the Program is not formalized, on occasion an individual will be admitted for an extended period of time or a request will be made for assessment, consultations, or appointments outside the Centre, or program services. These situations are currently addressed on an individual basis and depend greatly on the availability of resources at the Centre, the family situation, and the availability of community resources to meet the family's needs. Departments at the Centre use discretion in determining the extent of involvement possible.

Evaluation Mechanisms

The Program falls within the parameters of the Quality Assurance Program and has set standards and criteria. Reports and audits on the Respite Program are submitted by each, the Social Work and Nursing Departments. However, there is no formal mechanism in place at this time whereby both Departments meet on a regular basis to review or discuss the program's operations. A Respite Committee was active from 1987 to 1989 to review the Respite Program, to define changes, and to evaluate the changes following implementation, but they have not been active as a group since then.

Program Promotion

The Respite Program is not formally promoted in the community and

most seem to learn about it through support services or friends. A respite pamphlet is available at the Centre and is provided to new families who apply. The St. Amant newsletter occasionally features an article on respite. However, on the brochures of the Centre and on the brief descriptions about the Centre on the newsletter, the Respite Program is omitted as an outreach program.

Evaluation Procedure

An interest in an evaluation of the Respite Program was stimulated through work as a social worker at the Centre. A major question however, rested on whether the Centre would find an evaluation useful at this point in time, and if so, what would key individuals be interested in evaluating.

As part of the process of defining a practicum and evaluation, all documents, minutes, and program information were reviewed. In addition, ten interviews were conducted with eight key management and program personnel from the Centre and two community personnel who were connected with the Program. A semi-structured interview schedule was designed to provide some consistency throughout the interviewing process. A list of interviewees and the interview schedule is located in Appendix B and C.

Questions related to goals and objectives, perceived need, target population, scope of service, and models for service, funding issues, and perceived benefits of the Program. Each person was asked to prioritize questions of interest for evaluation.

Following a report to those who participated in the interview process, a formal agreement to proceed with an evaluation and the practicum was received from the Executive Director of the Centre. A recommendation was made that the previous Respite Committee operate as an evaluation committee with the addition of parents and the respite coordinator.

These activities formed steps in the evaluability assessment (Rossi & Freeman, 1987) to the extent that a program profile was delineated, issues for evaluation and a sense of priorities were identified, and agreement to proceed was provided by the Centre.

The Evaluation Committee

The Evaluation Committee was viewed as an important dimension in the evaluation process. In order to ensure clarity as to the purpose and function of the Committee, an outline was provided to the Executive Director summarizing the rationale, membership, parameters, and time frames involved. The outline is provided in Appendix D. This summary also provided a profile to give to individuals as they were individually requested to participate on the Committee.

As suggested by Patton (1986), this Committee was comprised of key individuals from administration, program management, service delivery, and consumer levels. The final membership was ten individuals with this writer acting as chairperson. A list of committee members is located in Appendix E. Although the Committee was larger than initially envisioned,

various interests, issues, and concerns relating to the program were represented. Also, having a broad based representation was consistent with the ecological framework which recognizes the interrelationships and diversity among systems. At the same time, having key stakeholders involved tends to increase the likelihood of the evaluation being relevant and useful (Patton, 1986).

A series of three meetings were held with the Evaluation Committee from the period of November 7, 1990 to December 5, 1990. At the introductory meeting, a history and overview of the Respite Program was provided and the purpose of the evaluation and the Committee restated. The group was encouraged to "free-wheel" and to probe into what was seen as an important issues and concerns for them.

The focus of the second meeting was a development of a program model. Using a framework by Rutman (1980), a model based on program documents was used to initiate discussion. The model was reconstructed by the group to provide an expanded version of the program components, outputs, goal and effects both intended and unintended, and the linkages. Both models are presented in Appendix F.

The model provided a conceptualization of the program and added clarity in terms of the intended and unintended effects. It was helpful in focusing on issues and concerns that needed to be addressed through evaluation and confirmed some of the priorities mentioned during the initial interview process.

Due to time limitations, the evaluation questions were not prioritized

by the group. However, based on the discussions, the primary goal and objectives were formulated by this evaluator and circulated to the Committee for their feedback as follows:

Evaluation Goal:

To gather information that might suggest ways to improve or modify the Respite Program so that the quality of service is maximized.

Evaluation Objectives:

To determine user satisfaction with various aspects of the Program and with quality of service provided.*

To determine whether the Program should be altered, modified, or expanded in extent and scope (amount and kind) of service, or in design (model of service).*

To determine staff perceptions of service implementation issues and effects of the service on families.*

To determine knowledge and needs of the general population for the Respite Program.

To determine whether to promote this program to the community and larger service system.

The Committee was informed that the focus of the evaluation would be the first three objectives as the feasibility of addressing all five objectives within the time framed allowed seemed minimal. They were requested to respond if they believed the priorities needed to be reconsidered or re-ordered. No changes were recommended.

The third meeting was reserved for pre-testing three survey instruments developed to address evaluation questions pertaining to both

the consumer population and staff perceptions of the service. Due to a fairly lengthy period of time between the third and final meetings, letters or memos were sent to the committee members to keep them informed of the progress.

A final meeting was held after the results of the surveys were analyzed in order to present the findings, encourage discussion and, to get feedback on recommendations.

Research Design and Instrumentation

The basic research design of the study was a cross-sectional survey using purposive samples drawn from families utilizing the program and staff at the Centre. The study was exploratory in nature intended to generate basic descriptive data that would provide information for the Respite Program. All measures were self-reports based on one's perception or experience with the Program. There were several opportunities for parents to comment or provide suggestions throughout the questionnaire.

Family/Parent Survey. This survey was designed to generate information on parents' or families' perceptions of various aspects of the service provided and the need for service. The survey instrument is located in Appendix G. There were six sections to the survey:

Part A: General Satisfaction, adapted from the CSQ-8 (Client Satisfaction Questionnaire, Larsen, Attkison, Hargreaves, & Nguyen, 1979) measured six dimensions of overall client satisfaction;

Part B: Access and Availability of Service, tailored to address implementation, procedural, and accessibility dimensions, including the scope of service and the extent to which service is available;

Part C: Benefits and Effects, consisted of an 5 point scale tailored specifically to test the program model developed by the Evaluation Committee;

Part D: Service Pathways and Support Services, adapted from the University of Manitoba Research Group Questionnaires (Marginet, 1986);

Part E: Child Characteristics, adapted from St. Amant Developmental Day Program Evaluations;

Part F: Sociodemographic Information on families completing the survey.

Each section of the twelve page survey was colour coded for ease of administration and to reduce the tedium of a relatively lengthy questionnaire. Many questions in the survey had spaces for comments or suggestion from parents.

Nursing Survey. This questionnaire, designed for the nursing department, was divided into two distinct sections. The survey instrument is located in Appendix H. The nurses completed both Parts A and B, but the nursing assistants completed only the second section as they are not involved in the procedures addressed in Part B. The sections were divided as follows:

Part A: Procedures and Implementation Efforts, tailored

specifically to address program implementation issues and to identify gaps, issues, or specific difficulties.

Part B: Effects/Benefits, measured staff perceptions on the effects/benefits of the program. This section also asked staff to provide their opinions on the service model and to provide suggestions that might enhance the program's operations.

As with the parent survey, staff were provided with opportunities throughout the questionnaire to comment or make recommendations on various aspects of the program.

Clinical/Medical Staff Survey. This questionnaire was also divided into two sections, Part A and Part B similar to the nursing department instrument. This survey instrument is located in Appendix I.

Part A: Procedures and Implementation Efforts, tailored specifically to address consultation and implementation issues, record keeping and the perceived need for service.

Part B: Effects/Benefits, addressed staff perceptions of the effects/benefits of program. This part, identical to Part B of the nursing survey, also asked for staff opinions on the model of service and recommendations that might enhance their work with the program or its operations.

Sample Populations

There were three sample population: families; the nurses and nursing

assistants; and the clinical/medical staff.

The Families. The sample population included all families who utilized respite at St. Amant from January 1987 to December 1990 whether or not they were currently using the program. Following consultation with social workers at the Centre, recommendations were made by the workers not to send questionnaires to four families: in one case, the child was recently deceased; another situation was volatile because of a recent apprehension; and two cases from the North West Territories did not have parents involved in the respite admissions as they were placed in a chronic care hospital. These cases were therefore excluded from the sample. Four families were not located due to address changes, leaving a final sample of 77 families. Forty nine (49) surveys were completed and returned for a response rate of 64%. Thirty (61.%) of the respondents used the program in 1990, 3 (6.1%) last used the program in 1989, while 8 (16.3%) of the respondents last used the program in 1988 and 1987 respectively.

The Nursing Staff. This sample included nurses and nursing assistants on all units regardless of whether a respite bed was currently designated on their unit. The head nurses requested an approximate number of surveys for each units. In total, 105 were requested but only 21 were distributed to nurses and 46 to nursing assistants for a total distribution of 67 surveys. Sixteen nurses and 37 nurses aides responded. The response rate calculated actual distribution, yielded a response rate of 76.1% for nurses and 80.4% for nursing assistants. Based on the number

originally requested, the overall response rate would be fairly low (53/105= 50.5%). Both the distribution of the questionnaires and the response rates may have been influenced by the impending nurses strike which occurred two weeks following. The distribution and response rates may have also been influenced by the degree of involvement in the Program. The results show as units that do not normally have respite admissions tended to have either lower response rates or no responses.

The Clinical/Medical Staff. This sample included medical staff, occupational therapists, physiotherapists, speech therapists, recreation, psychology, volunteer, and Day Development Program staff. Nursing administration and social workers who coordinate the program were included for a sample of 31 individuals. Twenty five (25) returned the questionnaires for a response rate of 81%.

Data Collection Procedures

The family surveys were mailed out to families with a pre-stamped return envelope. A covering letter explaining the intent of the survey and an introductory page was attached to explain the objectives and purpose of the evaluation along with general instructions and information on obtaining results of the survey. Families were encouraged to participate whether or not they were currently using the Respite Program. Issues of confidentiality were addressed. A three week time frame was given for completion of the survey. A follow up letter was mailed out at two weeks in order to increase the response rate.

The distribution of the nursing department surveys was done primarily through the head nurse on each unit. The evaluator arranged through the Director of Nursing to attend a Head Nurses' Meeting to provide information on the survey and to get their feedback on the best procedure for distribution. The evaluator was prepared to meet with groups on each unit but the head nurses felt that they could distribute the surveys on their units. Each survey had an introductory page similar to the parents' survey providing general information and instructions for completion and obtaining results. All questionnaires that were not distributed were to be returned so that a response rate could be calculated on those actually distributed. A memo was forwarded to all unit coordinators one week following distribution to encourage returns and to increase the response rate.

A similar approach was used with the Clinical Departments. The evaluator arranged with the Program Director to meet with Department Directors to discuss the research and to request their input in the distribution of the surveys.

Data Analysis

Both qualitative and quantitative methods of analysis were used. Scores on the quantitative measures were analyzed using the Statpac Computer Program (Walonick, 1986) using primarily frequency distribution and descriptive statistic analysis options. Open-ended questions were analyzed using qualitative methods.

Dissemination of Results

The information on the results and recommendations of this evaluation was handled in a variety of ways:

1. A presentation was made to the Evaluation Committee in order to discuss results, and to solicit further suggestions and recommendations;
2. An information session was held for staff at St. Amant to share the results and recommendations;
3. A letter was forwarded to parents who requested the results on the survey/questionnaire;
4. An executive summary was be prepared for the administration and the directors of the coordinating departments.

CHAPTER 4

PARENT SATISFACTION AND STAFF PERSPECTIVES ON THE RESPITE PROGRAM

The aims of this study were to determine satisfaction with services, to determine whether the program should be altered, modified, or expanded in scope or extent of service, and to determine staff perceptions of implementation efforts and effects of the service on families. This chapter will present the results of the parent and staff surveys.

Satisfaction with human services is generally rated quite highly (Lebow, 1982, 1983; Nguyen et al, 1983; Blais, 1990). As a functional guideline, 80% is used as the acceptable standard in studies concerning satisfaction (Lebow, 198?, in Trute, 1988). Therefore, in this study, where results show more than 20% negative score, it is suggested that attention should be given to those aspects of service.

Parent Survey

The Parent Survey was divided into 6 sections, Sociodemographic Profile, General Satisfaction, Accessibility and Availability, Effects and Benefits, Service Pathways and Support Services, and Client Characteristics. These will be reviewed in succession.

Sociodemographic Profile of Families

As stated earlier, 49 families responded to the questionnaire on the

St. Amant Respite Program. Almost 61% of the parents in this sample used the program within the past year while 39% last used the program in the three years previous, 1987-1989.

As shown in Table 4.1, most families (61%) using the St. Amant Respite Program resided in Winnipeg. Thirty eight percent lived in rural Manitoba, with 20% of those families living more than 50 kilometres from Winnipeg.

About 55% of the families who answered the questionnaire were two parent families and 27% were single parents. A number of foster and adoptive parents were represented. On average, two other children lived at home. Mothers' mean age was 36 years (SD. 1.08) and fathers' mean age was about 37 years (SD. .87)

Almost 65% of families had a least one parent working with 22% of the families having both parents working full time. Approximately 30% were on limited incomes such as pensions or social allowances. There was a wide range of yearly family income from under \$20,000 to over \$50,000 with the average yearly family income being approximately \$26,000 (SD, 1.289).

Generally, the profile of families shows a 60-40 ratio of urban-rural families. Single parents made up more than 25% of the sample. Many families would be considered low income families according to Statistics Canada's most recent low-income cut off line which currently stands at

TABLE 4.1

SOCIODEMOGRAPHIC PROFILE OF FAMILIES USING RESPITE

<u>VARIABLE</u>	<u>NUMBER OF RESPONDENTS</u>	<u>PERCENTAGE</u>	<u>MEAN</u>
Residency (N=49)			
Urban	30	61.2%	
Rural (+50 miles)	10	20.4	
Rural (-50 miles)	9	18.4	
Family Type (N=49)			
Two Parent	27	55.1%	
Single Parent	13	26.5	
Foster Parent	3	6.1	
Other	6	12.2	
Parents' Ages			
<u>Mother</u> (N=47)			
under 20 years	*	*	
20-29	5	10.6%	
30-39	21	44.7	
40-49	10	21.3	
50-59	8	17.0	
60 +	3	6.4	36.4 yrs.
<u>Father</u> (N=37)			
under 20 years	*	*	
20-29	1	2.7%	
30-39	15	40.5	
40-49	13	35.1	
50-59	7	19.0	
60 +	1	2.7	37.8 yrs.
Family Income (N=41)			
Under \$19,999	10	24.4%	
20-29,999	12	29.3	
30-39,999	10	24.4	
40-49,999	4	9.8	
Over 50,000	5	12.2	\$25,744
Employment Status (N=42)			
Both Working	9	21.4%	
One Parent Working	13	31.0	
Full & Part Time	5	11.9	
Neither Employed	6	14.3	
On Pension	3	7.1	
Other	6	13.3	

\$28,081 for a family of four (Statistics Canada, Jan. 1991).

Finally, about 77% of the questionnaires were completed by mothers with only 13% being completed by both parents. The average time taken to complete the twelve page survey was 26 minutes (Range 10-75 minutes).

General Satisfaction

With regard to General Satisfaction, the vast majority of respondents reported relatively high satisfaction scores, most being 92% to 98% satisfied with all dimensions as shown in Table 4.2. By dichotomizing the four point scale to, satisfied and not satisfied, the highest score, 98% was reported on satisfaction with overall quality of service. Satisfaction was lowest with the extent to which the Program has been able to meet needs for respite at about 92%.

TABLE 4.2

SATISFACTION WITH RESPITE PROGRAM

<u>SATISFACTION DIMENSIONS</u>	<u>(N)</u>	<u>SATISFIED (3 + 4)</u>	<u>DISSATISFIED (1 + 2)</u>	<u>MEAN</u>	<u>SD</u>
Kind of Respite	(49)	95.9%	4.1%	3.36	.56
Needs Met	(48)	91.6	8.3	3.35	.63
Recommend to a Friend	(49)	95.9	4.1	3.50	.65
Services Helped	(46)	97.8	2.1	3.50	.64
Satisfied with Quality	(49)	98.0	2.0	3.51	.54
Would Come Back	(48)	93.6	6.3	3.59	.67

*NOTE: 1, very dissatisfied; 2, dissatisfied; 3, satisfied; 4, very satisfied

Generally, the overall satisfaction with the program as rated by parents was relatively high. However, it is not unusual for satisfaction to be rated highly in human services. The literature suggests evaluating specific aspects of service in order to pinpoint the elements that may be causing difficulties or dissatisfaction (Blais, 1990; Lebow, 1983; Pascoe & Attkisson, 1983; Ware, Snyder, Wright, & Davies, 1983).

Accessibility and Availability

In this section, specific aspects of program implementation are examined including: regulations and requirements relating to the pre-admission process, satisfaction with specific aspects of services, availability of service, and the desire to have a separate unit for service as an alternative to the current model of placing individuals on wards or units.

In relation to preadmission regulations and requirements, relatively few parents reported difficulties with completing the application, obtaining a medical report, or acquiring an Order of Supervision. However, 42% of the parents reported difficulties obtaining specimens. Another 25% reported difficulties with signing the Voluntary Placement Agreement (VPA) as a condition for admission. Table 4.3 shows the distribution of the sample by difficulty with requirements.

TABLE 4.3

DIFFICULTIES WITH REQUIREMENTS AND REGULATIONS

REQUIREMENTS/ REGULATIONS	(N)	DIFFICULT	NOT DIFFICULT
Completion of Application	(41)	2.4%	97.5%
Obtaining Medical Report	(41)	4.8	95.1
Obtaining Specimen	(41)	41.5	58.5
Signing V.P.A.	(40)	25.0	75.0
Signing Order of Supervision	(15)	13.3	86.6

*Rows may not total 100% due to rounding off

Some statements provided by parents that related to the difficulties with obtaining specimens included: "it's always a problem" and "my child fights the throat swab every time". Another parent from a rural area indicated that she had to travel to a small urban centre to take in specimens. However, obtaining specimens for each admission was a requirement only until March, 1988. At that time, it was changed to a requirement for the first admission only.

In order to determine whether most parents having difficulties obtaining specimens were using the program before the change in 1988, a crosstabs analysis was completed. The results showed that 37% who answered yes were involved in 1987 or 1988, while 64% were last involved in the program in 1989 and 1990. This finding would suggest that

obtaining specimens may still be presenting some difficulty for parents even though it is a requirement only for the first admission. It may be that some parents have difficulties accessing transportation to have samples taken by their physicians. Possibly, they do not have easy access to a public health nurse to assist them, or as one parent indicated, the child may fight these procedures. The figures along with the qualitative statements would suggest a need to review this requirement.

Approximately 25% of the parents indicated they were dissatisfied with the procedures involving the signing of the VPA. As indicated earlier, under the CFS Act of Manitoba, the VPA is a legislated requirement which allows parents to maintain guardianship while the child is in temporary care. The signing of the VPA is completed with a CFS worker in the area where the parents reside.

By far, the bulk of the comments on requirements and regulations related to the signing of the VPA. They were varied but critical. For example:

CFS inadvertently switched the family allowance over on signing of the VPA...lots of trouble getting it straightened out.

Had difficulty reaching the CFS worker...wouldn't return calls...Could it not be done at St. Amant?

The red tape was definitely a problem...

The worker made us feel that we were abandoning the child rather than planning a holiday.

...seems requirements are different with each social worker in different areas of the city.

I had a very hard time with the VPA...felt I was signing my son away...

There was reluctance on the part of the SW to sign...we needed to be firm.

We have used the service only once because of the problem getting government approval.

Although quantitatively it may seem that parents had more difficulties with specimens, the comments regarding the VPA were far more numerous. This suggests that, for many parents, the VPA poses a problem in accessing the program.

In the next section, questions were directed at measuring specific service dimensions. A four point scale (1, very dissatisfied; 2, dissatisfied; 3, satisfied; 4, very satisfied) was constructed to measure satisfaction with a number of dimensions including: the interview and application process; the tour and information provided; the child's care during admission; the effects of the physical surroundings; amount of activity available; and interest taken by staff. Table 4.4 shows satisfaction according to these service dimensions.

Satisfaction with all dimensions ranged from approximately 92% to 100%, except for satisfaction with the amount of activity provided. This was rated at 80%, somewhat below the other areas and just at the acceptable functional standard for satisfaction.

TABLE 4.4

SATISFACTION WITH SPECIFIC ASPECTS OF SERVICE

<u>SERVICE DIMENSION</u>	<u>(N)</u>	<u>SATISFIED</u>	<u>DISSATISFIED</u>	<u>MEAN</u>	<u>SD.</u>
Interview and Application	(47)	95.7%	4.3%	3.38	(.70)
Tour and Information	(45)	100.0	*	3.53	(.50)
Child's Care	(48)	97.9	2.0	3.58	(.53)
Physical Surroundings	(48)	91.6	8.3	3.40	(.64)
Activities Available	(46)	80.0	20.0	3.11	(.70)
Interest by Staff	(48)	100.0	*	3.63	(.48)

NOTE: *1, very dissatisfied; 2, dissatisfied; 3, satisfied; 4, very satisfied

Comments provided by parents showed that many of them wanted more interaction and recreation activities or programs for their children when they were admitted for respite. Some indicated that the playroom especially on 1 East was inadequate in terms of size and kind of activity. Other parents suggested the use of more volunteers so that children had more individual attention. For some parents, the lack of activity and interaction was an aspect of care that posed concern. This may affect their response to leaving the child on the unit, and possibly their ongoing use of the service. In terms of the various dimensions of

service, the availability of activities appears to be the area where parents experienced the greatest dissatisfaction. The degree of dissatisfaction with this dimension indicates a need to examine the situation more fully to determine possibilities for alternatives.

In the next section, on **physical surroundings**, almost 92% reported being satisfied. However, a number of comments are worth noting, for instance one person noted that she was worried that someone might hurt her son. Another indicated that the cottage area was satisfactory but found the wards unsuitable. Someone stated that the surroundings were too much like a hospital while another suggested that a two bed unit would be an improvement. One individual noted that the institution was a big change for her child but she found it was bright and clean. Another respondent pointed out that the playroom was too small for the number of children.

It is possible that the high ratings may be related to the way the question was asked or interpreted. Some seemed to interpret satisfaction with the physical surroundings as being a matter of the units being clean and well kept, while others considered safety issues or the overall impact of the ward-like surroundings. The safety issue has been raised by staff and is validated by a number of incident reports. The comments suggest that for some parents, the physical environment does pose a concern although quantitatively, the item produced fairly high satisfaction ratings. In respect to safety issues, it may be helpful to review the incident reports concerning children who have been injured during respite admissions to determine the specific number and nature of the incidents

and whether any preventative steps can be taken.

Again, in relation to specific aspects of service, a 100% satisfaction rate is reported for interest taken by staff. A number of positive comments were stated with most parents indicating they found staff helpful, friendly, and accommodating. It seems that parents in this sample feel staff do take an interest and this is commendable. On the other hand, possibly asking parents whether they also find staff approachable would give additional information regarding the comfort levels in interacting with staff.

The availability of service to families was measured by a four point scale (1, never available; 2, sometimes available; 3, frequently available; 4, always available). Table 4.5.1 shows the breakdown according to the specific dates and the amount of time that families perceived they were able to access the Program. The figures show that there is a wide range of values with mean scores of 2.8, between sometimes and frequently available, for both dates and amount of time requested.

TABLE 4.5.1

AVAILABILITY OF RESPITE SERVICE

ASPECTS OF AVAILABILITY	(N)	4 YES ALWAYS	3 YES FREQUENTLY	2 SOMETIMES	1 NO NEVER	MEAN	SD.
Requested Specific Dates	(45)	22.2%	40.0%	31.1%	6.6%	2.78	(.87)
Time Required	(45)	23.4	42.6	27.7	6.3	2.83	(.86)

By dichotomizing the groups into positive and negative values, Table 4.5.2 shows that only 62% were able to get the dates and 66% the amount of time requested for respite.

TABLE 4.5.2

AVAILABILITY OF RESPITE SERVICE

<u>ASPECTS OF AVAILABILITY</u>	<u>(N)</u>	<u>ALWAYS FREQUENTLY</u>	<u>SOMETIMES NEVER</u>
Specific Dates	(45)	62.2%	37.7%
Time Required	(47)	66.0	34.0

It is important to note that the availability of service may be more highly rated if considering the numeric values alone. For instance, when the qualitative comments were considered, 6 people who responded that they could "frequently" get the dates and times requested also qualified this by stating that unless certain conditions were met, ie. making arrangement long in advance, time and dates would tend not to be available as requested. If these conditions are considered as indicators that services are only sometimes available, then 49% of the respondents were able to arrange for specific dates and 53% were able to arrange for the amount of time required. Table 4.5.3 shows the adjusted values, taking into consideration the qualitative comments.

TABLE 4.5.3

AVAILABILITY OF RESPITE SERVICE WITH ADJUSTED VALUES

<u>ASPECTS OF AVAILABILITY</u>	<u>ALWAYS FREQUENTLY</u>	<u>SOMETIMES NEVER</u>
Specific Dates	48.9%	51.1%
Time Required	53.2	46.8

In other words, only about half of the respondents found that services are available to them as requested. This suggests that the need for service is greater than the availability, at least for the times the family want the service. According to statistics kept, there is a tendency for families to want weekends and holidays, so it may be that the services are more often available, but not at the requested times. This data may be further skewed by the fact that occasionally long term beds are used by respite admissions. That is, when families do get service, it may not be because a respite bed is available.

In order to determine whether parents who have children going to different units found services more available than others, a crosstabs analysis was completed. About 71% of parents who did not find services available for dates requested used services on unit 1 East. Similarly, 75% of parents who failed to find service not available for the time requested also used 1 East. This unit serves young children or adolescents who are ambulant or non-ambulant. Clearly, this sample of parents point to a need for expanded service for this particular group of

children.

Generally, parents perceive access to the programs as being fairly limited. According to the earlier discussion on need, knowing that the service is limited may reduce the number of requests if parents believe service is not likely available (Kettner et al., 1990). On the other hand, some families have now started to ask for important times as far as a year or two in advance. Another implication of not having enough service available, is that the program may not be available in sufficient amounts to do what is intended to do, for instance, it may not be available in sufficient amounts to reduce stress for families. In this respect, it would be difficult to measure effectiveness or impact of the program.

The final question in this part of the survey related to the development of a separate unit as an alternate model for respite service. Respondents were equally divided between yes, 46% and uncertain, 46% while only 8% specified no. The parents' comments provided additional feedback on this issue. Those who indicated yes, also noted that a separate unit is desirable under these conditions:

If it would open more long term beds for adults.

A separate unit could make more space available.

So that we could get more respite; one weekend every two months is not enough.

If it meant more people contact...

If there were extra workers and volunteers...

It would feel safer than leaving child on 1E.

Those who were uncertain provided the following comments:

...mixing young and old???

If a child is ambulant, a cottage setting is the best.

Only because there is so much demand...If there was a separate unit, then respite would be easier to get.

If there are more beds available, yes...otherwise it doesn't matter.

If service is more available, then yes.

There was only one person who commented against a separate unit and that person felt that contact with others on the ward (1E) was good for her child. Generally, comments by parents tended to reveal that a unit would be helpful if it increased the amount of service available or if it increased the amount of interaction with the child.

A crosstabs analysis was performed to determine whether parents using a particular unit tended to favour a separate unit more than others. The results showed that 46% of parents had children going to 1 East, 32% to 3 East, 14% to 2 East, and 9% to 3 West. Because 1 East and 3 East tend to be the wards where younger and, in the case of 1 East, ambulant children are admitted, this finding might indicate that parents of the younger children tend to want a separate unit more than those with adult children or alternately, it might mean that they want more service.

By way of summary, parents pointed to various dimensions or operations that potentially block access to the program. These include

difficulties with obtaining pre-admission specimens, difficulties signing the VPA, the limitations on the availability of service, and the lack of sufficient activity and interaction for their children. Although the item on physical surroundings rated a relatively high score, comments suggested that some parents were concerned about the physical environment. In respect to the notion of a separate unit, parents were equally divided between wanting a unit or being uncertain about a separate unit. Judging from the comments, most would be in favour if it increased the amount of service available and the quality of the interaction for their children.

Effects and Benefits

The next part of the survey measured the parent's perception of effects and benefits of respite. This approach has a built in bias as it was based on self-reports of parents without corroborating evidence from other methods. Nevertheless, as discussed in the literature on stress and coping, parents' perceptions can be a critical indicator of the usefulness of the program and provide important information by which to validate the intended or unintended effects outlined in the program model.

Using a 5 point agreement scale (1, strongly disagree; 2, disagree, 3, uncertain; 4, agree, 5, strongly agree), parents were asked to what degree they perceived respite might affect or benefit their families. The actual distribution of the scores are shown in Table 3.6.1 in Appendix J. The mean scores and the percentage of agreement for each item is shown in Table 4.6.2.

Agreement was relatively high, ranging from 72%-92% for the following effects: respite reduces stress, promotes a positive relationship, improves family functioning, provides time to regain energy, and helps prepare for placement. Approximately 70% believed that respite helped keep their child at home longer or delayed placement. Only 11% agreed that it increased family tension. The mean scores for these dimensions were between 4 and 5, agree and strongly agree. The highest mean score was reported for provides time to regain energy at 4.6 followed closely by respite reduces stress at a mean of 4.5. The lowest mean, was with respite increases family tension at 2.1.

TABLE 4.6.2

PARENTS PERCEPTIONS ON EFFECTS AND BENEFITS OR RESPITE

EFFECTS/ BENEFITS	(N)	PERCENT AGREEMENT (4 & 5)	MEAN	SD
Reduces Stress	(46)	95.6%	4.52	.58
Promotes Positive Relationship	(48)	77.1	4.04	.82
Improves Family Functions	(46)	80.6	4.07	.73
Time to Regain Energy	(47)	96.8	4.62	.57
Child at Home Longer	(46)	69.7	4.04	1.04
Increases Family Tension	(46)	10.6	2.13	.98
Helps Prepare for Placement	(47)	91.5	4.30	.68

*NOTE: 1, strongly agree; 2, disagree; 3, uncertain; 4, agree; 5, strongly agree and percent agreement = 4 + 5

Several parents who commented on effects and benefits indicated that it reduced stress and tension, allowed time for normal family functioning, relieved pressure of one parent caring for a child 7 days/week, relieved pressure felt by siblings and parents, and gave marriage a chance to recuperate. Others reported that it was the only way they could take a break without "having to punch a time clock" while another was thankful for two good nights sleep. Three addressed the issue of placement; two reported that it made the adjustment easier and the other reported that if it was not for respite, the child would have to be placed.

Those who reported negative effects felt that the child seemed lonely, withdraws, or cries when admitted to the ward. One person felt that the child's condition deteriorated after respite due to insufficient attention but stated it was the only way to get a break for more than a day. Another parent felt there were negative effects but pointed out that the child reacts with any change. One mother stated that she felt guilty because it seemed she was "dumping" the child. Another parent pointed out that tension was highest at the time of the first admission but dissipated with ongoing use of the service.

Many described using their time during respite to attend to instrumental activities such as housework, shopping, and appointments while others took the opportunity to go on vacations or do things they otherwise felt restricted from doing.

Generally, the same effects were experienced by parents but they varied in degree. Despite the fact that some effects rated higher

agreement than others, it is appropriate to consider them all as valid effects as outlined in the program model developed by the Respite Evaluation Committee (See Appendix F). The fact that some families might experience increased tension raises awareness of a potential need to support the family. Possibly a procedure such as acquiring feedback after the first admission and/or on a yearly basis from families can provide important information in this area.

Service Pathways and Support Services

This section was directed at obtaining information on: how people learned about the Respite Program, reasons for program utilization and/or termination, and utilization of other support services.

The greatest source of information about the Program was the Community Services social worker at 42% followed by the family physician or pediatrician at 22%, and SMD at 18%. Only 6% learned about the program from the Respite Program pamphlet. Table 4.7 shows the distribution of the sample by source of referral.

The Respite Program is not formally promoted, so families seem to be learning about the program primarily through formal support services. The drawback with this is that some individuals are more knowledgeable than others about support services such as the Respite Program. Some may be hesitant to refer or have families use institutional services because of their own bias. These factors raise questions related to equitable access to information and subsequently, access to service.

TABLE 4.7

RESPITE SERVICE PATHWAYS

<u>SOURCE OF INFORMATION</u>	<u>Z</u>	<u>(N)</u>
Community Services Worker	42.9	(21)
Physician/Pediatrician	22.0%	(11)
Society for Manitobans with Disabilities	18.4	(9)
St. Amant Day Program	12.2.	(6)
Child and Family Worker	12.2	(6)
Family/Friends	10.2	(5)
Respite Pamphlet	6.1	(3)
OTHER: PHN, Compsan CDC, CNIB		

*Column does not add to 100% as families may have learned about the program from more than one source.

According to Marginet (1986), in her study of well adjusted families in Manitoba, the need for advice regarding access to services was ranked the highest of importance among fourteen dimensions. She concluded that families need and want more information on support services available to them. Having the information is the first step to accessing service. On the other hand, providing information and/or promoting a program such as respite, potentially would increase the demand for service.

In relation to program utilization, 53% (26 families) reported they used the program in the last year while 47% (23 families) indicated that they did not. As shown in Table 4.8, of the 26 families currently using respite, only 12% used respite on a regular basis, 31% occasionally, and 27% used it because of special qualifications and training of staff. On the other hand, for those not currently using respite, a total of 70% were placed: 44% were placed at St. Amant while another 26% were placed in group homes or foster homes.

The low number of families using respite on a regular basis may be related to the lack of available service to meet their specific needs. The respite coordinator corroborates this fact in that many families have requested respite at the rate of at least once per month, often weekends, but they are unable to get it. On the other hand, a high proportion not using respite now are placed, many at St. Amant. This suggests that some families may use respite to help prepare for placement. Although exact numbers are not known, many families apply for respite and subsequently apply for long term. The actual impact of respite utilization on decisions to place poses a possible question for further research.

In respect to other reasons for not using respite, comments related primarily to the eligibility for service. For instance one person commented that her child is "too old... she is 21 and not entitled". Another parent indicated that she no longer used it because her child was a foster child while yet another was not aware she could use respite unless her child was in the St. Amant Developmental Day Program. These

TABLE 4.8

DISTRIBUTION OF THOSE USING OR NOT USING RESPITE

USE RESPITE (53.1% N = 26)	%	(N)	DO NOT USE RESPITE (46.9% N = 23)	%	(N)
On a Regular Basis	11.5%	(3)	Use Other Forms	26 %	(6)
For Emergencies	23	(6)	Child in Foster Care	13	(3)
Only Occasionally	30.8	(8)	Child in Group Home	13	(3)
Because of Special Training	26.9	(7)	Child in St. Anant	43.5	(10)
Other	30.8	(8)	Transportation Problems	4.3	(1)
			Dissatisfied with Service	8.6	(2)
			Dissatisfied with Physical Surrounding	4.3	(1)
			Dissatisfied with Care	0	
			Enrolled Just in Case	8.6	(2)
			Others	21.8	(5)

*Columns may not add up to 100% as parents could choose more than one item.

comments tend to suggest that some families may not be clear about eligibility. A final comment came from parents who indicated that they "avoided respite because of the negative feelings from government agencies regarding the VPA".

Table 4.9 shows that many families are using other forms of respite

as alternatives. Community Respite and the Department of Family Services were the most frequently cited formal respite supports, each at 38%. CFS resources followed at 22% while informal supports such as family was used 18% and friends only 9%. Based on previous research which shows that families will tend to use informal supports first before using formal supports (Dunst et al., 1986), these figures suggest a fairly low utilization of the informal support network. This might suggest that the support networks in this sample population may be insufficient or unable to mediate the effects of stress, or perhaps that the sample is biased towards difficult to care for children.

TABLE 4.9

ALTERNATIVE SOURCES OF RESPITE

<u>SOURCES OF RESPITE</u> <u>(N = 49)</u>	<u>Z</u>	<u>(N)</u>
Department of Family Services	38.3	(18)
Community Respite Services	38.3	(18)
Child and Family Services	22.9	(11)
Family	18.0	(9)
Friends	8.5%	(4)
Other	10.4	(5)

*NOTE: Columns do not add up to 100% as some families may have multi-sources of respite.

The preferred form of respite reported by this population was the combination of both in-home and out-of-home respite at 62% while 28% preferred out-of-home respite. Only 10% cited home-based respite as their preference. This seems to validate studies discussed earlier which suggest that families require a range of respite services (Cohen, 1982). However, it contradicts the studies where families show a strong preference for home-based services (Upshur, 1982).

Because the impact of respite relates to the utilization of other support services (Intagliata, 1986) families were asked what services they are currently using, and to rate which they found most helpful, least helpful, or needed but could not get. The most frequently utilized service were school programs at 70%, respite at 60%, and physiotherapy at 45%. Nineteen families, cited various forms of respite as the most helpful service followed by day care and school. Several services were cited as least helpful but each was cited only once. For services that are needed but not available, respite was cited most frequently at seven times, while speech therapy, and long term placement at St. Amant for adults were both specified twice. Many other services such as recreation programs, adult workshop, and more information on services were cited, but only once.

The findings for the most helpful service and the most needed service was reported to be respite. Although sample bias may be involved in this finding, the study by Marginet (1986), also pointed to respite as being a highly utilized service and one that requires expansion. Marginet, in her study of well-adjusted families with disabled children living in

Winnipeg, reported that families ranked respite fourth in importance among fourteen other services.

Client Characteristics.

The next section pertains to the characteristics of the individuals admitted for respite. Figures showing characteristics of this population is located in Appendix K. Of the 49 children/adults admitted for respite, 47% (23) were female and 53% (26) were male. Ages ranged from 1 to 43 years with the mean age being 11 years (SD. 9.012) and the median, 8 years. Only 8 individuals, or 16%, were 18 years of age or over.

In this sample, 59% had seizures and 21% of this group had seizures that were not controlled with medication.

Almost 51% of the individuals admitted for respite experienced some impairment with vision while 19% were assessed as blind. Most had good hearing, 76% but 24% experienced some difficulty or severe impairment.

Forty percent (40%) were reported severely delayed in communication, while another 47% used non-verbal modes of communication (bliss, symbols, gestures). Only 14% had verbal skills.

For activities of daily living for instance feeding skills, 54% were completely dependent, 25% needed some assistance. In respect to dressing skills, 78% were completely dependent on others and 18% required assistance. Only 4% could dress themselves without any assistance. Only 37% had good walking skills and the remaining 63% required assistance or were wheelchair dependent.

In respect to behaviours that are maladaptive in nature, 38% demonstrated some degree of destructive behaviour, 43% showed some degree of aggressive behaviour, and 30% were reported to be self-abusive. About 62% exhibited self-stimulatory behaviours. About 26% of the parents in this sample indicated that their child would run away if not supervised.

In terms of adaptive behaviours, only 24% of the parents believed that their children would be able to defend themselves if approached by another child who was aggressive. Approximately 65% of those admitted were reported to need assistance in the area of leisure and recreation while 29% did not have any play skills. The majority of parents, 70%, indicated that children had at least some difficulty adapting to changes in routine while 28% reported that children had a good capacity to adapt to change.

Generally, the profile of individuals admitted shows a fairly disabled population with multiple disabilities. There was almost an equal distribution of male and female persons, most being under 18 years of age. Most are non-ambulant and require a fair amount of help with daily care. Many demonstrate maladaptive behaviours and conversely, few had strong adaptive behaviours.

According to statistical records, on average, children were admitted 5 times over a 4 year period (Median: 4 admissions; refer to Appendix L). There was a broad range, for instance, 14 individuals were admitted only once in the four year period while one individual was admitted 37 times.

There was a wide range, from 2 to 217 days, spent in respite (Mean:

47.35 days; Median: 30 days). The breakdown for total number of days spent in respite is contained in Appendix M.

As shown in Table 4.10, the most frequently used units were 1 East with 39% of the admissions followed by 3 East with 29%.

TABLE 4.10

UNIT ACCORDING TO LAST ADMISSION

<u>Unit</u>	<u>Number</u>	<u>Percent</u>	<u>(N=49)</u>
1 East	19	38.8%	
2 East	5	10.2%	
3 East	14	28.6%	
3 West/North	9	18.4%	
Maple/Riverside	2	4.1%	

Summary of the Parent Survey

Generally, parents reported high satisfaction with the Respite Program. However, there were several aspects of services where difficulties or concerns were noted. This included: difficulties obtaining specimens, concerns about signing the VPA, dissatisfaction with activities, and to some extent, dissatisfaction with the physical surroundings. Parents did not find the availability of service adequate, particularly for ambulant children and adolescents with difficult behaviours. The parents primary reasons for wanting a separate unit seemed to be related to the desire for more services, or more activities and interaction with their children. The sociodemographic profile of

families showed about 25% as single parents, and many families were in the lower income ranges. The profile of children showed a fairly disabled population with multiple disabilities. Generally, the need for respite service for this population seemed to surpass what was available to meet their requirements.

Nursing Department Survey

The Nursing Survey was divided into two sections: Part A addressed procedures and implementation efforts, while Part B was concerned with perceived effects and benefits of the program. As noted earlier, 16 nurses and 37 nursing assistants (N=53) from 5 different units answered the Nursing Survey. The nurses completed both Parts A and B while the nursing assistants completed only Part B. As in the parent survey, functional guideline of 80% agreement or satisfaction is recommended as the acceptable standard so any results showing more than a 20% negative score could be regarded as a point of concern.

Part A: Procedures and Implementation Efforts

In the first section, nurses were asked to indicate on a four point scale (1, not at all; 2, occasionally; 3, frequently; 4, always) to what degree certain requirements for the Respite Program might interfere or making work more difficult. Table 4.11 provides a breakdown of the areas and the extent of perceived difficulty.

Contacting physicians for medications rated the highest concern with

frequent difficulties reported at least 31% of the time and occasional difficulties 56% of the time. Many comments by the nurses concerned difficulties in contacting physicians to confirm orders especially during evenings and weekends. This was a problem particularly if parents brought in medications that were inconsistent with the medications specified by the physician on the medical report. If the child's physician was not available, the physician "on call" was not always able to verify orders.

TABLE 4.11

NURSING SURVEYDIFFICULTIES WITH REQUIREMENTS/REGULATIONS

<u>REGULATIONS/REQUIREMENTS</u>	<u>(N)</u>	<u>1</u> <u>NOT AT ALL</u>	<u>2</u> <u>OCCASIONALLY</u>	<u>3</u> <u>FREQUENTLY</u>	<u>4</u> <u>ALWAYS</u>	<u>MEAN</u>
Contacting Physician For Medications	(16)	12.5% (2)	56.3% (9)	25.0% (4)	6.3% (1)	2.25
Obtaining Pre-Admission Specimens	(15)	53.3 (8)	26.7 (4)	20.0 (3)	*	1.67
Obtaining Consents From Parents	(15)	26.7 (4)	60.0 (9)	6.7 (1)	6.7 (1)	1.93

Obtaining preadmission specimen results rated a frequent problem 20% of the time. Consistent with results from the parent survey, this is an aspect of service warranting attention when using a 20% guideline. The requirement to have specimens taken for respite admissions has been a long standing question by program personnel. It may be beneficial to determine how the results are used, whether a need still exists, and if so, how to

better facilitate the process.

Although obtaining consents from parents was not a frequent difficulty, the mean is somewhat higher, 1.9%, compared to the mean for difficulties with preadmission specimens, 1.7%. It appears that more nurses experienced difficulties obtaining consents, but the problem was not rated as frequent a concern as contacting physicians.

Generally, all areas seem to be creating some difficulties although contacting physicians was rated the greatest problem. Examining all the implementation requirements to determine whether some of them could be minimized or alleviated may be worthwhile.

For the section on the preadmission interview and assessment and the completion of nursing information forms, only 5 of the 11 nurses (45%) who are involved in this area actually completed both parts. In other words, for first time admissions, the admitting nurse may not have met the child or parents as intended through the preadmission assessment procedures. One purpose for this process is to familiarize the family with the unit coordinator to reduce some of the stress at the time of admission. If nursing staff who complete the preadmission assessment are not available to admit the child, then this procedure may not benefit the child or family to the degree intended.

Two nurses did comment that the involvement in the preadmission assessment helped in the decision for unit placement, but they did not specify in what regard. Given that "unit placement" is prescribed by the age, size, and care needs of the individual, the procedure should reflect

some benefit other than the decision for unit placement. On the other hand, the procedure does reflect the participation of the nursing staff in assessing the care needs of children for their units. Although this may be helpful to the nursing staff, there are no written guidelines concerning situations where the child is found eligible for the program, but the unit coordinator indicates that the child's care cannot be adequately provided for on the existing respite units. This area may need to be reexamined to determine how effective the procedure is for the family, whether it assists in coordinating aspects or complicates them, and how decisions concerning eligibility are affected.

Of the 11 nurses involved in the actual first admission process, 45% reported they always read or reviewed the information and 55% reported they read or reviewed it most of the time before the family and child came in for the first admission. Generally, the information could be found on the ward chart, but 20% reported that information was on the chart sometimes. Because various staff deal with the individual, it would seem that having information easily accessible is an important aspect of care provision. From this perspective, effort should be directed to having the information always available on the clinical ward chart. It may be helpful also, for information to be reviewed before the first admission as parents are otherwise faced with repeating information already provided on the preassessment application.

In respect to consultations with other staff, not including social work, only 27% felt they consulted frequently and 53% consulted

occasionally. Reasons for consultations ranged from clarification on prescriptions, for recreational activities, dietary needs, equipment and for volunteers. It does seem from this data that nurses do consult with other departments in varying degrees regarding various aspects of care. Directly or indirectly, the scope of service may go beyond primary care on the unit.

Most nurses indicated that it was helpful to have a social worker present with the family on the first admission. Only one nurse (6%) stated it was not at all helpful. Approximately 33% consulted with the social work department on a frequent basis and 47% at least occasionally regarding respite admissions. Most felt that social workers were usually available, but 21% felt that they were not readily available to consult about respite. Comments regarding degree of availability indicated that social workers were not usually available on weekends when most respites are admitted and were not available for evening consultations. Another reported that due to schedules, meetings, and days off, social workers were not readily available during the day. It appears that availability of social workers was an issue for some nursing staff. It may be useful to examine what the specific needs for social work services might be and how the problems have or have not been resolved to date in order to determine the need to restructure social work involvement.

About 73% of the nurses reported being dissatisfied or very dissatisfied with activities available for respite. Several commented on the need for more recreational activities and planned programs. Some felt

that offering activities to respite individuals means displacing a permanent resident from that activity. This is an aspect of the program of significant concern for nursing staff and one that is corroborated by the parents' perceptions as noted earlier in the findings. This area appears to be a priority and it may be helpful to look at the possibility of using more volunteers and recreation activity workers in the respite program as an immediate alternative in dealing with this issue.

Nurses commented on several issues, gaps or procedural difficulties.

These included:

- * A need for more coordination with social workers regarding times and days of admission;
- * A need for a more efficient method for drug/medication orders;
- * A need for more activities and a homelike atmosphere;
- * A higher staff ratio at times as respites can be time consuming for the unit;
- * A need for an area for mobile young persons with a safe but stimulating environment.
- * Consideration of safety and privacy issues of the residents;
- * A process to improve returns of medical forms and specimen results;
- * Indication that admissions from the North West Territories have been difficult and confusing in respect to appointments and transportation arrangements.

Suggestions included:

- * To have consent forms signed prior to admission;

- * To have orders verified prior to admission;
- * To provide written information to parents regarding medications, etc.
- * To have a separate respite area.

In summary, the nursing staff pinpointed several dimensions of implementation that could be addressed to improve the operation or efficiency of the service. These include improving procedures for obtaining specimen results, consents from parents, and medication orders. In addition, the need for activities for individuals admitted ranked as a high priority. The comments also suggest a need to improve coordination efforts with the Social Work Department.

Part B: Effects and Benefits (Comparison of Nursing and Clinical Results)

Both nurses and nursing assistants were asked to complete the section on Effects and Benefits. They were asked to indicate their perceptions of the effects of the Respite Program on families, the individuals admitted, and the residents. They were also asked for their opinions on the effects of the ward-like environment and about the notion of a separate unit for respite admissions. Because the clinical staff were also asked to complete this section, the results of the clinical sample will be included in this discussion for comparison purposes.

The perception of effects and benefits was measured on a 5 point agreement scale (1, strongly disagree; 2, disagree; 3, uncertain; 4, agree; 5, strongly agree). Table 3.12 shows the comparison and distribution of results from nurses, nursing assistants, and clinical

TABLE 4.12

COMPARISON DISTRIBUTION ON PERCEPTIONS OF EFFECTS/BENEFITS

EFFECTS BENEFITS	SAMPLE POPULATION	1 STRONGLY DISAGREE	2 DISAGREE	3 UNCERTAIN	4 AGREE	5 STRONGLY AGREE	MEAN
Worthwhile Service	Nurses	*	*	*	15.4%	84.1%	4.85
	N/A's	*	*	5.6%	16.7	77.8	4.72
	Clinical	*	*	*	20	80.0	4.80
Recommend to Family	Nurses	*	*	7.7%	38.5%	53.8%	4.46
	N/A's	*	2.8%	2.8	44.4	50.0	4.42
	Clinical	*	*	8.0	28.0	64.0	4.56
Reduces Stress	Nursing	*	*	*	30.8%	69.2%	4.69
	N/A's	*	*	11.3%	22.2	66.7	4.56
	Clinical	*	*	4.0	32.0	64.0	4.60
	Parents	*	*	4.1	36.7	53.1	4.52
Individual Benefit	Nurses	*	7.7%	53.8%	23.1%	15.4%	3.46
	N/A's	*	5.6	38.9	44.4	11.1	3.61
	Clinical	*	4.0	60.0	16.0	20.0	3.52
Negative Effects on Individual	Nurses	*	7.7%	30.8%	53.8%	7.7%	3.61
	N/A's	2.8%	30.6	38.9	27.8	*	2.92
	Clinical	*	8.3	75.0	16.7	*	3.09
Lives at St. Amant	Nurses (N=12)	16.7%	50.0%	8.3%	16.7%	8.3%	2.5
	N/A's	*	16.7	38.9	36.1	5.6	2.0
	Clinical	*	25.0	66.7	8.3	*	2.83

NOTE: *N/A's - NURSING ASSISTANTS

*NURSES - N = 13

N/A's - N = 36

CLINICAL - N = 25

PARENTS - N = 44

*Row may not add to 100% due to rounding off

staff on six dimensions. For the dimensions: respite is a worthwhile service, would recommend this service to family/friends, and respite reduces stress for families, the results show fairly high and consistent ratings among all three sample populations with means ranging between 4 and 5 (agree and strongly agree).

This finding demonstrates a fairly positive attitude toward the program and a perception that it has a beneficial impact. The latter result, respite reduces stress for families, compares closely with the parents' mean of 4.5. There was much more uncertainty with the other dimensions with the means ranging from 2.9 to 3.6 for the items regarding the benefits of the program and in terms of the possible negative effects on the individual.

Nursing assistants tended to be most positive recognizing more benefits and less negative effects. In terms of the respite admissions enhancing the lives of residents at St. Amant, the greatest disagreement was with the nursing staff at 67% and the lowest was with the nursing assistants at 17%. The greatest uncertainty rested with the clinical staff at 67%.

When a crosstabs analysis was completed on the nursing sample, both nurses and nursing assistants, to determine whether any particular unit tended to show more agreement than others, nursing staff on 3 East and 1 West tended to agree that respite admissions do enhance residents lives. About 62% of the 3 East staff and 50% of the 1 West staff showed agreement with this item. Mapleside/Riverside and 1 East tended to show most disag-

reement with 71% of the Mapleside/Riverside Staff and 50% of the 1 East staff disagreeing that respite admissions enhance residents' lives.

This finding may relate directly to the characteristics of the individual admitted. For instance, 1 West, with only the occasional admission, would admit an older adolescent/young adult who is fairly aware of his/her surroundings, is able to communicate to some extent, and who tends to be more readily assimilated with the resident population. Three East admits very young non-ambulant children who do are not able to interact with other residents to any great degree. On the other hand, 1 East and Mapleside/Riverside tend to admit individuals who are fairly active and demanding in terms of behaviour and supervision needs. Often, they need to be segregated from others who are aggressive. Also, 1 East tends to have the greatest demand in terms of the number of respite admissions and may feel the strain involved in the turnover.

For the question relating to the effects of the ward-like environment on individuals admitted the results of the three staff populations were again compared using a scale of 1, definitely not; 2, uncertain; and 3, yes, definitely. As shown by Table 4.13, about 64% of the nursing staff, 50% of the nursing assistants, and 42% of the clinical staff felt there was an effect of some kind. The greatest uncertainty was with the clinical staff with a score of 54% possibly because they are the least involved in the care of individuals admitted for respite.

TABLE 4.13

STAFF COMPARISONS ON THE EFFECTS OF THE WARD-LIKE ENVIRONMENT

<u>SAMPLE POPULATION</u>	<u>(N)</u>	<u>3 YES, DEFINITELY</u>	<u>2 UNCERTAIN</u>	<u>1 DEFINITELY NOT</u>	<u>MEAN</u>	<u>SD</u>
Nursing	(13)	76.9%	15.4%	7.7%	2.69	.61
Nursing Assistants	(36)	50.0	41.7	5.6	2.46	.60
Clinical/Medical	(24)	41.7	54.2	4.2	2.38	.56

Several comments made by the nursing staff tended to be directed at potentially negative effects. They indicated concerns such as individuals admitted would lose out due to lack of activities while residents lose out due to increased restrictiveness. Several noted that the playroom is noisy and frightening and the ward was generally a stressful environment. Others pointed out difficulties for those who are toilet trained but do not have good access to bathroom facilities or privacy. Some indicated that individuals who are admitted with hearing aides or glasses often must remove them as others might destroy them.

Comments by the nursing assistants and the clinical staff seemed somewhat more tempered. Some comments by the nursing assistants indicated that some individuals really enjoy respite but some have a difficult time adjusting, that there were "positive and negative effects". Some believed it was quite an adjustment from being at home but another saw this as not necessarily a negative effect, but a rather a change. There were comments

indicating that having respite admissions is upsetting and disruptive especially in the cottage areas and that regimentation and routines make it difficult for the individuals who come in for respite.

Many of the clinical staff who commented indicated that the effects would depend on or vary with the individual and the unit where they were admitted. One commented that adjustment may have less to do with a "ward-like environment" than with the fact that this is a "different setting" for the child. Another indicated that the "ward life is uninspiring at best" while others noted that the lack of a stimulating, home-like environment was detrimental.

It is difficult to be precise about the reasons for the differences between groups. Although the uncertainty with the clinical staff is probably related to the fact that many of them not involved, the reasons for the differences between nursing staff and nursing assistants is less clear. Perhaps the nurses are responding from an overall perception of the program while nursing assistants are perceiving effects from their own personal experiences in providing care to respite individuals. This is an area that could have further research potential.

In regards to the development of a separate unit, as with the parents survey, the nurses, nursing assistants, and clinical staff were asked whether they would like to see a separate unit developed for the respite program. Table 4.14 shows the distribution of these results using a 3 point scale: 1, definitely not; 2, uncertain; and 3, yes, definitely. The highest agreement for a separate unit was with nurses and the parents

unit at 54% and 46% respectively. The greatest uncertainty rested with the clinical staff at 64% followed by parents again at 46%.

TABLE 4.14
STAFF AND PARENT COMPARISONS ON THE NEED FOR A SEPARATE UNIT

<u>SAMPLE POPULATION</u>	<u>(N)</u>	<u>3</u> <u>YES,</u> <u>DEFINITELY</u>	<u>2</u> <u>UNCERTAIN</u>	<u>1</u> <u>DEFINITELY</u> <u>NOT</u>	<u>MEAN</u>	<u>SD</u>
Nurses	(13)	53.8% (7)	15.4% (2)	30.8% (4)	2.23	.89
Assistants	(35)	25.7 (9)	14.3 (5)	60.0 (25)	1.66	1.86
Clinical/Medical	(25)	12.0 (3)	64.0 (16)	24.0 (6)	1.88	.59
Parents	(48)	45.8 (22)	45.8 (22)	8.3 (4)	2.38	.63

Again, a crosstabs analysis was done on the nursing sample to determine whether any particular unit tended to favour a separate unit. The results show that about 88% of the Mapleside/Riverside Staff and 60% of 1 East respondents favour a separate unit. About 81% of the 3 West staff tended to oppose the idea of a separate respite unit followed by 3 East staff at 77%, and 1 West at 67%. The differences on agreement regarding a separate unit may be related to staff perceptions of how well the individuals admitted integrate with the residents or with the routines of the ward. Alternately, it may be related to how staff react to the impact respite admissions have on changes in their routine and the extra demands this might place on them.

For all sample populations, there were numerous comments on the

issue of a separate unit ranging from the positive to the negative with many comments addressing the uncertainties. On the side of the affirmative, comments were directed at the positive effects of a home-like setting with a greater possibility of activities being geared to individuals' needs. Others indicated that a separate unit would be less disruptive for residents. Another stated that a separate unit is imperative to the functioning and expansion of the Program and that it would have overall benefits for those admitted, the residents, and the staff.

Those who were uncertain asked about the logistics of mixing young children with adults, about the space required, and about staffing requirements for such a unit. Others felt that the interaction with residents might be beneficial for some, but not for others.

In respect to the comments that were more negative in nature, some noted that if the ward atmosphere was not suitable for respite admission, then it should be viewed as not suitable for our residents. Others indicated that it would be "uncomfortable" to see money going to such a unit for respite when the needs of the residents are so great. Some felt that a separate unit would be detrimental to those who benefit from interactions on the ward. Yet, another noted that if there was a separate unit for respite admissions, it would still not be a home environment.

In summary, staff seem to perceive the Respite Program as worthwhile and beneficial to families. However, there are definite group differences in respect to the units/wards involved, especially in their perceptions

of the extent to which respite benefits resident and in their perceptions of a need for a separate unit as an alternate model for the service. Nursing staff tended to be more negative than other staff about their experiences or perceptions of how respites effect the residents. Units 1 East and Mapleside/Riverside were most in favour of a separate unit. As stated earlier this may be related to the characteristics of individuals admitted to the areas and the demands or the strains on staff and residents.

The Clinical Survey

A number of departments and a total of 25 of 31 individuals including occupational therapists, physiotherapists, psychologists, nursing administration, pediatricians, speech and language pathologists, nutritionists, social workers, and individuals from medical records, day care and the volunteer department responded to the survey. There was representation from each department.

Again, Part A addressed implementation and procedural issues while Part B, on the effects and benefits and the question of a separate unit, was identical to Part B of the Nursing Survey. Because the results of Part B were integrated into the results of the Nursing Survey, they will not be discussed again under the results of the Clinical Survey.

Part A: Procedures and Implementation Efforts

The first question related to the number of consultations that

clinical staff would receive for the respite program. About 73% responded that they were never consulted or rarely consulted. Twenty two percent (22%) were consulted once or twice per month while one person (5%) reported being consulted weekly.

There were many reasons for consultation including: suggestions for care and management, 60%; need for information, 52%; assessment, 40%; liaison with other agencies, 36%; referral, 32%, and equipment needs, 16%. Feeding, scheduling, and liaison between physicians and the ward were "other" reasons provided.

In terms of the degree the Respite Program might interfere with their work with the residents, 45% did not feel that it interfered at all and 56% indicated it interfered only to a mild degree. The case for the Social Work Department is somewhat different due to the coordinating function and it was difficult to estimate how much time was taken away from regular caseloads to deal with the Respite Program.

About 53% of the clinical staff reported that they kept some records of their consultation on the nature of involvement, correspondence, recommendations, and documentation of services provided. Fifty percent (50%) felt records were not necessary while another 50% thought it might be helpful to develop some system for records. A few commented that while documentation is kept on a clinical chart it is not easily retrieved in order to gauge degree or frequency of involvement. Some reported that even though they have a system they would like to enhance it to make it more useful.

Again, in the case of the Social Work Department, several kinds of records are kept regarding VPAs, lists for medical updates, lists of requests, files for documentation, intermittent audits, and annual reports with information on the Respite Program. The Department reported a need for various kinds of information that is not easily accessible, for instance, the actual amount of time spent being directed to Respite Program activities, documentation of the total number of requests, demand patterns ie. weekend, weekday, summer holidays. Unmet needs, information on characteristics of families or individuals using the Program, and regular feedback and evaluation by participants were other areas specified.

For the purpose of this evaluation, the Department agreed to keep a record of activities for a one month period effective March 11, 1991 to April 9, 1991. Activity sheets were designed along with the social workers to record this information. (Refer to Appendix N).

During this period of time, 32 requests for Respite were made by families already using the program and 13 new referrals were at some point in the intake process. Approximately 19 hours were directed to intake activities such as tour and information, application, coordination, and preparation for presentations to the Admissions and Discharge Committee. Another 9.5 hours were spent coordinating and following up on the 32 requests, while approximately 12.5 hours were spent on administration or general coordination such as follow up with medicals, VPA's, meetings with unit coordinators, etc.

The total number of hours recorded was 41.0 or an average of 10.5 hours per week on the program. According to discussions with staff, this is believed to be a low estimate. This particular month's recording did not account for any emergency or "respite plus" situations which usually involves more time. Also, there is believed to be some error in recording time as was impossible to account for every minute spent on activities and to record them accordingly. Based on these factors, it may not be unreasonable to expect that an average of 1.5 days per week are devoted to the program for that particular month. However, the social work staff feel that the recording is not reflective of what needs to be done, such as providing more support for families, completing important documentation, follow-up, and program planning.

These statistics suggest that the respite caseload is a fairly active caseload. It may be useful to review the activities and time spent on the program over another time period to provide a more accurate reading and comparison of data. It may also be helpful to review and restructure some of the activities that could possibly be coordinated by other departments. For instance, it may be more appropriate for nursing to coordinate the yearly medical updates as this relates more closely to their role of providing care for the child. In addition, assigning a set number of social work hours for to the respite program may reduce the strain of monitoring a large residential caseload along with an active respite caseload on a part time basis.

In the next section, staff were asked their opinions on whether

respite admissions would benefit by services from their respective departments. Approximately 68% of the clinical staff indicated that those individuals who were admitted for respite would benefit from services offered by their departments. Some staff suggested that their role might include coordination of medical care, seizure reviews, feeding assessments, home treatment programs, consultation with subspecialists, general assessments, information and referral for counselling or support, and seating or equipment reviews. Others indicated that they would not be involved as they understood that many of the individuals admitted for respite care receive services in the community and therefore, would not need services from their departments. In general, staff were positive about the possible benefits of their involvement.

Respondents were asked to identify gaps, issues, or procedural difficulties that they may have encountered. In respect to gaps and issues, staff indicated that in some situations, individuals admitted for respite admissions seem to have fallen between the cracks of the medical system and would benefit from a total needs evaluation that is multidisciplinary in nature. Others reiterated concerns about limited bed availability on certain units, the lack of programs or activities, and the need for more respite care for special populations such as young ambulant adolescents.

Many procedural difficulties were also identified including:

- * The lack of advance information on diet, feeding problems, and special products required (Nutrition Department);

- * Concerns about the extent of involvement or scope of service expected. For instance, if assessments are not to be done, to what extent should departments be dealing with the wards' requests for management suggestions or equipment?
- * Concerns about outdated medical reports or inconsistent information especially regarding prescription orders;
- * Concerns about the lack of information on respite admissions and the fact that some departments are provided with admission information while others are not;
- * Requests for information on how the Program is funded and whether departments need to use a separate budget when providing service.

The clinical staff also provided **suggestions** to enhance the service. Among these included:

- * A small summary on the individual to some departments such as nutrition and pharmacy to prepare for nutritional, pharmaceutical needs;
- * Consideration for increased pharmacy services to provide medication profile and facilitate admissions in order to alleviate medication administration problems;
- * Specification of procedures for long term respites;
- * An inservice on the Program with discussion from departments;
- * Guidelines that would specify expectations of professional staff;
- * More direction and information on funding especially in respect to long term respite admissions;
- * Clarification on the differences between long term respite, a short

term admission, or a training admission, and the implications for professional involvement.

Some of the final comments provided by the clinical staff indicated that the service was viewed as an essential component of the Centre's overall programming and that it should be a focus of the outreach services. Some clinical staff indicated that the community at large needs to know more about the Program as many parents have limited information.

Summary

Generally, most of the clinical staff view the Respite Program as being a worthwhile service to families. Many of the clinical staff, however, are not involved with respite admissions. For those who are involved, they seem to be positive about the potential benefits of their involvement. On the other hand, they seem confused about the extent to which they should be involved. There also seems to be some sense of some questions regarding differences between respite and other programs as noted by the comments. Several staff suggested more specific guidelines, inservices, and clarification regarding various aspects of the program. Some departments reported a need for more communication and information, for instance, in the case of dietary requirements.

The situation for the Social Work Department is considerably different because of the coordination aspects. This department reports a need for various forms of information that would be easily accessed for both general operations and program planning. There is a sense that more

time is taken from the residential program than realized. However perhaps recording the nature of activities and time spent over another time period is necessary before and conclusive statements can be made.

CHAPTER 5

DISCUSSION AND RECOMMENDATIONS

This study was exploratory in nature and designed to gather information that might suggest ways to modify or improve the effectiveness of the Respite Program at St. Amant Centre. This section is based on the survey results as well as meetings with the Respite Evaluation Committee and dialogue with staff. The discussion will be directed at the objectives specified for the evaluation.

Consumer Satisfaction with the Program

In relation to the first evaluation objective, consumer satisfaction, the Program received relatively high ratings. The fact that the Program rated in the 90th percentile would suggest that generally parents are satisfied with the Program. However, as literature suggests, specific aspects need to be measured separately in order to better understand dimensions of the Program that may be responsible for dissatisfaction (Lebow, 1983; Ware et al., 1983). In this regard, parents identified key access and implementation issues and/or concerns related to obtaining specimens for initial admissions, and the signing of the VPA. In addition, parents did not find the amount of activity for their children nor the availability of service adequate to meet their requirements.

Another point, gleaned from comments by parents who no longer use the program, was the lack of clarity concerning eligibility for the

respite program. As indicated earlier, approximately 20% of parents who no longer use the program seemed to be misinformed about eligibility. Although this is relatively few in number, this was one of the three most frequent reasons for not using the Program, only next to having children placed and using other forms of respite. This is a point to keep in mind when providing information to families.

Need for Expansion or Modifications to the Service

A second objective of the evaluation was to determine the degree that services needed to be expanded or altered in scope and design. The questions focused on satisfaction with the availability of service (extent and scope of service), physical environment, and aspects concerning care. A review of client characteristics and sociodemographic information provided a profile of families using the program. A question was specifically directed at gaining opinions on the development of a separate unit.

In respect to availability or extent of service, the results suggest that many parents do not find the service adequate and many would like to have more respite time on a regular basis. In particular, the results from parents and available statistics indicated a need for more respite service on 1 East. This is the only unit admitting young children and adolescents who are ambulant and, in many cases, difficult behaviours are involved. As some studies show, this is not an uncommon population to have problems locating service, even though these families would

presumably need more respite because of the intensity of the demands (Upshur, 1982; Apolloni & Triest, 1983; Cutler, 1986).

The need for increased services for this population is important from another point of view also. As discussed earlier, many families do not seem to have or use an informal support network for respite. In addition, many children seem to have high care needs and/or are behaviorally demanding. The sociodemographic profile of families also shows that many families are in the lower socioeconomic range with approximately 25% being single parents. This information suggests that families may be at risk for high stress, and possibly family disruption or harsh treatment of children, especially in situations where all these factors are present over time (McCubbin & Patterson, 1983; Tracy, 1990; Seagull, 1987; Garbarino, 1976).

Another critical point in the assessment of need for more service is involves the parents' expressed need for service. Parents, particularly those using 1 East, not only perceived a need for respite, but also expressed a need, i.e. they actually attempted to obtain the service. Although the exact demand statistics were not known, the program staff corroborated the need for more regular and emergency respite especially during high demand periods such as holidays and weekends. In considering expansion, it may be helpful to keep demand statistics to measure not only the number of people served, but also those not served and the circumstances surrounding the lack of service provision.

In terms of relative need, this sample of families' need for more

respite is consistent with other studies in Manitoba regarding services for disabled children and their families (Marginet, 1986; Trute, 1988). Considering that the program at St. Amant is only one of many options available, it would be prudent to become acquainted with the plans for respite expansion in the wider social support network in order to consider how those changes may impact on the program at St. Amant. For instance, if agency budgets restrict respite use in the community, then St. Amant may be more in demand because it is not considered as part of the family's yearly respite allowance. However, if agencies are provided with resources to expand respite services, then the demand for services at St. Amant may be quite different. Ultimately, the political and economic environment will shape decisions through the availability of fiscal resources.

In general, parents did not express a need to have the scope of service expanded. That is, they did not request more options within the service such as therapy or consultation except during respites of long duration. Perhaps, they understand respite to be just that, or possibly they receive supplemental services in the community as part of an overall care plan.

In terms of the staff response to the scope of service, most clinical staff indicated that individuals would benefit from services but 75% of the staff are rarely involved and seem to understand that for respite admissions, their involvement is not mandated. Some staff, however, do respond to consultations and requests for service for respite

admissions. Because resources are not specifically allocated for respite consultations or assessments, time is taken away from the residential programs. This may be more problematic in "respite plus" situations where more resources may be expended in assessing, making arrangements, and consulting with the community.

There is confusion evident between what may be referred to as "respite plus" and cases that might fit better with the Community Assessment Program, an outreach program designed to provide assessment and consultation services. The difference between "respite plus" and a community assessment becomes blurred in some situations. This is particularly the case if assessments and consultations are requested for respite admissions. However, in the case of the Community Assessment Program, staff are expected to account for time and resources expended and this is billed back to the region, while with the Respite Program, no consistent accounting seems to exist. It appears staff is requesting clarity and guidelines to differentiate the kind of service and the fiscal arrangements for involvement that go beyond the present scope of the regular respite admission.

On the issue of activities, parents reported significant concern regarding the lack of activities available for children during admission. Similarly, nursing staff indicated that this can have a detrimental effect on both individuals and residents on certain units. It is important to note that the scores for satisfaction with physical surroundings were significantly higher than scores for satisfaction with activities. This

suggests that increasing the amount and kind of activities available, especially on particular units where this is a noted problem, is a higher priority than the need to change physical surroundings. Increasing activities should be given serious consideration as a way of improving the quality of care. The effects of improving the interaction through activities would not only be beneficial for the persons admitted, but would also help parents to deal with separation effects that often accompany leaving their child.

The question of a separate unit for respite has long been discussed as part of the Five Year Plan and renovation plans. However, reaching an agreement on a separate unit as an alternative for service delivery and design is complicated by a number of factors.

First, in relation to physical environment, families reported a relatively high satisfaction rate of 90%. Although there were some comments concerning the institutional nature of the environment, safety, and crowding in some areas as noted earlier, parents did not seem to focus on the physical surroundings as a reason to alter the model of service. The parents' desire for a separate unit does not seem related solely to the physical surroundings. Parents in this study tended to favour the separate unit either presuming or noting that it would be desirable if having the unit would provide more time to meet their needs for respite services, and if it would improve the interaction component for children.

However, the same parents who express a need for service now, may not need the service at a later point, or may need a different kind of

service as their child grows. As noted in previous research, the fact that "need is elastic" and tends to change over time complicated the decision. This elasticity can also extend to demand, the fact that demand may change with a change in service provision, for instance if people believe there is a real possibility of getting service they tend to ask for more service (Kettner et al., 1990). The question becomes, how much more service is enough?

Another factor to consider is that not all parents explicitly wanted a separate unit. Parents with younger more mobile children tended to favour the unit more than those with adult children. This is fairly consistent with literature that suggests the needs of families for respite tend to vary with the life cycle (Suelzle & Keenan, 1981; Lutzer & Brubaker, 1985). Similarly, staff who worked on units with children who were ambulant and had difficult behaviours tended to favour a separate unit, although there were some group differences among staff as noted earlier. Also, there was a group quite opposed to a separate unit and seem to perceive that the needs of the residents would be displaced by resources expended on the Respite Program. Other questions were raised about the logistics of mixing young children with adults and about the feasibility of staffing the unit adequately to provide quality services.

Another related, but broader issue, is the extent to which a separate unit in an institution constitutes an acceptable strategy for expanded respite services. This remains a controversial issue as respite care in institutions is considered by some to be the most restrictive form

of respite (Cutler, 1986; Salisbury & Griggs, 1983). However, perhaps it can be best answered in terms of understanding the degree of restrictiveness from the view of the family. For instance, if the unit meets both family and child needs, and if the family is secure with that model of service, then perhaps this model service is the least restrictive (Cutler, 1986). This presumes that the family is aware of other options for respite service.

The effects of the institutional environment on the children must be given further consideration. It does seem reasonable that large wards and lack of activity have a negative effect on the individual. However, the degree that this negative effect is related directly to the ward is not precisely known. The effects could be attributed to other factors such as separation effects or merely by being in an unfamiliar environment.

Considering the many issues and perspectives, if a separate unit would increase the availability and accessibility of services while at the same time improve the quality of care, then it would seem reasonable to continue to work toward this goal. However, it would be prudent to simultaneously deal with the potentially negative reactions apparent from some of the staff comments. Providing opportunities to learn about the potentially positive consequences of a respite unit may reduce some of the negative overtones and fears that resources for residents will be negatively affected by this decision.

In respect to the perceived benefits/effects of respite programs,

some researchers argue that respite evaluations have not demonstrated the true impact of respite on the family (Intagliata, 1986). Nevertheless, the families' perceptions of such benefits as stress reduction, resurgence of energy, or reduced likelihood of out-of-home placement are important considerations as noted in both the Double ABCX (McCubbin & Patterson, 1983) and Adaptational Models of Family Functioning (Crnic, et al., 1983). The section on Effects and Benefits addressed both the perception family's have on the effects of respite, and it also served to validate the Program Model developed by the Respite Committee. (Refer to Appendix F, Reconstructed Model).

All effects were confirmed although the agreement was much higher for some effects than for others. Certain effects could be considered unintended effects, for instance, the fact that respite is reported by some to increase family tension especially for those who initially begin to use respite. The unintended effects may alert us to a need for interventive action with some families. In this respect, the Respite Program Model developed by the Evaluation Committee seems to be a fair representation of the intended and unintended effects and should remain as constructed.

The results from staff surveys show substantial agreement on the point that respite is a worthwhile service for families and favourable views toward the program could be gleaned from the comments. A number of implementation issues, however, were indicated and have already been noted previously. What seems to be salient among these issues is a need for an

ongoing mechanism for communication and program coordination efforts. In this respect, it might be useful for the two coordinating departments, the program directors and coordinators, to meet regularly to identify operational problems and take a collaborative and comprehensive approach to corrective action.

A need for systematic, easily accessible, continuing data is a vital aspect which would lead to increased efficiency of operations, service delivery, and feedback for accountability purposes. Data would provide information on demand characteristics, resources expended, program coverage, and legal and regulatory criteria that must be reviewed as part of the program's operations. As discussed earlier, such data can be pertinent when deciding to expand service.

Similarly, regular and systematic evaluation or feedback from participants, perhaps after the point of the first admission and yearly thereafter, would provide longitudinal and comparative data on the Program as part of an ongoing monitoring effort.

In summary, families seem highly satisfied with the overall quality of service they receive through the Respite Program, with mention already given to those aspects of service that need attention. The need for more services, particularly for the ambulant children with difficult behaviours is evident, but must be considered in the realm of overall plans in the community to develop respite supports for families with disabled children. The notion of a separate unit is appealing in its potential to improve the quality of care. Families see its importance primarily in terms of

improving interaction and increasing the availability of services. Staff see this program as being worthwhile for families and express a positive view toward it. On the other hand a number of operational and implementation issues, discussed earlier, need attention in order to increase the efficiency of the program.

RECOMMENDATIONS:

In general, the St. Amant Respite Program is a fairly active program and one that potentially could stand independent of the residential service component. Working towards a program with clear goals and objectives, a defined structure, allocated resources, information systems, and evaluation dimensions would strengthen the program and improve the efficiency of the service. Having a mechanism, such as a Respite Committee with strong leadership, is viewed as a vital component for program enhancement or development.

The recommendations are based on the feedback provided by parents, staff, and from available documents and statistics. The recommendations are grouped in the areas of program development, coordination and communication, direct services, evaluation, and promotion. An asterisk (*) denotes a recommendation for priority or immediate action.

A. PROGRAM DEVELOPMENT:

Al. * That a mandate be given to the two primary coordinating departments, Social Work and Nursing, to form a group structure, a "Respite Committee", to:

a) function on an ongoing basis to promote program development, ensure coordination, review operations and implementation difficulties noted by parents and/or staff, and make recommendations to the administration; and

b) provide follow-up to the findings and recommendations of this evaluation.

A2. * That goals and objectives for the program be reviewed and specified and that guidelines for service components such as emergency or crisis respite and "respite plus" be established.

A3. * That an easily accessible data base or information system be developed and implemented, and that the specific information needs for this system be defined by the coordinating departments.

B. COORDINATION AND COMMUNICATION:

B1. * That roles, responsibilities, and procedures be clarified in order to enhance coordination. A number of areas have been noted by staff as posing difficulties. These include coordination of time and dates for admissions, signing consent forms, returning medicals, providing information to parents, and dealing with high demand periods such as holidays, weekends.

B2. * That the pharmacist and/or medical director be included in pertinent discussions and assist in defining procedures that might assist in dealing with difficulties noted in regards to obtaining orders for medications.

B3. * That the need for specimens for the first admission be reassessed and possibly simplified if the procedures continue to be a requirement.

B4. * That there be consultation with the Director of Childrens' Special Services regarding the many concerns noted by parents regarding the signing of the VPA.

B5. That consideration be given to restructuring some of the coordinating responsibilities. For instance, the possibility of nursing rather than social work completing follow-up on annual medical reports may be one area to consider reassigning as the need for medicals is primarily related to the nursing

component of care. Another area to review might be the coordination of the nursing preassessment phase and the initial admission phase to ensure that families experience maximum benefit by the process.

B6. That following the development of guidelines for the various components of service, a meeting with staff, particularly clinical staff, be held to provide general information on the Respite Program and to clarify issues raised through the evaluation survey .

B7. That a program manual for the Respite Program be developed and made available to all departments.

C. DIRECT SERVICES TO FAMILIES:

C1. * That immediate efforts be directed at increasing the amount and kind of activities available for those admitted for respite possibly through drawing on the services of the Volunteer and Recreation Departments and/or training of some volunteers specifically for the program.

C2. * That the availability of services be addressed as respite needs seem paramount at this time for families trying to access the program. For the immediate future, increasing the number of beds to deal with the demand is an option that may assist families and could be useful in determining how much of an increase in service is possible. However, this increase must be considered along with the current fiscal and human resources available.

C3. That consideration be given to provide families with information regarding their eligibility for the program by formally writing them in addition to a phone contact.

C4. That the scope of the Respite Program, i.e. the options or kinds of services available, be limited or considered only along with other outreach efforts already provided by the Centre to ensure that expanding the scope would not duplicate these services or vice versa, for instance, as in the case of the Community Assessment Program, .

C5. That efforts to change the model of service should address the gap in respite services. At this time, the Program seems to serve a vital role in filling a gap in

service for multiple needs children. The notion of a separate unit is appealing in many ways, but at the same time, somewhat controversial and must be considered in terms of the stated needs of families, overall efforts to expand outreach, resources available, and plans for respite services in the context of the wider social support system in the community.

D. EVALUATION:

D1. * That an evaluation questionnaire be developed and sent out yearly to program participants to determine satisfaction with services and to define any service delivery problems that might require corrective action. This would allow families an opportunity to make suggestions and allow participation in a service intended to meet their needs. A systematic evaluation such as this would also provide longitudinal or comparative data on the Program.

D3. That a brief form soliciting feedback after the first admission be developed to alert service staff to special needs or problems families might encounter in first using respite.

E. PROMOTION:

E1. * That the purpose of the respite pamphlet be defined and developed into an appealing format. It could be especially helpful in providing information to families to access the program, for public relations, or to market the program if this is intended.

Generally, families seem highly satisfied with the overall quality of service they receive through the respite program. The strength of the program seems to be related to the overall quality of service and the interest taken by staff. This aspect was almost undisputed by parents. However, efforts to define the program structure, improve coordination and communication, deal with implementation issues, and possibly expand the service would further enhance this program for families who find respite at St. Amant a vital part of care and support for their disabled children.

CHAPTER 6

PRACTICUM EVALUATION AND CONCLUSIONS

The summary and conclusions will be discussed in relation to the objectives set for the practicum as put forth in the Introduction. The limitations of the research and further recommendations for research will also be presented.

Program Evaluation Using Consumer Feedback: The Client Satisfaction Approach

It has been asserted that respite can be best understood and evaluated from the perspectives of families who use it (Salisbury & Intagliata, 1986). In terms of the practicum the first objective related to evaluating the Respite Program using a design which would recognize the importance of families' perceptions and perspectives. Client satisfaction research provided a broad base by which to understand the multiple dimensions involved instance, satisfaction with specific aspects of service, its delivery process, form, and content.

A cross-sectional survey of consumers was useful in measuring overall satisfaction, but it proved to be more valuable in pinpointing specific aspects of the service that may be prohibiting access. The approach also allowed parents to provide their opinions on the design and development of the program.

Similarly, the staff surveys provided information on implementation

issues and isolated aspects of service that were of concern. The feedback and suggestions are useful in setting priorities and making modifications to improve the day to day operations of the service.

Developing the instrumentation was challenging and time consuming. An attempt was made to modify a standardized questionnaire (CSQ-8, Larsen, et al., 1979), to adapt others used in research in Manitoba (Marginet, 1986), and at St. Amant in the Developmental Day Program. While this provided a good base, questions needed to be developed to address regulations and implementation areas specific to the Respite Program itself. Pre-testing was most useful in gleaning out double-barrelled, leading, or confusing questions.

The data analysis provided another challenge both in terms of the quantitative and qualitative data. As put forth in the practicum objectives, developing some degree of competency in using a computerized statistical analysis was important. However, having only a beginners knowledge, using the computer program met with its occasional exasperating moments. The most valuable lessons had to do with the importance of making decision on how to dealing with missing data. The qualitative data was useful in clarifying many dimensions, but using qualitative methods was extremely time consuming given the magnitude of the comments.

Particularly outstanding in the overall process, was the incredible number of details and decisions that needed to be made, including everything from sample size to envelope size.

The Respite Evaluation Committee

The Respite Evaluation Committee was a structure used to facilitate the evaluation process and in order to make the evaluation relevant and useful to key people needing the information (Patton, 1986). An evaluation by the committee members provided feedback on the use of this approach. A copy of the Respite Committee Evaluation form is located in Appendix O.

Seven of the nine committee members completed the evaluation form distributed at the final meeting. All respondents reported that they found the approach useful for developing questions for evaluation and that it increased the likelihood of the evaluation being useful and relevant, and that it provided information needed. Only one of the respondents was uncertain whether he/she would recommend the approach to others but the reason for the uncertainty was not noted.

All respondents rated the organization and six respondents rated the content of the meetings highly, (between 4 and 5). However, comments regarding the length of the meeting suggested that more time was needed. Most meetings were scheduled for one hour except for the final meeting which was scheduled for one and one-half hours. About half of the respondents felt more time was needed for the last meeting, and this was certainly the case as the meeting went well into overtime. The group may have been able to digest the information and have more input into the recommendations if more time was allotted. In retrospect, two meetings to review the findings and to discuss recommendations have been

preferable.

Although there was some initial concern by this evaluator regarding individuals' comfort levels in such a diverse group of people, no one indicated any hesitancy to put forward views and most reported that they had sufficient opportunity to put forth issues. However, one respondent felt uncertain that sufficient opportunity was provided to put thoughts forward for discussion.

The main concern in dealing with the Committee was related to its size and the fact that finding a suitable time and a sufficient length of time to meet was often difficult, if not a frustrating process. While individuals seemed interested in attending, frequently they noted their time restrictions.

One question posed to the Committee was an open-ended question that asked them to comment on any areas of the program evaluation had the greatest impact. Many commented that the consumer feedback provided specifics regarding areas that were presenting problems to families while at the same time, the feedback grounded their own perceptions of problem areas for families. Others were surprised by some of the group differences among staff.

One outcome of the final meeting was a directive by the Executive Director, to have the coordinating departments develop a committee to deal with issues raised by the evaluation. Through prior discussions with the directors of the coordinating departments, this recommendation was viewed as pertinent and acceptable.

The Literature Review

In respect to the literature review, the initial intention was to have a very focused and defined review. However, there was an early realization that respite did not stand merely as a service to give a break to parents, but that it was a part of and existed in the context of much broader frameworks and systems and that it should be understood in that way.

The literature on the ecological model, was a constant reminder of the interrelationships and the impact between systems, the need for families to negotiate with systems, the impact of those system on the family. In addition, the decision to involve various systems in the evaluation process took the form of an ecological approach to evaluation. The discussion and recommendations for the program were based, in part, on the ecological implications for policy, services, and practice as outlined by Bubolz and Whiren (1984) and stated in Chapter One. Involving the parents in the Respite Committee and using parents' perspectives, was also consistent with the ecological framework. It provided credence to the perceived needs of families, and also acknowledged that they should have a voice in the design and development of services intended for them.

The ecological framework, with its emphasis on communication, coordination, and cooperation helped in recognizing a need for the two coordinating departments to meet together to deal with the issues in a holistic way rather than dealing with problems and decisions in a heuristic fashion.

The literature on stress and coping helped to delineate the relationship between stress, coping, and the role of supports and services in mediating stress. The two models discussed (Double ABCX and the Adaptational Model) provided a good conceptual base for this understanding. In this respect, factors such as the differential needs of families, recognizing respite in the context of other social supports needed by families, and the need to provide information on relevant resources to families were addressed.

The respite literature contributed to a comprehensive understanding of the role of respite care as a service, the various models, the potential impact on families and the differential respite needs of families.

Finally, the literature on program evaluation was invaluable to the practicum experience in understanding the need to focus, plan around specific information needs, and to always consider relevancy and utility. The consumer satisfaction research, provided a base to understand the multiple dimensions involved as well as the limitations of the research method.

Internal vs External Evaluation

At many points during the evaluation process, knowledge of the program and familiarity with it provided a basis for raising questions and exploring issues. Being an "insider" was a benefit in knowing the nuances, understanding the organizational structure, and in facilitating

communication. However, at times there was a subjective sense that observations, interpretations and/or recommendations may be biased. On several occasions opinions of others was helpful in dealing with this issue. Also, trying to obtain more objective information was helpful, as was in the case of having social workers record and document their activities. It is not known to what extent an insider may have more or less influence on policy or recommendations in this particular situation.

Limitations of the Study/Suggestions for Further Study

As stated in the introduction, the study was planned and implemented for a specific population of respite consumers. Because the study used a purposive samples, the findings are relevant to the context of the program, but any extensions or generalizations must be made with caution. Also, consumer satisfaction in the human services tends to be overrated so there are implications involved in viewing the results only from a general perspective without giving consideration to specific dimensions or aspects of the service. Therefore, general satisfaction must be recognized as only approximate indicators of satisfaction.

Almost 75% of the respondents were mothers. As indicated earlier, a limitation noted by Crnic (1983) in previous research is the focus on the mother-child dyad. Although the ecological model would suggest that the mothers' perceptions would have an influence on the families, it is difficult to estimate the extent to which a mother's view is representative of her family's. Also, the study did not focus questions on the

effect of respite on the siblings.

In terms of the surveys completed by staff, there were group differences noted that were of interest. Most notably were the differences between nurses and nursing assistants on the effects of respite admissions on individuals and residents. This raises questions especially in cases where differences occurred on the same units. The sample size may be partially responsible, but further research might determine what other factors might be influencing the differences.

Also, the sample of parents with older children was fairly small, and in order to better determine the differential needs of these parents and individuals, more research could provide information or substantiate research completed in this area.

Another area of potential research is related to the impact of respite use on long term placement. This is especially relevant as many of the families in this study who are not currently using respite, have placed their children.

This practicum provided the opportunity to integrate theory and practice. The experience in using a consumer satisfaction in the context of program evaluation has been a positive one that has yielded many insights. The need to evaluate and design programs in the context of client need is clearly, fundamental to providing programs that are effective and responsive.

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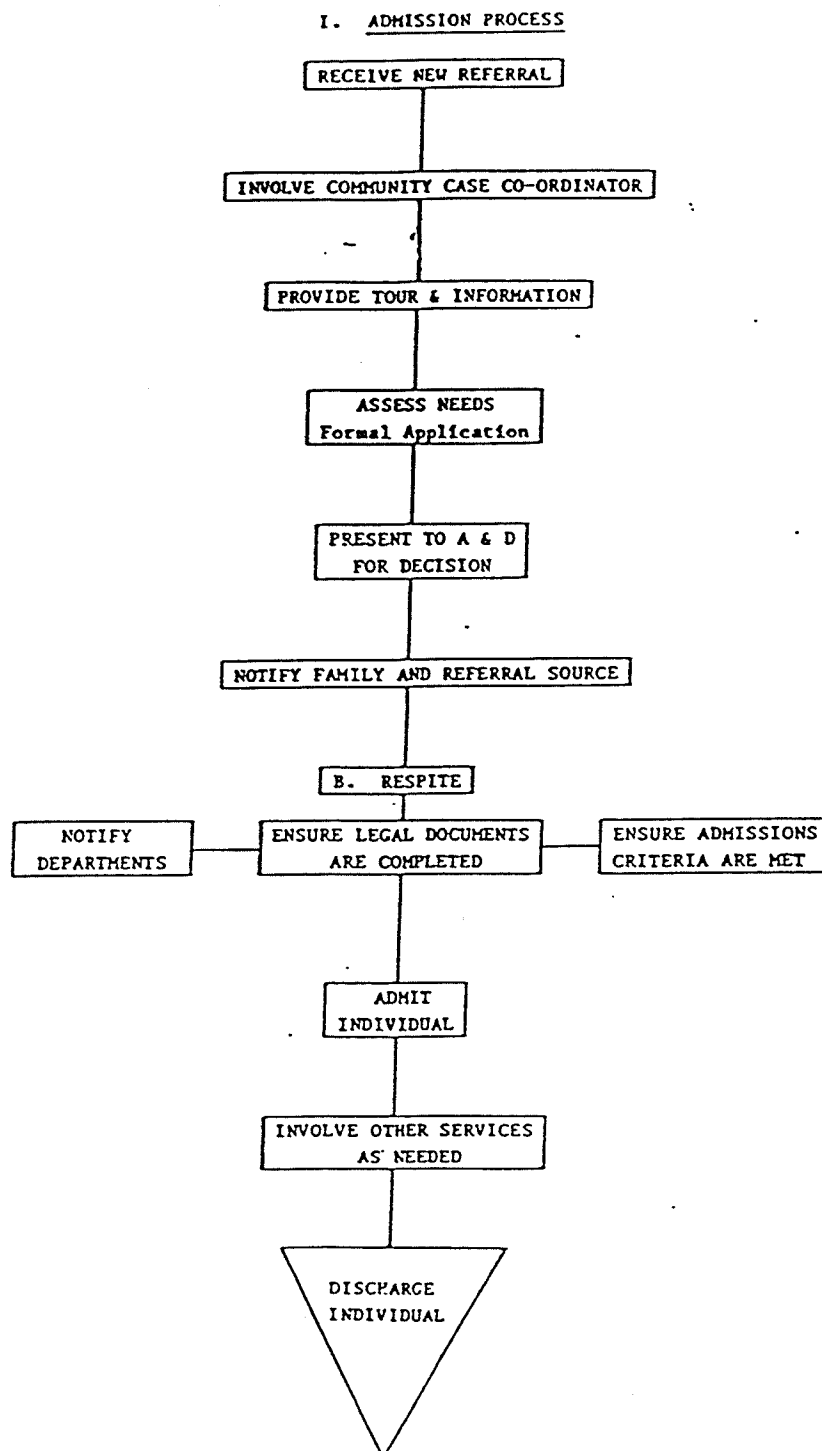
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APPENDICES

APPENDIX A

FLOW CHART OF RESPITE ACTIVITIES



APPENDIX B

LIST OF PRE-EVALUATION INTERVIEWEES

Sister Gabrielle Cloutier	Executive Director
Ivy Kopstein	Director of Social Work
Brian Law	Director of Children's Special Services (Province of Manitoba)
Lynn LePage	Assistant Director of Nursing
Susan Lindskog	Social Worker, Respite Coordinator
Shirley Meszaros	Assistant Executive Director of Nursing
Jane Rogala	Unit Coordinator 1 East
Dr. Carl Stephens	Assistant Executive Director of Programs
Jean Strutinsky	Social Worker, Child Development Clinic
Tam Yamashita	Director of Physiotherapy

(Interviews were held during the period of August 2, 1990 to August 29, 1990).

APPENDIX C...

PRE-EVALUATION INTERVIEW SCHEDULE

NAME: _____

PURPOSE:

I am now in the process of defining a practicum for my course of study for my MSW. I am most interested in exploring the area of respite care for the developmentally disabled and through this exploration, I will specify a focus. Because I wish to make the research relevant to both the Centre and my area of work, I would like to spend a few minutes with you for the purpose of getting feedback from you on what you see as significant issues regarding respite.

BACKGROUND:

With the changes in philosophy and service delivery in the field of mental retardation, for example deinstitutionalization and normalization, there has been a corresponding change in utilization of institutions as a locus of service. St. Amant has attempted to respond to the changes and needs in the community. One way has been to develop and implement a respite program which assists parents and other careproviders to maintain children/adults with a developmental disability in the community. This program provides another option on the continuum of care/service.

QUESTIONS:

In your opinion, what is the primary goal or objective of the respite program at St. Amant?

To what extent is there a need for a respite program at the Centre? (extent = service provided/total service required)?

What is the scope of the program? Do you think the scope of the program is broad enough? (scope = range of services in the program)?

Who uses institutional respite? Who should use it (eligibility issues)?

Who knows about it? Who should know about it (access issues)?

Are the services adequate? If not, what might correct the inadequacies?

Are there any funding issues that are of concern?

What impact do you believe the program is having or should have on users?

What are some of the specific issues that you encounter in your dealing with varying aspects of respite that might benefit from investigation or research?

Do you perceive a need for any aspect of the program being evaluated?

Do you believe the Centre will have a continuing role in the delivery of a respite program in the next 5-10 year? How will it compare to its current role? Will the communities capacity to deliver respite have an effect?

Is there anything you would like to add that we have not covered in our discussion?

Is there anyone else that you feel I should speak with regarding respite?

Thank you for your time and the information you have provided. It is greatly appreciated. I am sure it will be helpful and I will try to keep you informed as to the direction I take with this project.

APPENDIX D

EVALUATION COMMITTEE

RATIONALE FOR THE EVALUATION COMMITTEE:

- *Representation from various levels/systems is consistent with the ecological framework;
- *A participatory strategy is a method of increasing the likelihood of the evaluation being relevant and useful.

FRAMES OF REFERENCE/PARAMETERS:

Group size: 5-6 members (a small group ie. for practical reasons and decision making).

Group composition: representation from administration, program management, service delivery and consumer levels.

Purposes:

To develop a program profile ie. to explicate the problem that underlies the goals and effects; to operationalize objectives; to specify outcomes and review program design.

To clarify and define the reasons and purposes for the evaluation and to develop an evaluation model ie. What elements and objectives will be considered for inclusion in the evaluation?
ie. What do we want to know?

To identify who will be using the evaluation and for what purposes. How are we going to use the evaluation?

To provide feedback on survey instrumentation, results, and recommendations.

Timeframe:

The committee will endure for the period of the evaluation process (tentatively, Oct. 1990 to May, 1991).

It is expected that the input will be more intense at the initial stages ie. developing a program profile, evaluation model, and instrumentation.

A minimum of 2-3 meetings is projected for the months of Oct. and Nov. 1990 to lay the groundwork for the evaluation.

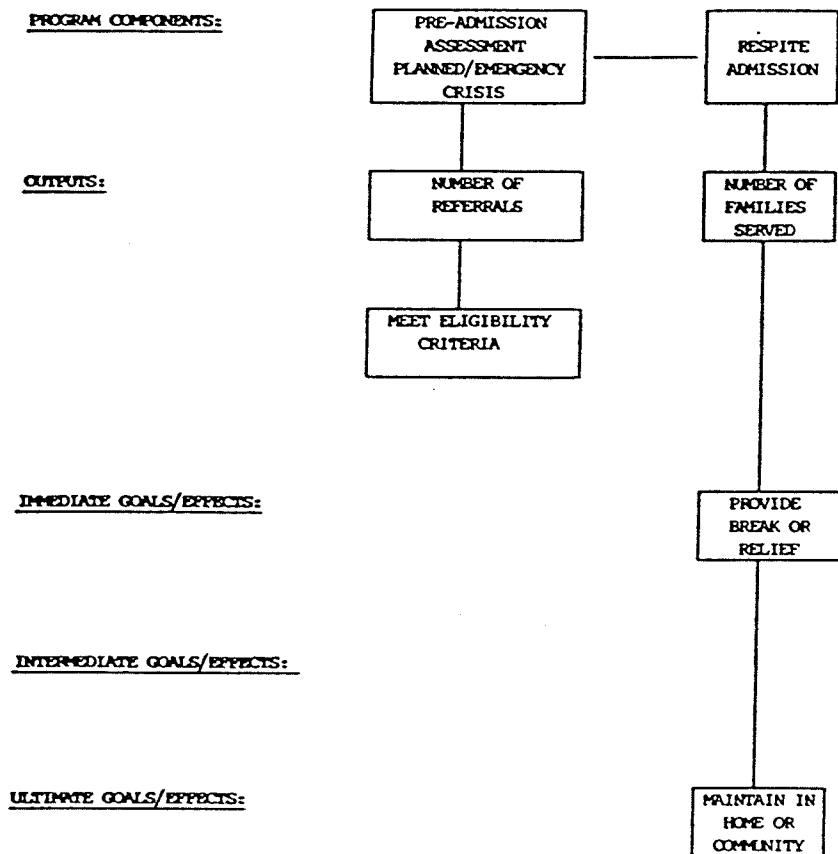
APPENDIX E

RESPITE COMMITTEE MEMBERS

Sister Gabrielle Cloutier	Executive Director
Valerie Amos	Parent
Jan Coates	Director of Pharmacy
Kathy Edgar	Parent
Ivy Kopstein	Director of Social Work
Susan Linskog	Social Worker, Respite Coordinator
Shirley Meszaros	Assistant Executive Director of Nursing
Dr. Gina Rempel	Medical Director
Dr. Carl Stephens	Assistant Executive Director of Programs
Jo Verstraete	Chairperson

APPENDIX F

RESPITE PROGRAM (DOCUMENTS MODEL)

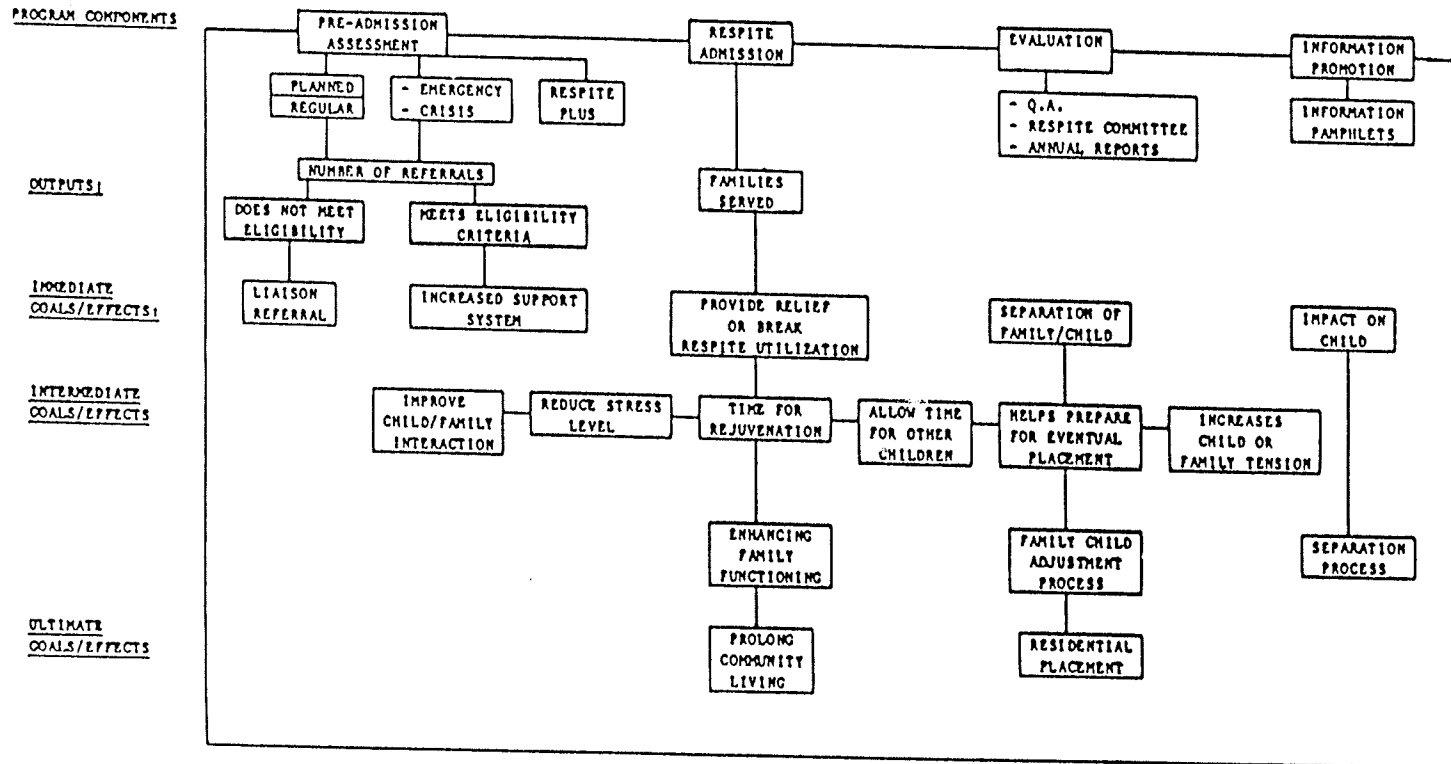


APPENDIX F

RESPITE PROGRAM MODEL

(Reconstructed from Interviews, Documents, & Respite Committee Meetings)

ST. AMANT CENTRE INC. MODEL OF PROGRAM STRUCTURE AND LOGIC



APPENDIX G. . . .

ST. AMANT RESPITE PROGRAM

PARENT SURVEY

INTRODUCTION:

Respite programs have been developed over the last few years to respond to the needs of families who are caring for disabled persons. Similarly, St. Amant has been operating a Respite Program for approximately 15 years to offer an "out of home" respite option to families.

In the past five years, there have been a number of changes implemented. Some have been legislated, such as the introduction of the Voluntary Placement Agreement (VPA) for children under the age of eighteen years. Other changes have been made to improve the day to day operation of the program. For instance, we now involve the family physician or pediatrician as the medical contact for respite admissions in order to maintain a "continuity of care" for the individual.

If you are using the program now, it is important for us to know how changes like these and how the program in general might be affecting you. It is also important for us to know what changes you would like to see in order that the program can better meet the needs of your particular situation.

If you have used the program in the past, but are not using it now, we would like to know why this might be and what your particular needs were at the time you used the program. Even if you are no longer using the Respite Program, your information will still be valuable.

We hope that this questionnaire will also provide you with the opportunity to provide comments and suggestions about what you feel is important aspects of respite care for families with disabled children and adults.

Again, this information will be treated as confidential in nature and in no way will it affect your use of the Respite Program.

GENERAL INSTRUCTIONS:

- * Most sections involve "circling" or "checking" your answer. Some sections ask for your comments or suggestions. If you do not have enough space, please feel free to continue your comments on the other side of the page. You may write additional comments whenever you wish to do so.
- * If you cannot answer the question, you can either mark N/A (not applicable); leave it blank; or state why you are unable to answer the question.
- * Please ignore the numbers beside the questions; they are for computer tabulation only.
- * When you have completed the questionnaire, just mail it in the enclosed pre-paid envelope by January 30, 1991.

To obtain a summary of the results you can phone . . . , to leave your name and address. The results should be tabulated by April or May, 1991.

Thank you for your time and interest in this survey.

PLEASE PROCEED

APPENDIX G

ST. AMANT CENTRE RESPITE PROGRAM

PARENT SURVEY

FOR STAFF USE ONLY

CODE # _____

PART A

In this first section, we would like to learn how you would generally rate the Respite services you received at St. Amant Centre. Please read each question carefully. CIRCLE YOUR ONE BEST ANSWER

PLEASE DO
NOT WRITE
IN THIS
SPACE

1. Did you get the kind of respite service you wanted?

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>
NO, DEFINITELY NOT	NO, NOT REALLY	YES, GENERALLY	YES, DEFINITELY

2/ _____

2. To what extent has our program met your needs for respite?

<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
ALMOST ALL OF MY NEEDS HAVE BEEN MET	MOST OF MY NEEDS HAVE BEEN MET	ONLY A FEW OF MY NEEDS HAVE BEEN MET	NONE OF MY NEEDS HAVE BEEN MET

3/ _____

3. If a friend were in need of respite, would you recommend the St. Amant Respite Program to him or her?

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>
NO, DEFINITELY NOT	NO, I DON'T THINK SO	YES, I THINK SO	YES, DEFINITELY

4/ _____

4. Have the services you received helped you to deal more effectively with your problems?

<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
YES, THEY HELPED A GREAT DEAL	YES, GENERALLY THEY HELPED	NO, THEY REALLY DIDN'T HELP	THEY DEFINITELY DID NOT HELP

5/ _____

5. In an overall, general sense, how satisfied are you with the quality of respite service you have received?

<u>4</u>	<u>3</u>	<u>2</u>	<u>1</u>
VERY SATISFIED	SATISFIED	DISSATISFIED	VERY DISSATISFIED

6/ _____

6. If you were to seek help again, would you come back to the St. Amant Respite Program?

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>
NO, DEFINITELY NOT	NO, I DON'T THINK SO	YES, I THINK SO	YES, DEFINITELY

7/ _____

*PLEASE CONTINUE

APPENDIX G

(2)

PART B

This section relates to more specific aspects of the Respite Program. We are interested in learning how you feel about the application process and various aspects of the admission itself.

PLEASE DO
NOT WRITE
IN THIS
SPACE

1. Did any of the following regulations or requirements make enrollment difficult or complicated? **PLEASE CHECK YOUR ANSWER**

	YES (2)	NO (1)
COMPLETION OF APPLICATION FORM	<input type="checkbox"/>	<input type="checkbox"/>
OBTAINING MEDICAL REPORT	<input type="checkbox"/>	<input type="checkbox"/>
OBTAINING SPECIMENS	<input type="checkbox"/>	<input type="checkbox"/>
SIGNING OF VOLUNTARY PLACEMENT AGREEMENT (under 18 years)	<input type="checkbox"/>	<input type="checkbox"/>
COMPLETION OF ORDER OF SUPERVISION (over 18 years)	<input type="checkbox"/>	<input type="checkbox"/>

COMMENTS/SUGGESTIONS: _____

8/

9/

10/

11/

12/

13/

2. In general, how satisfied were you with the interview and application process? **PLEASE CIRCLE YOUR ANSWER.**

4	3	2	1
VERY SATISFIED	SATISFIED	DISSATISFIED	VERY DISSATISFIED

COMMENTS/SUGGESTIONS: _____

14/

15/

3. In general, how satisfied were you with the tour and information provided to you during the application process?

4	3	2	1
VERY SATISFIED	SATISFIED	DISSATISFIED	VERY DISSATISFIED

COMMENTS/SUGGESTIONS: _____

16/

17/

4. Were you satisfied with your child's care during the respite stay or admission?

4	3	2	1
VERY SATISFIED	SATISFIED	DISSATISFIED	VERY DISSATISFIED

COMMENTS/SUGGESTIONS: _____

18/

19/

APPENDIX G

(3)

PLEASE CIRCLE YOUR ANSWER

PLEASE DO
NOT WRITE
IN THIS
SPACE

5. Were you satisfied with the physical surroundings or environment of the ward/unit where your child was admitted for respite?

4	3	2	1
VERY	SATISFIED	DISSATISFIED	VERY
SATISFIED			DISSATISFIED

20/

COMMENTS/SUGGESTIONS: _____

21/

6. Were you satisfied with the amount of activity available to your child during his/her stay on the unit/ward?

4	3	2	1
VERY	SATISFIED	DISSATISFIED	VERY
SATISFIED			DISSATISFIED

22/

COMMENTS/SUGGESTIONS: _____

23/

7. Were you satisfied with the interest taken by staff in helping you if you had questions or concerns during your child's stay on the ward/unit?

4	3	2	1
VERY	SATISFIED	DISSATISFIED	VERY
SATISFIED			DISSATISFIED

24/

COMMENTS/SUGGESTIONS: _____

25/

- 8a. When you call to request respite, are we able to meet your request for specific dates needed?

4	3	2	1
YES,	YES,	SOMETIMES	NO, NEVER
ALWAYS	FREQUENTLY		

26/

- b. When you call to request respite, are we able to meet your request for the amount of time needed?

4	3	2	1
YES,	YES,	SOMETIMES	NO, NEVER
ALWAYS	FREQUENTLY		

27/

COMMENTS/SUGGESTIONS: _____

28/

9. Would you like to see St. Amant develop a separate unit for respite rather than having children placed on the ward/units?

PLEASE CHECK YOUR ANSWER

☐ 3 YES ☐ 2 UNCERTAIN ☐ 1 NO

29/

COMMENTS/SUGGESTIONS: _____

30/

APPENDIX G

(4)

PART C

Respite is often seen as an important and essential service for families. In this section we are interested in learning how our Respite Program might affect your family.

Listed below are some statements about possible effects. Please indicate whether you strongly disagree, disagree, are uncertain, agree, or strongly agree with the statement. PLEASE CIRCLE YOUR ANSWER

PLEASE DO
NOT WRITE
IN THIS
SPACE

1. Respite reduces the stress in your family.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

31/

2. Using respite promotes a more positive relationship between child and the family.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

32/

3. Respite results in better overall family functioning, for instance, being able to get along better with one another.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

33/

4. Respite gives time to gain energy and rejuvenate.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

34/

5. Respite allows me to keep my child at home for longer. (i.e. It delays placement outside the home.)

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

35/

6. Respite can increase child or family tension.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

36/

7. Respite can help prepare for eventual placement.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

37/

APPENDIX G

(5)

PLEASE DO
DO NOT
IN THIS
SPACE

8. Do you have any comments on how respite benefits your family?

38/

9. Do you feel there are any negative effects on your family or child in using the St. Amant respite program?

☐ 3 YES

☐ 2 UNCERTAIN

☐ 1 NO

39/

PLEASE SPECIFY OR EXPLAIN ANY NEGATIVE EFFECTS: _____

40/

10. How might you spend or plan your time when your child is in for respite?

41/

PLEASE PROCEED TO PART D

APPENDIX G

(6)

PART D

In this section we are interested in learning how you heard about respite, why you have used respite, and about the other supports you might use. PLEASE CHECK ALL THAT APPLY TO YOU IN THIS SECTION.

1. How did you first hear about our program?

- | | |
|--|---|
| <input type="checkbox"/> 1 PHYSICIAN/PEDIATRICIAN | <input type="checkbox"/> 5 FAMILY/FRIENDS |
| <input type="checkbox"/> 2 CHILD AND FAMILY SERVICES | <input type="checkbox"/> 6 SAW RESPITE PAMPHLET |
| <input type="checkbox"/> 3 COMMUNITY SERVICE SOCIAL WORKER | |
| <input type="checkbox"/> 4 SOCIETY FOR MANITOBBANS WITH DISABILITIES | |
| <input type="checkbox"/> 7 OTHER: Please specify: _____ | |

2. Have you used our program in the last 12 months?

☐ 2 YES

If yes, please check all the answers in 2A that apply to your situation.

2A. I use respite

- ☐ 1 On a regular basis (at least 1x month)
- ☐ 2 For emergencies
- ☐ 3 Only occasionally
- ☐ 4 Because of special qualifications and training of staff at St. Amant.
- ☐ 5 Other: _____

☐ 1 NO

If no, please check all the answers in 2B that apply to your situation.

2B. I do not use respite because:

- ☐ 1 We use other forms of respite.
- ☐ 2 My child is in a foster home.
- ☐ 3 My child is in a group home.
- ☐ 4 My child is placed at St. Amant.
- ☐ 5 Transportation and distance problems.
- ☐ 6 Dissatisfaction with the availability of service.
- ☐ 7 Dissatisfaction with the physical environment.
- ☐ 8 Dissatisfaction with the quality of care.
- ☐ 9 Enrolled in the program "just in case the need arises" but have not used the program.
- ☐ 10 Other: _____

PLEASE DO NOT WRITE IN THIS SPACE

42/ 46/

43/ 47/

44/

45/

48/

49/

50/ 55/

51/ 56/

52/ 57/

53/ 58/

54/ 59/

60/

61/

62/

63/

64/

*PLEASE CONTINUE THIS SURVEY EVEN IF YOU DO NOT USE ST. AMANT RESPITE

APPENDIX G

(7)

3. What other forms of respite are available to you?

- ☐ 1 Friends ☐ 2 Family ☐ 3 Community Respite Services
- ☐ 4 Respite through Department of Family Services Worker
(Community Services Social Worker)
- ☐ 5 Respite through Child and Family Services (C.F.S.)
- ☐ 6 Other: Please specify _____

PLEASE DO
NOT WRITE
IN THIS
SPACE
65/
66/
67/
68/
69/
70/

4. If you had a preference, what form of respite would you use?

- ☐ 1 In Home Respite Care
- ☐ 2 Out-of-Home Respite Care
- ☐ 3 A combination of both in home and out-of-home respite care.

71/

5. Please specify which services you are currently receiving for your family and/or child. Please check "yes" if you are receiving the service. Please check "no" if you do not.

SERVICE	(2)	YES	NO	(1)		(2)	YES	NO	(1)	
Pre-school/Daycare					Respite/sitter service					72/ 79/
School					Homemaking					73/ 80/
Physiotherapy					Special Attendant Service					74/ 81/
Occupational Therapy					Adult Workshop Service					75/ 82/
Recreation Program					Other: _____					76/ 83/
Family Counselling										77/
										78/

6. Of all the service(s) you have received, past or present, which have been the most helpful? Why?

84/

7. Of all the service(s) you have received, past or present, which have been the least helpful? Why?

85/

8. What service(s) do you need but are unable to get?

86/

9. When you use respite, are you able to arrange for your child to continue his/her regular program?

- ☐ 4 YES ☐ 3 UNCERTAIN ☐ 2 NO ☐ 1 NOT APPLICABLE OR HAS NO PROGRAM

87/

PLEASE CONTINUE

APPENDIX G

(8)

PLEASE DO
NOT WRITE
IN THIS
SPACE

PART E

In this section we would like to learn about the special needs of persons who are admitted under our Respite Program. PLEASE PUT A CHECK BESIDE THE ONE WHICH MOST ACCURATELY DESCRIBES YOUR CHILD ON HIS/HER LAST ADMISSION FOR RESPITE.

What was your child's approximate age on his/her last admission? _____ 88/

What unit/ward was your child last admitted? _____ 89/

Vision:

☐ 4 GOOD 90/

☐ 3 SOME IMPAIRMENT

☐ 2 SOME IMPAIRMENT - NEEDS GLASSES

☐ 1 NO FUNCTIONAL VISION (assessed as blind)

Hearing:

☐ 4 GOOD 91/

☐ 3 SOME IMPAIRMENT

☐ 2 SOME IMPAIRMENT - NEEDS HEARING AIDS

☐ 1 NO FUNCTIONAL HEARING (assessed as deaf)

Communication:

☐ 7 HAS GOOD SPEECH AND UNDERSTANDING 92/

☐ 6 USES SPEECH BUT LIMITED OR DELAYED

☐ 5 SIGN LANGUAGE

☐ 4 USES SYMBOLS OR BLISS

☐ 3 GESTURES OR BODY LANGUAGE

☐ 2 SEVERELY DELAYED IN SPEECH AND UNDERSTANDING

☐ 1 NOT YET DETERMINED

Seizures:

☐ 3 NO 93/

☐ 2 YES, CONTROLLED WITH MEDICATION

☐ 1 YES, NOT CONTROLLED WITH MEDICATION

APPENDIX G

(9)

PLEASE DO
NOT WRITE
IN THIS
SPACE

Ambulation

- ☐ 5 GOOD WALKING SKILLS
- ☐ 4 NEEDS HELP OR ASSISTANCE
- ☐ 3 USES EQUIPMENT (walker, crutches)
- ☐ 2 USES WHEELCHAIR (independent)
- ☐ 1 USES WHEELCHAIR (needs help or supervision)

94/

Dressing:

- ☐ 4 CAN DRESS SELF
- ☐ 3 NEEDS VERBAL REMINDERS
- ☐ 2 NEEDS SOME PHYSICAL ASSISTANCE
- ☐ 1 COMPLETELY DEPENDENT ON OTHERS

95/

Eating:

- ☐ 4 CAN FEED SELF
- ☐ 3 NEEDS VERBAL REMINDERS
- ☐ 2 NEEDS SOME PHYSICAL PROMPTING OR ASSISTANCE OR SUPERVISION
- ☐ 1 COMPLETELY DEPENDENT ON OTHERS FOR FEEDING.

96/

Behaviour:

- a) Destructive Behaviour?
 - ☐ 1 YES, OFTEN ☐ 2 OCCASIONALLY ☐ 3 NO, NOT AT ALL
- b) Aggressive toward others (biting, hitting, pinching, hair pulling, others)?
 - ☐ 1 YES, OFTEN ☐ 2 OCCASIONALLY ☐ 3 NO, NOT AT ALL
- c) Self Abusive?
 - ☐ 1 YES, OFTEN ☐ 2 OCCASIONALLY ☐ 3 NO, NOT AT ALL
- d) Self-stimulating behaviours (e.g., rocking)?
 - ☐ 1 YES, OFTEN ☐ 2 OCCASIONALLY ☐ 3 NO, NOT AT ALL
- e) Hyperactive?
 - ☐ 1 YES, OFTEN ☐ 2 OCCASIONALLY ☐ 3 NO, NOT AT ALL
- f) Running Away?
 - ☐ 1 YES, OFTEN ☐ 2 OCCASIONALLY ☐ 3 NO, NOT AT ALL

97/

98/

99/

100/

101/

102/

APPENDIX G

(10)

PLEASE DO
NOT WRITE
IN THIS
SPACE

Safety:

Is your child able to protect him/herself if approached by another child who is aggressive?

- ☐ 3 YES ☐ 2 UNCERTAIN ☐ 1 NO

103/

Recreation and Leisure Skills:

- ☐ 4 GOOD PLAY SKILLS
☐ 3 CAN PLAY OR DO ACTIVITIES IF GUIDED TO JOIN OTHERS
☐ 2 NEEDS PHYSICAL HELP OR CONSTANT SUPERVISION
☐ 1 NO PLAY SKILLS

104/

Attention and Concentration Skills:

- ☐ 4 GOOD ATTENTION SPAN
☐ 3 NEEDS VERBAL REMINDERS WHEN DOING TASKS/ACTIVITIES
☐ 2 NEEDS ACTIVE PHYSICAL AND VERBAL GUIDANCE
☐ 1 SEVERELY LIMITED IN ABILITY TO DO AN ACTIVITY/TASK

105/

Ability to Adapt to Changes:

- ☐ 4 GOOD ABILITY TO ADAPT TO CHANGES
☐ 3 SOME DIFFICULTY WHEN ROUTINE IS CHANGED
☐ 2 SOME BEHAVIOUR REACTIONS WITH CHANGE (needs longer adjustment period)
☐ 1 SEVERE DIFFICULTY WITH TRANSITION OR CHANGES

106/

PLEASE PROCEED TO FINAL SECTION, PART F

APPENDIX G

(11)

PART F

Finally, we would like to know just a little about you so that we will be able to understand how various people feel about the issues we have been examining. THIS INFORMATION WILL BE TREATED AS CONFIDENTIAL. PLEASE CHECK YOUR ANSWER

Family Residency:

☐ 1 URBAN (City of Winnipeg) ☐ 3 RURAL (within 50 miles of the city) 107/

☐ 2 RURAL (over 50 miles from Winnipeg)

What is your postal code: _____

PLEASE DO
NOT WRITE
IN THIS
SPACE

108/

Family Type:

☐ 1 TWO PARENTS (biological parents) ☐ 2 FOSTER PARENTS 109/

☐ 4 OTHER: _____ ☐ 3 SINGLE PARENT

Mother's Age

☐ 1 under 20 years

☐ 2 20 - 29

☐ 3 30 - 39

☐ 4 40 - 49

☐ 5 50 - 59

☐ 6 60 & OVER

Father's Age

☐ 1 under 20 years

☐ 2 20 - 29

☐ 3 30 - 39

☐ 4 40 - 49

☐ 5 50 - 59

☐ 6 60 - 69

110/ 111/

How many other children are in the home? _____

112/

What are their ages? _____

113/

Is anyone else living in the family home disabled?

☐ YES

☐ NO

114/

What was the approximate total income last year (1990) in your household?

☐ 1 UNDER 19,999

☐ 4 \$40,000 - \$49,999

☐ 2 \$20,000 - \$29,999

☐ 5 \$50,000 or more

☐ 3 \$30,000 - 39,999

115/

APPENDIX G

(12)

PLEASE DO
NOT WRITE
IN THIS
SPACE

Employment:

- ☐ 1 BOTH PARENTS WORKING FULL TIME
- ☐ 2 ONE PARENT WORKING FULL TIME
- ☐ 3 ONE PARENT WORKING FULL TIME AND ONE PARENT WORKING PART TIME
- ☐ 4 NEITHER EMPLOYED
- ☐ 5 ON PENSION
- ☐ 6 OTHER - PLEASE SPECIFY: _____

116/

Were you born in Canada?

- ☐ 1 YES ☐ 2 NO

117/

If no, what was your country of birth? _____

118/

How long have you been in Canada? _____

119/

People often see themselves belonging to ethnic groups such as aboriginal Canadian, Polish, Vietnamese, Filipino, etc. How would you describe your ethnic affiliation?

120/

Who answered this questionnaire? ☐ 1 MOTHER ☐ 2 FATHER
☐ 3 BOTH PARENTS ☐ 4 OTHER

121/

Approximately how long did it take you to complete this questionnaire? _____

122/

We are grateful to you for taking the time to complete this questionnaire.

If you wish to receive the results of the survey please provide your name and address, or if you do not wish to state your name on the survey, please phone 256-4301, ext. 211 or 234 and leave your name and address.

APPENDIX H . . .

ST. AMANT RESPITE PROGRAM

STAFF SURVEY

INTRODUCTION:

In conjunction with the St. Amant Centre and as part of my graduate studies at the University of Manitoba, I am conducting an evaluation of the St. Amant Respite Program.

The St. Amant Respite Program has been operating for approximately 15 years. It serves as one of many types of respite services intended to provide support to families who care for disabled persons. Its uniqueness is in its expansive mandate: it offers "out of home" respite to both children and adults with various levels of disability in a setting where staff have experience and training to work with individuals with disabilities.

In the past 4 - 5 years there have been a number of changes implemented. Some have been legislated, such as the introduction of the Voluntary Placement Agreement for children under the age of 18 years. Other changes have been made to improve the day to day operation of the program, for instance, we now involve the family physician or pediatrician as the medical contact during respite admission in order to maintain a continuity of care for the individual.

It is important to know how changes such as these and how the program in general are affecting you and your work. It is also important for us to understand how respite affects the individuals admitted for respite and how those who live at St. Amant respond. Your perceptions and suggestions will provide information that can be used to modify and/or enhance the program.

This information will be treated as confidential in nature and you need not sign your name to the form. A summary of the results will be available in the Spring of 1991.

Please take time to complete the questionnaire. Although it might appear lengthy, it should take approximately 10 - 20 minutes to complete depending on your involvement with the Program.

GENERAL INSTRUCTIONS:

Most questions involve circling or checking your answer. Some sections ask for your comments or suggestions. If you do not have enough space, use the other side of the page. You may write in additional comments whenever you wish to do so. If you cannot answer the question, leave it blank; mark it N/A (not applicable); or state why you are unable to answer it.

You may discuss questions with each other but please complete the questionnaire individually. This questionnaire should be returned by December 31, 1990. You can direct it to Jo Verstraete through the Social Work Department mail.

Thank you for your time and participation in this survey.

Jo Verstraete
M.S.W. Student
December 18, 1990

APPENDIX H . . .

ST. AMANT CENTRE INC.

CODE # _____

NURSING SERVICE

RESPITE EVALUATION QUESTIONNAIRE

In this section, we are interested in learning about various aspects of the pre-admission process and the admission procedures as they apply to the Respite Program. Please read the questions carefully and **CIRCLE YOUR ANSWER**.

PLEASE DO
NOT WRITE
IN THIS
SPACE

1. Do any of the following regulations and requirements make your work with the Respite Program more complicated or difficult?

a) contacting physicians to get orders for medications?
 1 2 3 4
 NOT AT ALL OCCASIONALLY FREQUENTLY ALWAYS

2/ _____

b) obtaining pre-admission specimen results?
 1 2 3 4
 NOT AT ALL OCCASIONALLY FREQUENTLY ALWAYS

3/ _____

c) obtaining consents from parents?
 1 2 3 4
 NOT AT ALL OCCASIONALLY FREQUENTLY ALWAYS

4/ _____

COMMENTS/SUGGESTIONS: _____

5/ _____

2. Have you been involved with families in the pre-admission interview and application process? (This pertains to the "Pre-Admission Nursing Assessment Form" NOT the "Nursing Information" taken at the time of admission). **PLEASE CHECK YOUR ANSWERS**

☐ 1 YES (If yes, please go to 2A)

☐ NO 2 (If no, please go to 2B)

6/ _____

- 2A. When you have taken the Pre-Admission Nursing Application, do you always complete the nursing information on the first visit?

☐ 4 YES, ALWAYS

PLEASE GO
TO 2C

☐ 3 MOST OF THE TIME

☐ 2 SOMETIMES

☐ 1 NO, NEVER (IF NO, PLEASE GO
TO #3)

7/ _____

APPENDIX H. . .

(2)

PLEASE DO
NOT WRITE
IN THIS
SPACE

2B. Have you been involved in taking the nursing information at the time of the first admission?

8/ _____

☐ YES (If yes, answer 2C)

☐ NO (If no, answer #3)

2C. Do you read the information on the Nursing, Social Work and Medical application thoroughly before meeting the family and child on the first admission?

☐ 4 YES, ALWAYS

☐ 3 MOST OF THE TIME

☐ 2 SOMETIMES

☐ 1 NO, NEVER

9/ _____

PLEASE GO TO #3

PLEASE CIRCLE YOUR ANSWER

3. Is the "complete" Respite Application Form kept on the ward chart?

1 NO 2 SOMETIMES 3 MOST OF THE TIME 4 ALWAYS

10/ _____

4. Have you read the Policy and Procedure information on the Respite Program in the Nursing Manual?

1 NO, NOT AT ALL 2 SOME OF IT 3 MOST OF IT 4 YES, COMPLETELY

11/ _____

5. At the time of the first admission, do you find it helpful to have a social worker present with the family?

1 NO, NOT AT ALL 2 OCCASIONALLY 3 FREQUENTLY 4 YES, DEFINITELY

12/ _____

COMMENTS/SUGGESTIONS: _____

13/ _____

6. Are you satisfied with the kind of activities available on the ward for the individual admitted for respite?

1 VERY DISSATISFIED 2 DISSATISFIED 3 SATISFIED 4 VERY SATISFIED

14/ _____

COMMENTS/SUGGESTIONS: _____

15/ _____

7. What kinds of activities are available on your ward to individuals who come in for respite?

16/ _____

APPENDIX H . . .

(3)

PLEASE DO
NOT WRITE
IN THIS
SPACE

8. How often do you need to consult with other departments at the Centre regarding Respite admissions? (i.e., Recreation, O.T., P.T., Speech, Psychology, Medical Staff, Pharmacy, etc. DO NOT INCLUDE SOCIAL WORK)

1 2 3 4
NOT AT ALL OCCASIONALLY FREQUENTLY YES, ALWAYS

17/ _____

9. What would you consult about?

18/ _____

10. How often do you need to consult with Social Work at St. Amant regarding St. Amant admissions?

1 2 3 4
NOT AT ALL OCCASIONALLY FREQUENTLY YES, ALWAYS

19/ _____

COMMENTS/SUGGESTIONS: _____

20/ _____

11. Do you generally find St. Amant Social Workers available to answer your questions or to consult regarding Respite admissions?

1 2 3 4
NOT AT ALL NOT READILY FREQUENTLY ALWAYS AVAILABLE
AVAILABLE AVAILABLE AVAILABLE

21/ _____

If not available, what is the nature of the difficulty?

22/ _____

12. Are there any gaps in service, issues or procedural difficulties with the Respite Program that you wish to identify?

23/ _____

13. Do you have any suggestions that might facilitate your involvement with the Respite Program?

24/ _____

13. Do you have any suggestions that might enhance the service or make the program more effective?

25/ _____

APPENDIX H . . .

NURSES AND NURSING ASSISTANTS

CODE: _____

PLEASE DO
NOT WRITE
IN THIS
SPACE

PART 2

In this section we are interested in learning about the possible effects of Respite admissions on the individuals admitted as well as the individuals that live at St. Amant. Listed below are some statements about possible effects. Please indicate whether you strongly disagree, disagree, are uncertain, agree, or strongly agree with the statement.

PLEASE CIRCLE YOUR ANSWER

1. Respite is a worthwhile service for families.

1	2	3	4	5
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

26/ _____

2. I would recommend St. Amant respite to a friend of family if there was a need for respite.

1	2	3	4	5
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

27/ _____

3. Respite reduces stress in families.

1	2	3	4	5
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

28/ _____

4. In general, the individuals admitted for respite benefit from the program.

1	2	3	4	5
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

29/ _____

5. There are negative effects on the individual admitted.

1	2	3	4	5
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

30/ _____

6. The lives of individuals who live at St. Amant are enhanced by respite admissions.

1	2	3	4	5
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

31/ _____

7. Do you have any comments about the effects of the respite program on families, individuals admitted, or residents of St. Amant Centre?

32/ _____

APPENDIX H

(5)

PLEASE DO
NOT WRITE
IN THIS
SPACE

8. Do you believe the ward-like environment has an affect on the individual being admitted? **PLEASE CHECK YOUR ANSWER**

☐ 3 YES, DEFINITELY ☐ 2 UNCERTAIN ☐ 1 NO, DEFINITELY NOT

Please explain your answer: _____

33/ _____

34/ _____

9. Would you like to see St. Amant develop a separate unit for respite admission rather than have individuals integrated on the ward? **PLEASE CHECK YOUR ANSWER?**

☐ 3 YES, DEFINITELY ☐ 2 UNCERTAIN ☐ 1 NO, DEFINITELY NOT

Please explain your answer. _____

35/ _____

36/ _____

10. Do you have any other comments or suggestions for the Respite Program?

37/ _____

PART 3

Finally, would you provide us with the following information:

What unit/ward are you currently working? _____

38/ _____

What is your department? _____

39/ _____

THANK YOU FOR YOUR TIME IN COMPLETING THIS QUESTIONNAIRE.

PLEASE RETURN THIS FORM IN AN "INTER-DEPARTMENTAL" ENVELOPE TO:
JO VERSTRAETE, SOCIAL WORK DEPARTMENT

APPENDIX I

ST. AMANT RESPITE PROGRAM

STAFF SURVEY

INTRODUCTION:

In conjunction with the St. Amant Centre and as part of my graduate studies at the University of Manitoba, I am conducting an evaluation of the St. Amant Respite Program.

The St. Amant Respite Program has been operating for approximately 15 years. It serves as one of many types of respite services intended to provide support to families who care for disabled persons. Its uniqueness is in its expansive mandate: it offers "out of home" respite to both children and adults with various levels of disability in a setting where staff have experience and training to work with individuals with disabilities.

In the past 4 - 5 years there have been a number of changes implemented. Some have been legislated, such as the introduction of the Voluntary Placement Agreement for children under the age of 18 years. Other changes have been made to improve the day to day operation of the program. For instance, we now involve the family physician or pediatrician as the medical contact during respite admission in order to maintain a continuity of care for the individual.

It is important to know how changes such as these and how the program in general are affecting you and your work. It is also important for us to understand how respite affects the individuals admitted for respite and how those who live at St. Amant respond. Your perceptions and suggestions will provide information that can be used to modify and/or enhance the program.

This information will be treated as confidential in nature and you need not sign your name to the form. A summary of the results will be available in the Spring of 1991.

Please take time to complete the attached questionnaire. Although it might appear lengthy, it should take approximately 10 - 15 minutes to complete depending on your involvement with the Program.

GENERAL INSTRUCTIONS:

- * Most questions involve circling or checking your answer. Some sections ask for your comments or suggestions. If you do not have enough space, use the other side of the page. You may write in additional comments whenever you wish to do so.
- * If you cannot answer the question, leave it blank; mark it N/A (not applicable); or state why you are unable to answer it.
- * Please ignore the numbers beside the questions; they are for computer tabulation only.
- * This questionnaire should be returned by January 30, 1991. You can direct it to Jo Verstraete through the Social Work Department mail.

Thank you for your time and participation in this survey.

Jo Verstraete
January 11, 1991

PLEASE PROCEED

APPENDIX I

ST. AMANT CENTRE INC.

CODE: _____

RESPITE EVALUATION SURVEY

MEDICAL/CLINICAL DEPARTMENTS

In this section, we would like to learn to what extent departments are involved in the Respite Program. Please read the questions carefully and CIRCLE YOUR ANSWER.

PLEASE DO NOT WRITE IN THIS SPACE

1. Have you been contacted by ward staff or the Social Work Department for consultation on respite admissions?

1	2	3	4
NO, NEVER	YES, APPROXIMATELY 2 - 3 TIMES A YEAR	YES, APPROXIMATELY 1 - 2 TIMES A MONTH	YES, AT LEAST WEEKLY

2/ _____

2. To what degree do you think this interferes with your work or services to other residents at the Centre?

1	2	3	4
NOT AT ALL	TO A MILD DEGREE	TO A MODERATE DEGREE	TO A GREAT DEGREE

3/ _____

COMMENTS/SUGGESTIONS: _____

4/ _____

3. Do you keep records on your consultations/involvement with respite admissions?

1	2	3
NO, NEVER	YES, CERTAIN ASPECTS	YES, ALWAYS

5/ _____

4. Do you think you need to develop a system of records for respite admissions?

1	2	3
NO, NOT AT ALL	YES, PERHAPS	YES, DEFINITELY

6/ _____

IF YES, PLEASE SPECIFY: _____

7/ _____

5. What kind of service would you provide when you are consulted for respite. (CHECK ALL ANSWERS THAT APPLY TO YOUR SITUATION)

	NO	YES		NO	YES	
INFORMATION	<input type="checkbox"/> 1	<input type="checkbox"/> 2	EQUIPMENT NEEDS	<input type="checkbox"/> 1	<input type="checkbox"/> 2	8/ 11/
ASSESSMENT	<input type="checkbox"/> 1	<input type="checkbox"/> 2	SUGGESTIONS FOR MANAGEMENT	<input type="checkbox"/> 1	<input type="checkbox"/> 2	9/ 12/
REFERRAL	<input type="checkbox"/> 1	<input type="checkbox"/> 2	LIAISON WITH OTHER AGENCIES	<input type="checkbox"/> 1	<input type="checkbox"/> 2	10/ 13/
OTHER: (Please specify) _____						14/

APPENDIX I

(2)

PLEASE DO
NOT WRITE
IN THIS
SPACE

6. Do you feel there are individuals who would benefit from services from your department during respite admissions?

NO 1 ☐

UNCERTAIN 2 ☐

YES 3 ☐

15/

If yes, please specify how: _____

16/

7. Are there any gaps in service, issues, or procedural difficulties with the Respite Program that you wish to identify?

17/

8. Do you have any suggestions that may enhance the service or make the program more effective?

18/

PLEASE PROCEED TO PART 2

APPENDIX I

(3)

PART 2

In this section we are interested in learning about the possible effects of Respite admissions on the individuals admitted as well as the individuals that live at St. Amant. Listed below are some statements about possible effects. Please indicate whether you strongly disagree, disagree, are uncertain, agree, or strongly agree with the statement.

PLEASE CIRCLE YOUR ANSWER

1. Respite is a worthwhile service for families.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

PLEASE DO
NOT WRITE
IN THIS
SPACE

19/

2. I would recommend the St. Amant Respite Program to a friend or family if there was a need for respite.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

20/

3. Respite reduces stress in families.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

21/

4. In general, the individuals admitted for respite benefit from the program.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

22/

5. There are negative effects on the individual admitted for Respite.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

23/

6. The lives of individuals who live at St. Amant are enhanced by respite admissions.

<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
STRONGLY DISAGREE	DISAGREE	UNCERTAIN	AGREE	STRONGLY AGREE

24/

7. Do you have any other comments about the effects of the respite program on families, individuals admitted, or residents of St. Amant Centre?

25/

APPENDIX I

(4)

PLEASE DO
NOT WRITE
IN THIS
SPACE

8. Do you believe the ward-like environment has an affect on the individual being admitted? **PLEASE CHECK YOUR ANSWER**

☐ 3 YES, DEFINITELY ☐ 2 UNCERTAIN ☐ 1 NO, DEFINITELY NOT

Please explain your answer: _____

26/

27/

9. Would you like to see St. Amant develop a separate unit for respite admission rather than have individuals integrated on the ward? **PLEASE CHECK YOUR ANSWER?**

☐ 3 YES, DEFINITELY ☐ 2 UNCERTAIN ☐ 1 NO, DEFINITELY NOT

Please explain your answer. _____

28/

29/

10. Do you have any other comments or suggestions for the Respite Program?

30/

PART 3

Finally, would you specify your department. Please check your answer.

01 ☐ MEDICAL STAFF

08 ☐ SPEECH/LANGUAGE

02 ☐ NURSING ADMINISTRATION

09 ☐ RECREATION

03 ☐ CLINICAL RECORDS

10 ☐ VOLUNTEER

04 ☐ NUTRITION/DIETARY

11 ☐ PHARMACY

05 ☐ PSYCHOLOGY

12 ☐ SOCIAL WORK

06 ☐ PHYSIOTHERAPY

13 ☐ OTHER: _____

07 ☐ OCCUPATIONAL THERAPY

31/

THANK YOU FOR YOUR TIME AND INTEREST IN COMPLETING THIS QUESTIONNAIRE.

PLEASE RETURN THIS FORM TO: JO VERSTRAETE, SOCIAL WORK DEPARTMENT

APPENDIX J

TABLE 4.6.1

DISTRIBUTION OF EFFECTS

PARENTS PERCEPTIONS OF EFFECTS AND BENEFITS OF RESPIRE

EFFECTS/ BENEFITS	1 STRONGLY DISAGREE	2 DISAGREE	3 UNCERTAIN	4 AGREE	5 STRONGLY AGREE	PERCENT AGREEMENT (4 & 5)
Reduces Stress (N=16)	*	*	4.3%	39.1%	56.5%	95.6%
Promotes Positive Relationship (N=48)	*	4.2%	18.8	45.8	31.3	77.1
Improves Family Functioning (N=46)	*	2.2	17.4	52.2	28.3	80.5
Time to Regain Energy (N=47)	*	*	4.3	29.8	66.0	96.8
Child at home longer longer (N=46)	*	10.9	19.6	24.0	45.7	69.7
Increases from Tension (N=46)	30.4	37.0	21.7	10.6	*	10.6
Helps Prepare for Placement (N=47)	*	2.1	6.4	51.1	40.4	91.5

*NOTE: Rows may not add to 100% due to rounding off.

Respite Program Client Characteristics - Gender

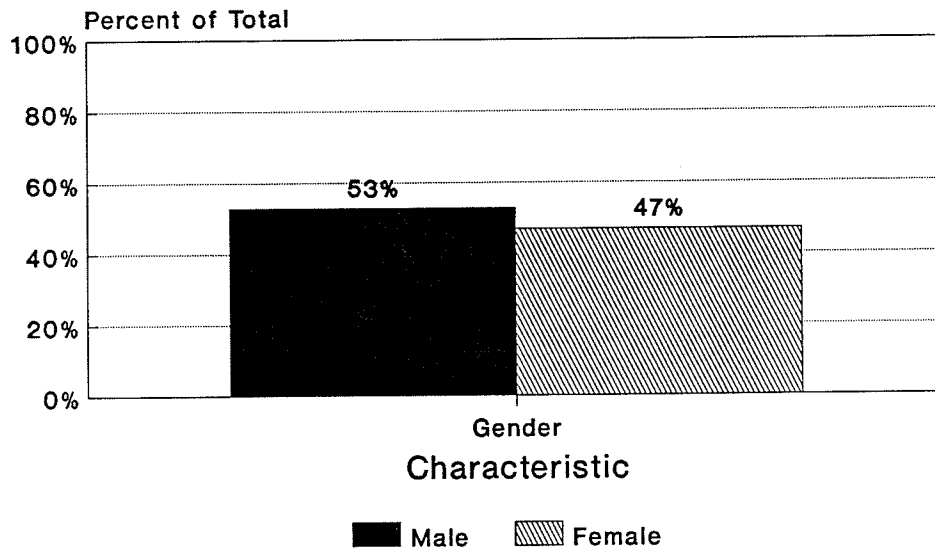


Figure 4.1

Respite Program Client Characteristics - Age

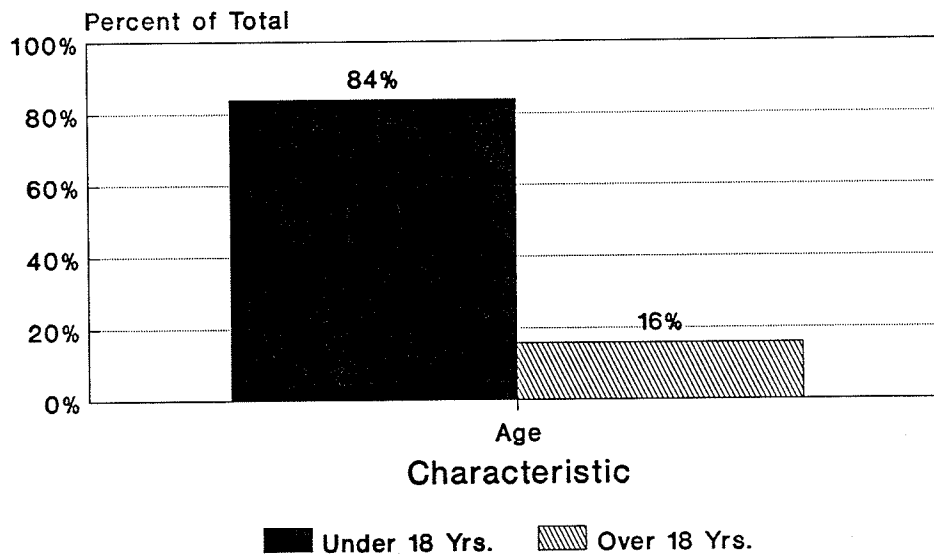


Figure 4.2

Respite Program Client Characteristics - Seizures

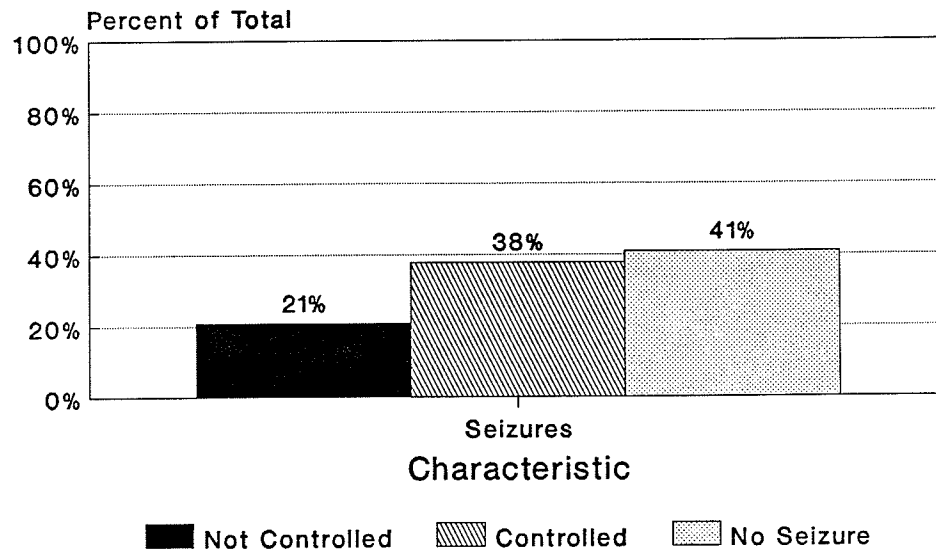


Figure 4.3

Respite Program Client Characteristics - Sensory

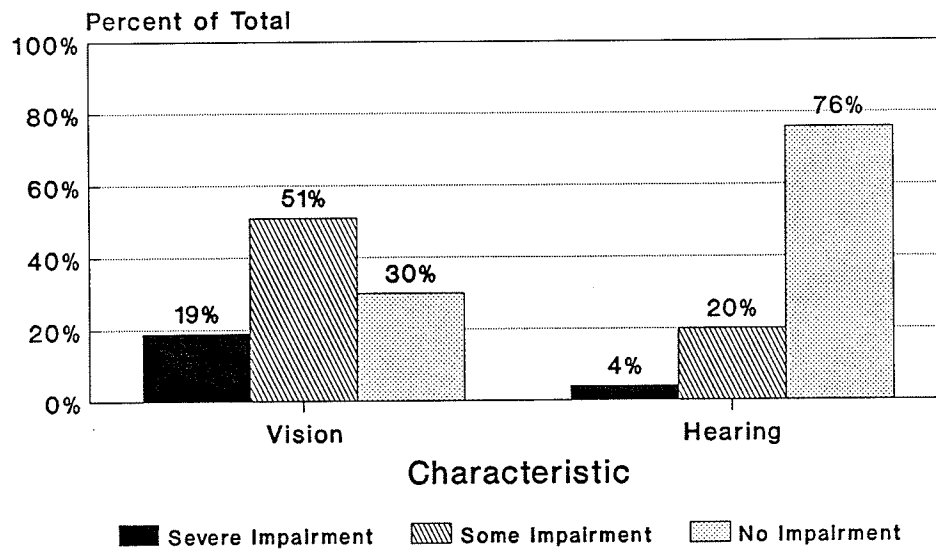


Figure 4.4

Respite Program Client Characteristics - Communication

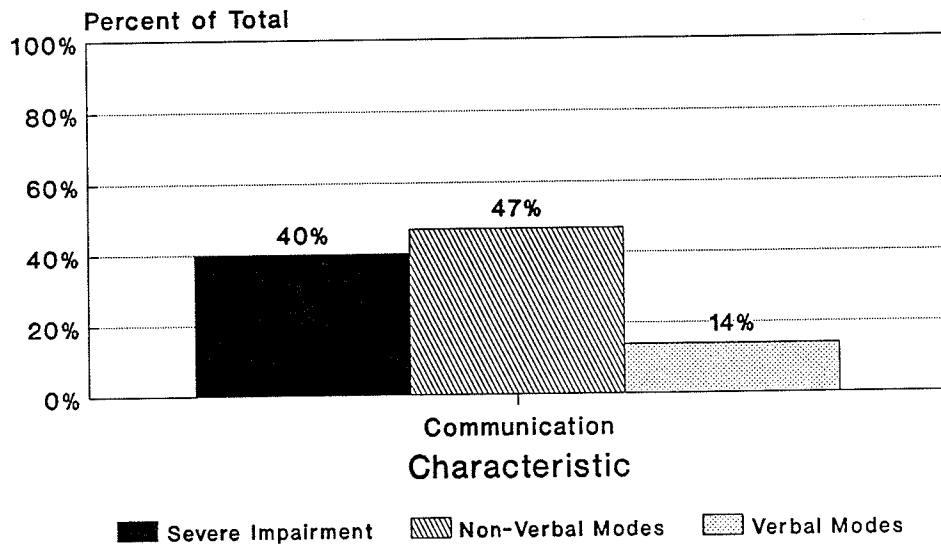


Figure 4.5

Respite Program Client Characteristics Activities of Daily Living

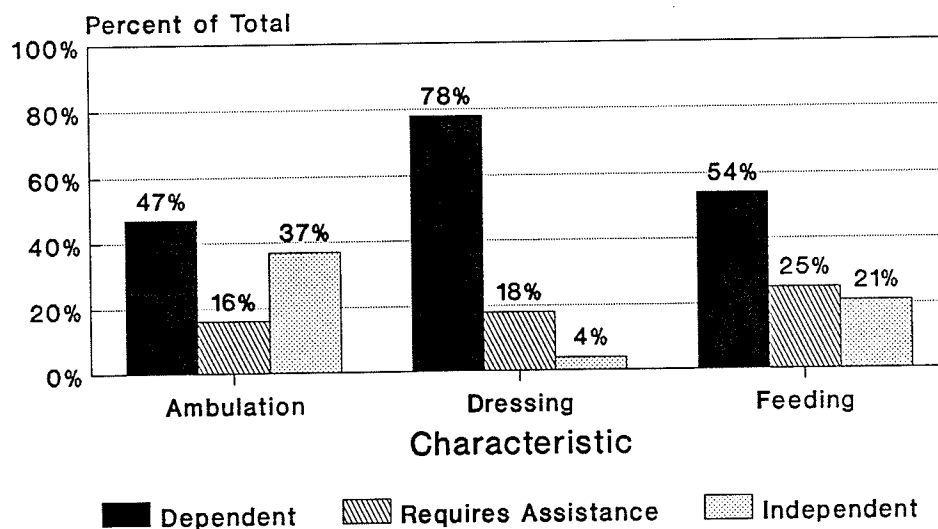


Figure 4.6

Respite Program Client Characteristics Maladaptive Behaviour

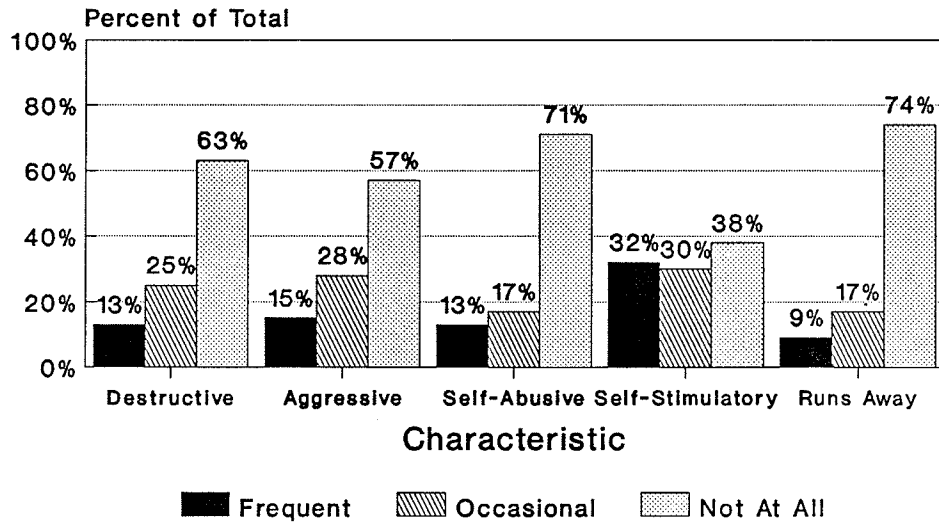


Figure 4.7

Respite Program Client Characteristics Adaptive Behaviour

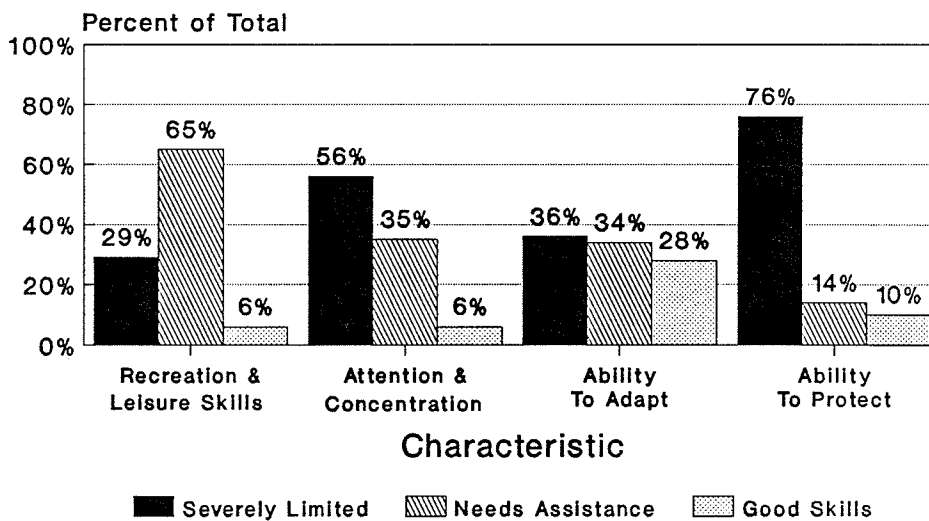


Figure 4.8

APPENDIX L

BREAKDOWN OF NUMBER OF ADMISSIONS

<u># OF TIMES ADMITTED (1987-1990)</u>	<u>NUMBER</u>	<u>PERCENT</u>
00 =	3	6.1 %
01 =	14	28.6 %
02 =	6	12.2 %
03 =	1	2.0 %
04 =	6	12.2 %
05 =	3	6.1 %
06 =	6	12.2 %
07 =	1	2.0 %
08 =	2	4.1 %
09 =	1	2.0 %
11 =	1	2.0 %
14 =	2	4.1 %
17 =	1	2.0 %
31 =	1	2.0 %
37 =	1	2.0 %
	-----	-----
Total	49	100.0 %

MEAN: 5.4 ADMISSIONS OVER 4 YEARS (1987-1990)

MEDIAN: 4 ADMISSIONS OVER 4 YEARS (1987-1990)

APPENDIX M

BREAKDOWN OF NUMBER OF DAYS SPENT IN RESPITE

<u>TOTAL # OF DAYS IN RESPITE</u>	<u>NUMBER</u>	<u>PERCENT</u>
000 =	2	4.1 %
002 =	1	2.0 %
003 =	2	4.1 %
005 =	1	2.0 %
007 =	2	4.1 %
008 =	3	6.1 %
010 =	1	2.0 %
011 =	2	4.1 %
012 =	1	2.0 %
016 =	3	6.1 %
020 =	3	6.1 %
027 =	1	2.0 %
029 =	1	2.0 %
030 =	2	4.1 %
032 =	2	4.1 %
033 =	1	2.0 %
034 =	1	2.0 %
035 =	1	2.0 %
045 =	1	2.0 %
048 =	1	2.0 %
050 =	2	4.1 %
054 =	1	2.0 %
060 =	1	2.0 %
070 =	2	4.1 %
071 =	1	2.0 %
079 =	1	2.0 %
092 =	1	2.0 %
107 =	1	2.0 %
113 =	1	2.0 %
119 =	1	2.0 %
128 =	1	2.0 %
145 =	1	2.0 %
146 =	1	2.0 %
171 =	1	2.0 %
217 =	1	2.0 %
Total	49	100.0 %

MEAN: 47.35 DAYS SPENT IN RESPITE OVER 4 YEARS (1987-1990)

MEDIAN: 30 DAYS SPENT IN RESPITE OVER 4 YEARS (1987-1990)

APPENDIX N...

SOCIAL WORK DEPARTMENT ACTIVITY SHEET FOR RESPITE PROGRAM

ST. AMANT CENTRE INC.

NEW REFERRAL/TIME SPENT (Time in minutes)

NAME OF CHILD OR FAMILY	INQUIRY	Tour/Information INTAKE	INTAKE COORD.	PRESENT. A & D	FIRST ADM.
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					
11.					
12.					
13.					
14.					
15.					
16.					
17.					
18.					
19.					
20.					

ADMINISTRATION TIME (Specify Activity and Time Spent)

1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	

ST. AMANT CENTRE INC.
CURRENT RESPITE USERS REQUESTS
MARCH 11 - APRIL 6, 1991

FAMILY/CHILD NAME	UNIT	COORDINATING REQUESTS/ACTIVITIES	SUPPORTIVE Time/Minute	NEEDS MET (Check /)			
				YES	NO	IF BED AVAILABLE	RESCHEDU
1.							
2.							
3.							
4.							
5.							
6.							
7.							
8.							
9.							
10.							
11.							
12.							
13.							
14.							
15.							
16.							
17.							
18.							
19.							
20.							
21.							
22.							
23.							
24.							
25.							

APPENDIX N

SOCIAL WORK DEPARTMENT ACTIVITY SHEET FOR RESPITE PROGRAM

RESPITE PROGRAM EVALUATIONRESPITE COMMITTEE

Generally, the purpose of the Evaluation Committee was to involve representatives from various program levels such as administration, service delivery, and consumer levels to be involved in the evaluation process.

PLEASE CHECK YOUR ANSWERS

1. From your perspective, do you think an Evaluation Committee is useful for:

N=7

- a) developing questions for evaluation?

7
YES

0
UNCERTAIN

0
NO

- b) increasing the likelihood that the evaluation is relevant and useful?

7
YES

0
UNCERTAIN

0
NO

2. Would you recommend this approach for evaluation to others?

N=6

5
YES

1
UNCERTAIN

0
NO

3. Do you think you had sufficient opportunity to put your thoughts and issues forward for discussion during the meetings?

N=7

6
YES

1

0
UNCERTAIN

0
NO

4. Did the survey provide you with the information needed?

N=7

7
YES

0
UNCERTAIN

0
NO

APPENDIX O

(2)

5. How would you rate the sessions on:

N=7

a) organization?	LOW		AVERAGE	✓	✓	✓	HIGH
	1	2	3	4			5
b) content?	LOW		AVERAGE	✓	✓	✓	HIGH
	1	2	3	4			5
c) length?	LOW		AVERAGE	✓	✓	✓	HIGH
	1	2	3	4			5

d) COMMENTS OR SUGGESTIONS:

6. From your point of view, what areas of the program evaluation had the greatest impact on you? (Feel free to comment on any aspects - the process, the results and findings, any surprises, etc.)

7. Do you have any recommendations for the program that have not been discussed?

Would you indicate your relationship to the program: (Please Check)

Administration 4Service Delivery 2Consumer 1