An Assessment of the Needs of People with Muscular Dystrophy and Related Neuromuscular Disorders

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ABSTRACT

It was the purpose of the present study to develop a methodology for assessing the needs of persons with neuromuscular disorders and to utilize the measures developed to assess the needs of a population of these clients residing in the provinces of Manitoba and Saskatchewan. The tools and procedures developed for this study were to serve as a prototype for the needs assessment of persons with neuromuscular disorders in other provinces or regions.

The needs assessment was undertaken in an effort to identify the human service program planning priorities for clients with neuromuscular disorders. A variety of informants were used to enhance the likelihood of identifying the most important needs of this population. Three separate assessment tools were developed. A client survey in the form of a mailed questionnaire was developed to elicit information about the self-perceived needs of clients; survey data were collected from 106 registered clients of The Muscular Dystrophy Association of Canada residing in Manitoba and Saskatchewan. An agency survey was developed to elicit information from agency representatives in these provinces about their perceptions of the needs of clients with neuromuscular disorders; data were collected through personal interviews with 33 key informants. An individual assessment format was developed to elicit information about a health-care professional's perceptions of the needs of the clients; a sample of 33 clients was randomly selected for a physical and functional assessment and interview. The findings of this study are based on a comparison of the needs identified by all three sources.

The findings indicated that the perspectives of need identified by each of the three respondent groups exhibit definite congruence, although the priority of the needs identified is different. The results of the client survey and the individual assessments showed the greatest agreement. It is suggested that the variation in the weighting of the needs identified by each of the respondent groups is based upon the identification of felt needs, or symptomatic needs, by the clients and the identification of real needs by health-care professionals.

The results of the study led to three major conclusions that suggest changes to the current service delivery system in Manitoba and Saskatchewan. In addition, based on the experience of undertaking this needs assessment project suggestions for revisions to the content of the tools developed and the procedure employed in administering each tool are offered, should a similar or larger assessment of the needs of a population of persons with neuromuscular disorders be undertaken in the future.

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INTRODUCTION

A newborn infant becomes the world's youngest heart transplant recipient. A young man, paralyzed below the waist pushes his wheelchair around the world. The case of a woman known to be carrying a severely deformed child is presented to a hospital therapeutic abortion committee. These true scenarios are testimony to the rapid and irreversible technological and social changes that characterize the times in which we live. They are changes that have had a dramatic impact on the way we define the term, "health".

In the past, when infectious diseases were the predominant cause of illness and death, health was defined in terms of the absence of disease. Today, health has come to mean more than simply not being ill. It is seen as a state of complete physical, mental, and social well-being. Viewed from this perspective, health ceases to be measurable strictly in terms of illness and death. The implication is that good health is a part of everyday life; that it is a quality of life.

Shifting family structures, an aging population, and medical progress that has increased life expectancy are all exacerbating certain health problems and creating pressure for new kinds of social support. Increasing awareness in our society of human and legal rights is adding public pressure for services appropriate to perceived "need", as well as raising expectations regarding quality of life. The question at issue has become how to provide an equivalent level of service for all deserving groups of clients.

Determination of needs is fundamental to the effective and efficient delivery of human services. Programs should be developed in response to needs that exist for services. There is, however, considerable controversy about how needs should be assessed. Although the most valid needs indicators are obtained through the direct assessment of individuals, the costs of this approach are prohibitive for any service agency with a large caseload. If such methods were feasible, the question to be addressed would be whether the needs of a population are even equal to the sum total of the needs of the individuals within it. Regardless of the process used to assess needs, the outcome for agencies planning health-care programs and services must reflect their mandate to serve the needs of their entire constituency.

Health-care professionals recognize that determination of the needs of an individual, physically disabled client involves careful and thorough assessment of the medical, functional, social and emotional needs of the person and his or her family. Coordination of services received in the hospital and in the community is essential and involves considerable planning and understanding of the individual's needs and of the services available.

Determination of the health-care needs of a population of physically disabled clients should, by extension, also involve thorough assessment of medical, social and emotional needs. "Needs assessment" or "community health planning" are the terms commonly used to describe the process of assessing the total needs of a large number of clients. Community health planning stresses the importance of evaluating societal values, government programs for the sick and the disabled, and geographic location. It is well understood that the needs assessment process should be undertaken prior to the implementation of programs and services and prior to the placement of staff in order to ensure that programs meet the actual, rather than the assumed, needs of the clients and to ensure that the staff hired have the qualifications and the skills to address these needs.

In reality, however, assessment of service needs is a neglected and misunderstood aspect of human service program planning, where programs emerge from within a highly political context of confrontation between special and general interest groups, social service ideologies, demands for service, and competition for access to finite resources. Minimal, if any, systematic "assessment" of client needs seems to occur. The result is that programs have been developed at community, provincial, and national levels that lack coordination, that overlap, and that compete for limited resources.

In general terms this study will attempt to develop a blueprint for social and health services program planning. Systematic and scientific techniques will be designed to identify the extent and the degree of need for specific services, within the context of large population, as opposed to individual assessment. The goal will be to begin progress towards a framework that will permit the identification of community needs and the matching of these needs with appropriate services to the benefit of all the stakeholders in this process -- those in need of, those who pay for, and those who deliver these services.

The Muscular Dystrophy Association of Canada, a national, voluntary health-care organization serving physically disabled children and adults with neuromuscular disorders, expressed interest in the development and application of needs assessment methodology in the planning of human service programs for their clientele. Presently, it is the role of the client services health-care professionals within this organization to identify the needs of clients with neuromuscular disorders and to plan, to advocate, and to implement, along with other government and voluntary sector personnel, appropriate community-based health-care and social services and programs for this population. Several factors contributed to the interest and commitment of The Association to become involved in a needs assessment research project:

1. The most recent registered client statistics of The Muscular Dystrophy Association of Canada indicate that clients with neuromusuclar disorders are living longer and are choosing to live in the community with their families, in group settings, or independently, as opposed to living in institutions. These trends towards prolongation of life and deinstitutionalization of persons with severe, chronic disability have raised numerous issues that demand formal assessment in order to determine if and how services should be provided to address the changing needs of this client group.

2. Limited funds are available for what appears to be an infinite number of needs. The range of the "needs" of clients with neuromuscular disorders reported to Association personnel by clients and their caregivers encompasses all aspects of clients' lives. Client services health-care professionals attempt to assess and address these needs on an individual basis, but

lack the knowledge and skills to consider the needs of the whole population for coordinated, cost effective services and programs.

3. The differences in provincially funded, government delivered human service programs throughout Canada have led The Association to develop its own client services programs and hire its own health-care staff that address the most apparent unmet client needs or the gaps in government funded services. As a result, no health-care staff have been placed in Manitoba and Saskatchewan where government funded universal medical equipment programs are much more generous in comparison to programs in other provinces throughout Canada. Increasingly, however, clients, caregivers, and health professionals in these provinces have requested assistance with unmet physical, emotional, social and even equipment needs.

The present study is part of a larger investigation undertaken on behalf of The Muscular Dystrophy Association of Canada. The specific objectives of the research reported on here are twofold:

1. to develop valid measures for assessing the needs of persons with neuromuscular disorders; and

2. to utilize the needs assessment measures developed in order to assess the needs of a population of clients with neuromuscular disorders residing in the provinces of Manitoba and Saskatchewan.

CHAPTER II

REVIEW OF THE LITERATURE

The focus of this study is on the development of a needs assessment procedure appropriate to the task of determining the health-care needs of a population of persons with physical disabilities. This chapter will begin with an historical examination of the contributions of educational and health-care doctrine to the development of the concept of "need". An operational definition relating the two disciplines will be suggested as a framework for this study. Next, the term "need" will be analyzed from the dual perspectives of how needs should be defined and who should define them. A model of health-care needs will be presented that incorporates both perspectives; this in turn will serve to introduce an examination of the value of self-estimates of need and a discussion on the needs of individuals and the needs of communities. The review of general needs assessment literature will conclude with a study of the measurement of needs indicators and the inference of need based on available indicators. Finally, based on both the general review and a specific review of research on the needs of persons with neuromuscular disorders four specific objectives for this research project will be suggested.

Operational Definition of the Concept of Health-care Needs

The doctrine of interests and needs in education was introduced by John Dewey early in the twentieth century. Dewey and his followers developed the concept of educational need as a way to advocate a "learner-centered", as opposed to a "subject-centered", approach to educational planning (Atwood & Ellis, 1971). The concept of need has received considerable emphasis in educational theory and practice (Atwood & Ellis, 1971) and many definitions from other fields have been incorporated into the development of a definition of educational need (Moore, 1980). Malcolm Knowles has defined educational need as "the discrepancy between what an individual (or organization or society) wants himself to be and what he is; the distance between an aspiration and a reality" (Knowles, 1970, p. 86).

The doctrine of needs in the health and human service fields grew out of observations in the mid-1960's that public programs should be guided by information about the needs of residents (Bell, Nguyen, Warheit & Buhl, 1978). Development of a concept of health-care needs was, however, retarded by the lack of a common, unambiguous understanding of what constitutes and who should define disablement, impairment, and handicap. The difficulty in addressing this issue has been a major reason for the lack of information about the needs of the disabled in our society.

The traditional concept of disease, known as the medical model, portrayed in Figure 1, has been the framework upon which health-care planning and service delivery have been based. This model is incomplete, however, because it fails to examine the consequences of disease. The World Health Organization has only recently begun to address this problem (World Health Organization International Classification of Impairments, Disabilities, and Handicaps, 1980, Figure 2). However, the World Health Organization's classification system to date provides only a conceptual resource, not operational tools as far as needs assessments or population surveys are concerned (Colvez & Robine, 1986).

Figure 1. Concept of disease according to the medical model

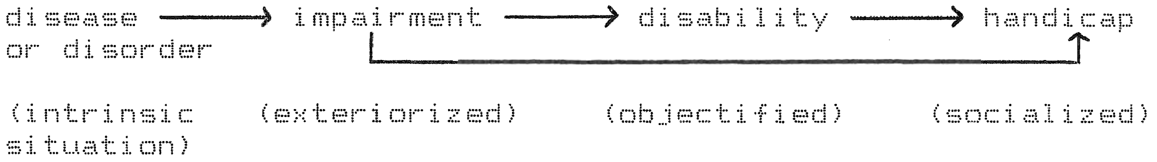

Figure 2. Consequences of disease model

The medical model evaluates health-care needs only on the basis of clinical disability, which is an objective measure of the manifestation of illness or pathology. Handicap, which is a result of perceived disability, a subjective measure, and clinical disability, the objective measure, are not incorporated into any determination of needs made according to the medical model (Greenwood, 1985).

In order to begin an examination of health-care needs operational definitions of the concepts related to these needs must be established. For the purpose of this study the term handicap will refer to the physical, economic, social, and emotional disadvantages experienced by individuals as a result of impairments and disabilities. Because education has been defined as the influence of learning on the capability of people to respond effectively to the problems and opportunities of their environment (physical, economic, and social) (Baker, 1976a), the notion presented in this paper is that adjustment to physical disability and handicap is an educational process; a learning process that occurs outside of the school system; that occurs in the context of the environment in which one lives and functions; that can promote resolution of the physical and functional limitations encountered in life; and that is a life-long activity. This is consistent with the concept of educational need which views a need as a discrepancy between an existing and a more desirable set of circumstances (Moore, 1980), where circumstances can be described in terms of proficiencies (knowledge, skills, and attitudes); performance (outcomes, results, and achievements); or situations and levels of competencies.

Both adult education and rehabilitation medicine have common aims in the development of self-directed, independent persons. Such adults would view themselves "as proactive, initiating individuals engaged in continuous re-creation of their personal relationships, work worlds and social circumstances, not as reactive individuals, buffeted by the uncontrollable forces of circumstance" (Brookfield, 1985, p. 48). For handicapped persons dependency in the biopsychosocial realms of life has, indeed, been dictated by circumstances beyond their control. Learning to adjust to physical disability is the process whereby the discrepancy between their existing and desired circumstances can be narrowed.

Definition of Need

In the development of needs assessments various measurements and techniques are used to obtain the data needed to define the "gap" between desired and actual performance, or the discrepancy between an existing set and a desired set of circumstances. The most popular concept seems to be that needs assessments measure the gap between "real" versus "ideal" needs, or "actual" versus desired" needs (Bullard, 1983). Simply put, need assessments are concerned with measuring the gap between what is and what could or should be.

Scissons (1985) advocates that a primary job of the needs assessor is to be very clear on what definition of need is being used in any given needs assessment project and to be able to justify this definition. He views it to be the job of the end user of needs assessment data to be certain that the definition of need used to compile the estimates of need is well known and that it relates to the situation to which it will be applied.

Definitions of the most commonly used concepts of the term, "need" are outlined below. Where applicable, information about how the particular concept of need relates to health-care and program planning issues is incorporated into each definition.

Basic needs. In this sense the term "need" indicates a deficient state that initiates a motive on the part of an individual similar to a "drive". This condition may be understood as a tension state, which causes gratification-seeking behaviour (Monette, 1977; Scissons, 1982). Need in this sense denotes an innate, unlearned condition (Monette, 1977). Abraham Maslow's hierarchy of needs (physiological needs -- safety needs -- love and belonging -- esteem -- self-actualization) suggests that an individual will be motivated to seek fulfillment of higher order needs only after the basic, lower order needs have been fulfilled (Baker, 1976b). It would, therefore, not be realistic to attempt to interest individuals in addressing group goals or community needs, if their own very basic or survival needs have not been met. Another problem with using the construct of basic human needs to make decisions about program planning is that these needs vary from person to person and from society to society, depending on the values considered important within a particular culture or society.

Real needs. "Real" needs are defined as the objective deficiencies of an individual, group, institution, or community with emphasis on the fact that the deficiency actually exists, as opposed to one that is only thought to exist (Atwood & Ellis, 1971). "Real" needs are those needs that an omniscient observer would identify. People have difficulty in objectively identifying their own needs, because they have a tendency to assume that what they perceive to be needed to accomplish a particular goal is what an omniscient observer would also perceive. A real need may or may not be recognized as such by the person involved.

Felt needs or expressed needs. This is the most commonly used form of the word "need" (Monette, 1977). Felt needs are what people recognize as the elements necessary to improve their situations (McMahon, 1970). Felt needs are closely related to "wants"; they are interests or conscious desires (Atwood & Ellis, 1971). Wants or felt needs alone are inadequate measures of need in that they are limited by the perceptions of individuals, their awareness of services available, their own self-awareness, and their willingness to depend on services (Monette, 1977). Felt needs can also be inflated by those who request a service without really needing it. In addition, a felt need may or may not be expressed in terms of a demand for services. When expressed, a felt need can be taken as a measure of unmet need; however, as an example, waiting lists for service, which are the result of expressed felt needs, are generally considered poor measures of the actual needs that exist (Monette, 1977). It should be emphasized that felt needs may also be real needs, but that often they are not. Felt needs may be derived from symptoms alone, rather than from the true problem (McMahon, 1970).

Normative needs or criterion needs. A need is considered to be "normative", when it constitutes a deficiency or a gap between a "desirable" standard and the standard that actually exists. The individual or group that falls short of the desirable standard is said to be in need

(Monette, 1977). Needs would, therefore, differ depending on the standards or criteria set. In addition, different assessors could set different standards. According to this definition the existence of a need is not a simple empirical fact, but rather a value judgement based on the criteria set by a particular individual, group or society. Normative needs would, therefore, change with time as a result of developments in knowledge and changes in the values of society.

<u>Comparative needs.</u> Need can also be measured by comparing the characteristics of people receiving a service with others who are not. People who exhibit the same characteristics as those already in receipt of a service are considered to be in need. The obvious questions are whether the original services are meeting needs, whether the level of supply is adequate, and whose responsibility it should be for making these determinations. "Comparative" need, by itself, is not an adequate measure of real need (Monette, 1977).

<u>Prescriptive needs.</u> When need is referred to in a prescriptive sense, four conditions are implied:

1. that an objective must be met;
2. that which is needed must be required or necessary;
3. that which is needed must already be lacking; and

4. that the objective must be mandatory or desirable (Atwood & Ellis, 1971). In view of these conditions any need should be evaluated according to the following four questions: one, what objective is served by fulfilling the need?; two, is the fulfillment of the need necessary for achieving the objective?; three, has the need already been met?; and four, to what degree is the objective mandatory or desirable?.

Motivational needs. A need, in the motivational sense, is a deficient state that initiates a motive on the part of the individual. It sets up a tension in a person causing him to want to do something (Atwood & Ellis, 1971). This concept is similar to the concept of drive that was described for basic needs, referring to a state of tension that causes gratification-seeking behaviour. This definition of need relates again to Maslow's hierarchy of needs that must be satisfied in a specific order. According to this definition, certain needs must be satisfied before others are even felt or recognized by the individual (Atwood & Ellis, 1971).

Symptomatic needs. "Symptomatic" needs are closely related to "felt" needs. They are used to describe needs that are considered real, but which are only manifestations of real needs. Symptomatic needs may be real needs at one level and, at the same time, a symptom of a need at another level (Atwood & Ellis, 1971). For example, if one has a hard day at the office, the need for a stiff drink may be real; however, it may be that the need for a drink is symptomatic of the more serious condition of alcoholism and the needs that result from this problem.

The definitions of need reviewed have eclectic origins, having derived meaning from research in such fields as psychology, sociology, and education. These definitions have also provided the framework for the classification of health-care needs by Chambers, Woodward, and Dok (1983) (Figure 3). Many of the concepts of need already reviewed have been incorporated in this classification.

1. WANT or "expected" services that are perceived by the public as expectations or rights
2. DEMAND or the type and amount of health services requested or desired by the public once they know the costs and prices involved
3. NEED or "ought to be" services that should be provided to the public on the basis of the perceptions of experts
4. USE or health services actually utilized
5. SUPPLY or "get-at-able" health service, either quantitatively or qualitatively

Figure 3. Health-care needs according to Chambers, Woodward and Dok

Information from any one of these categories can, according to Chambers and his colleagues, be used as a substitute for information about any other category, provided that the health-care system is in a state of equilibrium. The health-care system would be in a state of equilibrium if,

WANT = NEED = DEMAND = USE = SUPPLY AND QUANITY = QUALITY.

The implication of Chambers et al.'s equation is that in a perfect system the self-perceived needs of clients, their felt needs or wants, would equal their real needs. This relationship implies that clients' self-estimates of need should be a valuable source of information for the assessor of needs.

Self-Estimates of Need

In the early 1930's the first survey research to examine health-care utilization was undertaken. This work led to an awareness of the unequal use of health services by persons in different social and economic groups (Falk, Klein & Sinai, 1933; Zborowski, 1952; Saunders, 1954; Clark, 1959). Because it was apparent that certain groups of people were not receiving their "fair" share of the benefits available, research was precipitated into the question of whether a "medical-scientific" formula of health-care needs could be developed (Greenley, 1980). In spite of ongoing attempts to devise indices that rely on expert judgements of need for medical care, there has been no acceptable formula developed that determines what is needed care and what is not. Differences in societal and cultural values further complicate this determination.

Researchers have hesitated to incorporate clients' self-estimates of health-care needs into their work because of the lack of information available about the cognitive and motivational factors underlying individuals' responses to questions about their overall health and health-care needs. What has been overlooked is that the typical respondent, who has only a superficial knowledge of anatomy, physiology, and pathology, may, however, have available to him valuable "data" about his health status. These data include comparisons of past and present health, information about future expectations, knowledge of family history of illness, et cetera. The reluctance to incorporate this information into assessments of health-care needs stems from its apparent subjectivity.

The subjective expressed or felt needs of clients can, however, offer the assessor of needs two valuable sources of information: one, as indicators of real needs; and two, as symptoms that may lead to the discovery of real needs. Therefore, although clients' perceptions of their own needs may in fact represent only symptoms of real needs, often these symptoms must be relieved before the real needs can be revealed (Atwood & Ellis, 1971).

Because health-care needs assessment is concerned with instituting remedies to reduce or alleviate needs, it is particularly relevant that research findings have shown that a respondent's perception of his own health has more effect on his health related behaviour than does his "objective" health as assessed by medical professionals (Taylor, 1979). It seems, therefore, that client input offers an important perspective on the extent of the needs in question. This realization, however, raises the issue of whether the needs of individuals should be incorporated into a population needs assessment.

The Needs of the Individual versus The Needs of the Community

Most authors on the subject of needs assessment agree that the determination of needs is an important step in program planning. Programs should reflect the needs of all the individuals in a community. There is considerable controversy, however, in the needs assessment literature about whether the concept of need should be applied to individuals or to groups. Brackhaus (1984) advocates that the term, "need" is often inappropriately applied to society and institutions, when it should be applied only to individuals. In this regard she is correct. It is obvious that communities or systems do not have needs in the sense of interests, wants, or felt needs. The individuals within the system may have these needs, and some of their needs may have impact on the overall performance and requirements of the system. Scissons (1985) on the other hand advocates that it is only through combining needs assessments of individuals that a program for an organization or community can be developed. He suggests that the question for most needs assessors is not whether individual "X" needs an intervention program, rather whether there are enough people with a need in a particular area to warrant the implementation of programs and services. However, the consensus in the needs assessment literature is that the needs of a system are not equivalent to the sum total of the needs of the individuals within it (McMahon, 1970; Monette, 1977; Pennington, 1980b).

Examination of the end-product of a needs assessment adds another perspective to the problem of individual, as compared to community, needs assessment. What happens once needs have been identified? Assessment of the needs of the "whole" person is a popular concept in the field of health-care; in other words, assessment of one's "total" needs. However, this concept fails because, once identified, the total needs of clients are broken down again and each part allocated to a variety of specialists who have the skills, resources, and facilities to deal with each different part of the problem; once dealt with the parts are then put together again in an effort to achieve the original objective of meeting the individual's total needs. As an aside, the process of breaking down needs and referring these to specialists for remediation eventually reaches the point at which the process itself creates its own needs. Hence, the needs assessment process and the question of who should be assessed cannot be separated from the issue of ultimate service development and implementation.

The original objective of this study was to develop a cost-effective means of assessing the needs of a large population of clients in order to develop effective programs and services to meet their needs. Bearing this in mind, the relevant question is not whether the needs of each individual within the system should be addressed, or whether the system itself has needs, rather how all these needs can be represented in order to develop an accurate perspective on a problem which is clearly multidimensional.

Measurement of Need Indicators

Because individuals interact within the systems in which they live and work, they have needs related to interpersonal relations and collective issues. This highlights the importance of collecting needs assessment data from people from various role perspectives in a group, organization, or community.

It has already been shown that information about needs is both subjective and objective. Needs assessors will value different sources of information and will weigh it according to their own values when making decisions about programming. It, therefore, stands to reason that a combination of data sources will provide a more reasonable basis for making such decisions than will a single source. The following example illustrates this point:

> You might, by way of example, ask me to rate my ability as a lover, and if I were honest I would tell you what I think. If I were not honest, I might tell you what I think you want to know or what I would want you to know. In any case, you would get my perspective on my ability. You might, in order to balance things out, ask my wife about the very topic. If you were even more daring, you might ask friends, students, or people that you presume know me only slightly. Would you expect to get the same ratings from every case? What is likely is that, dependent on whom you asked (not to mention what you asked), you would hear different information. Which information would be more correct? That is a question that cannot be answered, because each measurement represents a unique perspective. If I think I am a magnificient lover and my wife thinks I am not, which assessment do you as a needs assessor accept? It is things like that they do not teach in graduate school! There are only two ways out of this dilemma. Cling dogmatically to a measurement philosophy that says one type of method, usually self-assessment, is best. I will call that the 'don't ask my wife' syndrome. The other way is to look for methods to obtain varying perspectives of the situation (the who shall we ask next syndrome), as well as some method to combine information that may at first glance appear to be contradictory. (Scissons, 1985, pp. 106-7)

Not every variable related to a problem or situation can, however, be studied in detail. Scissons' "who shall we ask next" philosophy implies that using a variety of informants will enhance the likelihood of identifying the most important components of a problem. The use of various methods will also help to counteract the unknown reliability and validity of many data collection techniques. The literature indicates that needs assessors do use multiple methods to collect data, but that the most commonly used data collection techniques are survey questionnaires and interview guides (Moore, 1980).

The shift towards a consumer focus in health-care has raised concerns about the use of surveys as data collection tools. The concern is that the orientation of the questions asked tends to define "need" in terms of the perceptions of the providers of services, rather than the consumers. Many studies have used structured questionnaires or interview schedules which have been based on the expectations of non-disabled people about disabled people and have reflected the structure and nature of services that are already available (Warren, 1985).

The validity and reliability of data from structured surveys rest upon the fact that responses to precisely worded questions administered according to precise rules can be replicated. Results can be reduced to numbers and subjected to cross-tabulation and statistical tests. The problem, as far a needs assessments are concerned, does not rest with the data-processing, but rather with the nature of the data. The collection of survey data is based on the assumption that the same question asked of persons who differ in many ways will produce answers which, for each person, are equally revealing of their beliefs, attitudes, and behaviour (Illsley, 1980). While this may hold true for social facts such as age, sex, residence and occupation, it does not apply to value-laden topics dealing with needs. Collecting data using open-ended techniques generates more individualized responses, but results in the methodological problem of analyzing similarities, differences and patterns in the data. In spite of the problems inherent in survey and interview techniques, we would be well advised to consider Illsley's point that, "In most fields the lack of good data means the past lack of people asking good questions" (Illsley, 1980 p. 107).

Inference of Need Based on Available Indicators

Most needs assessments are oriented to finding needs. The false assumption is that needs really exist. Needs, in fact, do not exist; they are inferred on the basis of data (Scissons, 1985); they are not empirically determinable facts, rather they are complex value judgements (Monette, 1979).

The function of needs assessments is often confused with the functions of research and evaluation. Each of these tasks attempts to answer different questions, although they may utilize many of the same information gathering instruments. Research questions inquire, "What can be done?"; evaluation addresses, "How well was something done?"; and needs assessments ask, "What should be done?" (Monette, 1979).

Pennington (1980a) suggests that the results from a needs assessment will provide two sets of data:

1. baseline data for making summative evaluation judgements regarding program impact; and
2. planning data for projecting alternative mechanisms to reduce the gap between current and desired circumstances. (pp. 10-11)

The information derived from needs assessment procedures does not automatically make apparent "what should be" done to reduce the gap between existing and desired circumstances. If a variety of data collection techniques have been used in the information gathering process, the needs assessor is faced with the problem of how to combine different measures of need. Where ranking scales have been used in order to produce a relative measure of need, the question is whether even the highest rated need warrants consideration. Since no benchmarks exist against which inferences of need can be compared, researchers usually target intervention programs on the highest rated need without regard to any absolute judgement about the importance of that need (Scissons, 1985). Two difficulties are obvious: one, little information exists that delineates actual techniques for analyzing needs information and for assessing or prioritizing specific needs (Barbulesco, 1980); and two, needs assessors are likely unable or uncomfortable with having to make decisions about the importance of a need, when this involves complex value judgements; judgements that involve ethical, policical, aesthetic, and economic issues.

In order to overcome these limitations an effective needs assessment should specify a method of assigning priorities and determining the importance of identified needs. It seems reasonable that development of the good questions that will produce the good data suggested by Illsley is an important first step. Freire (1970) suggests that the process should involve identification of the felt needs of a constituency, followed by discussion between the clients and the assessor until a concensus is achieved and any contradictions are eliminated. Consideration of past needs assessments undertaken in similar settings or with similar populations will also assist by providing a reference point from which categorization of newly identified needs can be approached. Finally, it is important to recognize that needs will be sifted through the "philosophical screen" of the sponsoring agency (Knowles, 1970). The goals and philosophy of the agency funding the study will influence the kinds of needs assessments done, the way the needs are analyzed and ranked, as well as the outcome in terms of on which needs the development of intervention programs are based.

Related Studies on the Needs of Persons with Neuromuscular Disorders

Neuromuscular disease is a group of over forty related disorders (Appendix 1) that are marked by wasting and progressive weakness of the voluntary muscles that control body movement. Neuromuscular disorders affect children or adults of either sex. Most forms are passed from generation to generation, but they can also occur as a result of spontaneous mutation in families with no history of the disorder.

The pathology of the majority of the neuromuscular disorders originates in the muscle, such as in the muscular dystrophies. These disorders present with a wide variation in incidence, severity, hereditary pattern, age of onset, initial muscle attacked, and rate of progression. The most common and severe form of muscular dystrophy is the Duchenne type. It is a hereditary, sex-linked recessive disorder that is transmitted by the mother, almost exclusively to male children. Up to 33% of Duchenne Muscular Dystrophy cases appear to be the result of spontaneous mutations of the gene either in the patient or his mother (Madorsky, Radford & Neumann, 1984). Duchenne Muscular Dystrophy is a rapidly progressive disorder with no remissions that eventually affects all muscle groups; life expectancy is limited to the early twenties (Muscular Dystrophy Association of Canada, 1984) with death resulting from respiratory infection or cardiac failure (Madorsky et al., 1984).

In other groups of neuromuscular disorders the pathology or defect is located in the nervous system, resulting in a muscular atrophy. Progressive Spinal Muscular Atrophy designates a group of disorders of varying severity, diagnosed in infancy, childhood, or adulthood. Amyotrophic Lateral Sclerosis is a severe muscular atrophy of adult onset.

Other related neuromuscular disorders include disorders of the neuromuscular junction, inflammatory myopathies, diseases of the peripheral nerve, myopathies due to endocrine abnormalities and less common myopathies. For most of the forty neuromuscular disorders there are no medical treatments available (Muscular Dystrophy Association of Canada, 1984).

Many of the neuromuscular disorders, because of their chronic and degenerative nature, cause great suffering and disability, as well as interferring with school, employment, and family relations. Beyond the costs to the individuals and their families there is a considerable cost to society and its health-care system.

Most studies of the needs of persons with neuromuscular disorders have focused on Duchenne Muscular Dystrophy. The physical aspects of this disorder have received continuous attention since its identification in 1868 (Madorsky et al., 1984). Recently studies have explored the psychological and emotional aspects of the disorder, concentrating on the intellectual impairment that presents in Duchenne Muscular Dystrophy, the high levels of chronic emotional stress experienced by the families of Duchenne Muscular Dystrophy patients, the prevalence of psychiatric disorder (Fitzpatrick, Barry & Garvey, 1986), and the availability of life expectancy information (Madorsky, 1984). No research papers specifically assessing the needs of clients with neuromuscular disorders were found.

The research undertaken in this study addresses timely issues that correspond to general trends in the health-care system; trends that have begun to examine three issues directly related to this study:

1. development of subjective health indicators, i.e., indicators of perceived health status (which even if not valid and comparable may have intrinsic value as indicators of community problems and needs);

2. measurement of functional impact of "ill-health", i.e., indicators of disability/incapacity (e.g., Sickness Impact Profile, the Activities of Daily Living Measure, and the Functional Limitation Profile); and

3. a shift away from the obsession with indicators towards the "characteristics" approach, organizing the information into a "health profile" (Hansluwka, 1985).

Summary of the Objectives of the Study

Having examined the literature related to this topic, the objectives in conducting an assessment of the needs of clients with neuromuscular disorders in Manitoba and Saskatchewan can be more specifically delineated as follows:

1. to develop a measurement tool and procedure that can serve as a prototype for the needs assessment of clients with neuromuscular disorders in other provinces or regions;

2. to elicit information on the nature and magnitude of human service needs from clients themselves;

3. to compare information received from clients and their families to data elicited when health-care professionals and human service agency representatives are asked to assess client needs; and

4. to determine priorities for program planning, service development and advocacy by The Muscular Dystrophy Association of Canada on behalf of its clients residing in the provinces of Manitoba and Saskatchewan.

CHAPTER III

METHODOLOGY

Design of the Study

This study was designed to be a descriptive epidemiologic survey: a demographic study that would describe the distribution of the needs of a population of clients with neuromuscular disorders residing in the provinces of Manitoba and Saskatchewan. The study was not designed to account for the changing needs of the population, but rather to identify and describe the distribution of needs within the population at a given point in time. Failure to account for the fact that needs are constantly changing could be considered a limitation of this study; it can also be interpreted as the first step in the process of developing the needs assessment methodology necessary to satisfy the first objective of this project, namely, to develop a measurement tool and procedure that can serve as a prototype for the needs assessment of clients with neuromusuclar disorders in other provinces or regions.

Three assessment methods were considered appropriate in view of the objectives of this study (see Figure 4).

	METHOD	PERSPECTIVE REPRESENTED	SOURCE OF INFORMATION
1.	client survey	clients or consumers	self-administered mailed questionnaire
2.	agency survey	government officials, health-care planners, health-care professionals, voluntary agency representatives	interviews with key informants
3.	individual assessment	health-care professional	interviews with clients

Figure 4. Needs assessment methods selected

The Sample

Muscular Dystrophy Association of Canada (MDAC) registered clients served as the target population for this study. It is important to note that The MDAC has a confidentiality policy which restricts release of client information. This study was possible only because the researcher was a paid staff member of The Association who had access to client files. In addition, prior to undertaking the research, a proposal for the study was presented to, and approved by, the Executive Committee of The MDAC.

The client survey sample.

The population of subjects available for this portion of the study was derived from the Prairies (Manitoba and Saskatchewan) client registration lists of The MDAC. Eligibility for registration with The

MDAC involves confirmation of a diagnosis of a neuromuscular disorder by a physician. There is no fee for registration. Although the clients on the Prairies registry did not represent the total number of persons who have neuromuscular disorders in these two provinces (i.e., not represented were people who have a neuromuscular disorder, but who have chosen not to register with The MDAC, people who are not aware of The MDAC, and people who are not aware of their diagnosis), it would not have been possible to identify the true population. A major reason for this is that in spite of official requirements many diseases are underreported. The desire of physicians to avoid social stigma for their patients, the pressures of other work, and laxity are among the reasons that have been given for underreporting (Chambers et al., 1983). In addition federal data from the Canada Sickness Survey, completed in 1951, and the Canada Health Survey, completed in 1979, are out-of-date. The same problems are encountered with provincial data as with federal data, the main distinction being that reports are more specific to smaller geographic areas. Profit and non-profit private health agencies, such as The MDAC, often have the best available prevalence statistics in their special disease registries.

Having determined that The MDAC registries in the two provinces represented a suitable study group for the mailed survey, considerable effort was expended to generate an accurate mailing list. Because no contact had been made with many of the registrants over many years, confirmation of the mailing list would have been ideal; however, telephone or mail follow-up was prohibitive from the perspective of the expenditure of dollars, effort, and time necessary to carry out such an endeavour. The consolation was that the study would also serve to update The MDAC registry of clients in Manitoba and Saskatchewan and that the response rate of the study could be adjusted to reflect the distinction between the "return" rate (those surveys returned by the postmaster or the family marked, "unknown address" or "deceased") versus the "response" rate (those surveys returned and answered). The "return" rate was insured by attaching a label for the postmaster, requesting return.

The population on the finalized mailing list for the client survey consisted of 97 MDAC registered clients, residing in Manitoba, and 126 clients, residing in Saskatchewan. Examination of the entire sample of the known population was attempted.

The agency survey sample. Thirty-three key informants, who were individuals knowledgeable about the needs of persons with neuromuscular disorders and/or the services available for the physically disabled (health-care professionals, representatives of government agencies, and representatives of voluntary agencies), served as the sample for the agency survey. Senior representatives with corresponding role responsibilities and corresponding positions in corresponding programs were approached in each province. The scope of the agencies included in the survey is outlined in Figure 5.

Government:	Special Education Programs Vocational Rehabilitation Programs Universal Medical Equipment Programs
Health-care:	Neuromuscular Disease Clinics Regional Rehabilitation Centres for Children Regional Rehabilitation Centres for Adults General Hospital In- and Out-patient Programs Home Care Programs Community Therapy Programs
Voluntary:	Societies for the Disabled Independent Living Centres Self-help/Advocacy Organizations of the Disabled

Figure 5. Agencies represented in the survey

<u>The individual assessment sample.</u> Sixteen clients in Manitoba and 17 clients in Saskatchewan were selected as the sample for the individual assessments by a health-care professional. The health-care professional who performed the assessments was an occupational therapist who specialized in rehabilitation medicine and functional assessments and who was the author of this report. Attempts were made to select clients representative of the disorders and the ages within the total population. It was, however, impossible for the researcher to travel throughout the two

provinces in order to generate a sample representative of the different regions within each province. Fortunately, the regional pediatric clinics in each province cooperated with the researcher, permitting assessments to take place during regularly scheduled clinic sessions. Because some clients travel to regional clinics from northern and rural areas in each province, it was felt that assessment of these clients would provide an indication of the needs of clients in these areas. The clinic coordinators in each province arranged appointments with the clients, notifying the researcher approximately one week in advance of the clinic date who would be attending. Unfortunately, this process was not possible for the adult population. The remaining clients required for the individual assessments were randomly selected from a condensed mailing list of the clients residing in the Winnipeg catchment area of Manitoba and the Regina and Saskatoon catchment areas of Saskatchewan.

Instrument Development

The primary aim in the development of instruments for this study was to incorporate the perspectives of both professionals and clients about the needs of persons with neuromuscular disorders. The specific rationale for the development of each of the three instruments will be described separately. In general terms each tool was developed to examine the following broad areas:

diagnosis and other socio-demographic information;
use made of available services;
perceived needs for further assistance;
preferences for settings of services;
preferences for type of professional/individual to render services;
functional ability in daily living and self-care tasks;
access to avocational and leisure pursuits;
employment potential and options; and
assistive devices used and needed.

Several versions of each tool were constructed and pretested. Input was sought from other authorities in the area of survey research design and functional measurements. Each of the three tools used in this project was developed for two purposes: one, to satisfy the objectives of this study; and two, to generate information of interest to The MDAC. Where relevant, information about the larger MDAC study will be included in this report.

The client survey. The final version of the client survey and cover letter can be found in Appendix 2. To counteract potential criticism that the questions asked are oriented towards a professional bias about the needs of clients the questionnaire was designed to incorporate two question formats: one, partially closed-ended questions, where answer choices are provided, but respondents have the option of creating their own response (in most cases the choices provided are unordered choices, although some questions offer ordered choices within this structure); and two, open-ended questions, which have no answer choices, rather allowing respondents to create their own answers in their own words. Because layout of a questionnaire may affect response rate and the accuracy of responses given (Woodward & Chambers, 1983), a guide to questionnaire construction (Woodward & Chambers, 1983) and a graphic artist were consulted. A brief explanation of the rationale for the development of the content of each section of the survey is given below.

The section, "Background Information", asks clients to provide diagnostic and socio-demographic information. In order to ensure that demographic data generated in this section could be compared with data from Statistics Canada, should this be desirable for future purposes, attempts were made to incorporate the wording suggested in the "Social Concepts Directory for Statistical Surveys" produced by Statistics Canada. Due to the genetic nature of most of the neuromuscular disorders questions to generate information about other family members who also have these disorders was included in the questionnaire. This information would allow the comparison of subpopulations (i.e., families with only one affected member versus families with more than one affected member), should this be desired at a future point in time, or if the results of this project indicated that this was an area warranting further investigation that could be undertaken by The MDAC.

A common complaint heard from clients and parents is that they have been inadequately educated by professionals about their child's or their own condition. In the second section of the questionnaire, entitled "Need for Information", clients are encouraged to indicate whether they have been able to obtain information related to their condition and to specify additional information that they are interested in receiving. Also explored here are the sources of the information clients have already received, as well as client interest in participating in individual or group educational sessions to learn more about their disorders or the services available to help them.

Improved prognosis for people with severe disability and the focus in rehabilitation on independence and independent living have resulted in a movement away from chronic care institutionalization to community living. Medical opinion has increasingly recognized that the benefits of community living can apply to even the most severely disabled provided that adequate support care and skilled medical-nursing backup are available (Hough & Torrance, 1984). Section three of the questionnaire, entitled, "Need for Medical Services" allows clients to report not only on what services they are receiving and what services they feel that they require, but also to offer their perspectives on the accessibility (in terms of eligibility, distance, and cost), and quality, of existing services.

The purpose of section four, "Need for Help with Daily Living Activities", was to develop a functional profile of the population of clients with neuromuscular disorders under study. For the purpose of this study "functional status" was measured in terms of the need for assistance with some or all activities of daily living. The literature was reviewed to identify relevant conceptual and methodological issues involved in measuring functional status. The content of questionnaire items used by other investigators to measure ability in the performance of activities of daily living were reviewed (Katz, Downs, Cash & Grotz, 1970; Gilson, Gilson, Bergner, Bobitt, Kressel, Pollard & Vesselago, 1975; Stewart, Ware, Brook, Davies-Awery, 1978; Hough & Torrance, 1984; Keith, 1984; Granger, 1985) and the scoring scale of Hough & Torrance's (1984) Activities of Daily Living measure was incorporated into the activities of daily living index developed for this section of the questionnaire. Clients are asked to rate their level of independence on a variety of self-care, daily living, and mobility activities. Clients are then asked to indicate who routinely provides physical assistance with those activities in which they are dependent and to describe the physical and emotional impact that the provision of this assistance has on their caregivers. On account of the progressive nature of neuromuscular disorders clients are also asked to indicate the amount of assistance with daily living activities that they believe they will require in the next five years. This question was designed to determine whether clients had realistic expectations and accurate understandings of their conditions.

Section five of the questionnaire, entitled "Need for Specialized Housing", was included solely for the purposes of the larger study by The MDAC. MDAC's interest was in examining the need for increased accessibility and barrier free design in the homes of clients with neuromuscular disorders in order to determine priorities for program development and funding.

In section six of the questionnaire, entitled "Need for Health-care Equipment", clients are asked to specify whether or not they are using or need a wide range of medical equipment items. Generation of the list of items was based on information about devices provided in other provinces to registered clients of The MDAC, as well as items frequently requested, but not provided by MDAC as part of its standard equipment program. Questions that ask clients to comment on the adequacy of government funded universal medical equipment provision and maintenance programs are included in this section.

Studies of the parents of children with DMD have shown that 76% of families identified psychological, rather than physical, issues as their major problems (Madorsky, Radford & Neumann, 1984). Clinically all neuromuscular disease clients and their families "seem" to present with at least as many psychosocial difficulties as physical difficulties. In order to determine the validity of this observation clients are asked to report on their support systems both within and outside of the family in section six, "Need for Emotional Support". They are also asked to indicate whether they would attend group functions with other clients and their families for social, educational, or mutual support and self-help purposes. Lastly, clients are asked to rate the importance of a list of psychosocial issues as pressing needs for themselves and their families.

Finally, in Section VIII, clients were given an opportunity to comment on any other issues of concern to them.

The agency survey. The agency survey form can be found in Appendix 3. The growth of community services and programs has had both positive and negative effects on the lives of the severely disabled. Many of these programs offer concrete, direct services; others offer only support. More recently, self-help and advocacy groups of the disabled have emerged (Hough & Torrance, 1984). In spite of this a commonly heard complaint is that there is a lack of coordination among services and some gaps in the level of provision to different groups. The agency survey was developed to provide a comparison between clients' knowledge of the services available to them to meet their needs, as reported in the client survey, and the impressions of service providers and administrators about the availability and accessibility of these services. This instrument was developed to generate information about existing service resources (i.e., the services offered by each agency, the population served, and the specific problems related to serving clients with neuromuscular disorders) and to determine whether additional services in the two provinces to address unmet needs are required. A review of various social and health agency surveys (Siegel, Attkisson & Carson, 1978; Chambers et al., 1983) provided suggestions for content and format that were incorporated into the agency survey developed for this study.

<u>The individual assessment.</u> The individual assessment form can be found in Appendix 4. The content of this instrument corresponds to the themes of the sections that make up the client survey. This instrument examines in greater depth selected items from the client survey in order that a comparison of needs as perceived by clients and needs as perceived by a health-care professional can be made. The

final section of the assessment allows clients and their families, as well as the professional to describe the most pressing needs, the biggest problems, and the greatest barriers facing the client and his family. The physical assessment measures used in this assessment were adapted or incorporated from measures previously used with neuromuscular disease patients (Vignos & Archibald, 1959; Vignos & Archibald, 1960; Vignos, Spencer & Archibald, 1963; Siegel, 1977; Horne, 1982).

The Procedure

The major activities of the first year of the project were planning and conducting the client and agency surveys and the individual assessments. The steps taken in implementing the needs assessment project are shown in Figure 6.

APPROXIMATE DATE	ACTIVITY
December 1986	-development of the first draft of the client survey and cover letter -development of the agency survey (Appendix 3) -telephone contact with key informants to arrange appointments for agency survey interviews -written follow-up to confirm appointments (Appendix 5)
January 1987	-pilot testing of the client survey and cover letter drafts to establish content validity (distributed to a total of 43 people, comprised of 12 MDAC registered clients from Ontario, 2 health-care professionals in Ontario, 2 health-care professionals in Manitoba, 2 health-care professionals in Saskatchewan, 9 MDAC client services staff, 11 MDAC board members, 4 research design specialists, and 1 lay person) (see Appendix 6 for letter with instructions to pilot testers)
January 5 to 9, 1987	-interviews with key informants in Manitoba
January 26 to 30 1987	-interviews with key informants in Saskatchewan
February 1987	-revision of client survey and cover letter (Appendix 2), incorporating input from pilot test phase
March 1987	-coding of master client mailing list -printing of survey
April 16, 1987	-mailing of client survey packages, including survey, cover letter, return envelopes with pre-paid postage, and coded address labels
April 1987	-development of individual assessment form (Appendix 4)

Figure 6. Stages of the needs assessment project

April/May 1987	-negotiations with pediatric clinics to gain permission to carry out assessments during clinic sessions -letters, outlining the purpose of the individual assessments and requesting client agreement to participate, mailed to clinic coordinators for distribution to clients (see Appendix 7, Manitoba and Appendix 8, Saskatchewan) -selection of remaining clients for individual assessment -telephone contact with clients and caregivers to arrange appointments for individual assessments
May 26, 1987	-follow-up letter to non-respondents of client survey (Appendix 9)
May 10 to 14, 1987	-individual assessments performed in Saskatchewan
June 1 to 5, 1987	-individual assessments performed in Manitoba
July and August 1987	-coding of data from client survey
September and October 1987	-entry of data into the computer at The University of British Columbia's computing centre, using the Statistical Package for the Social Sciences, expanded version (SPSSX) program
November and December 1987	-processing data and printing results of client survey

Figure 6 continued. Stages of the needs assessment project

Statistical Analysis

It was the purpose of this study to describe the distribution of needs in a population of clients with neuromuscular disorders. Due to the nature of the research question a descriptive statistical model was utilized.

For the client survey, frequencies of responses were calculated first. Based on these results, items of interest were chosen for further analysis by cross-tabulation. The variable for region (i.e., Manitoba and Saskatchewan) was included in each cross-tabulation, such that each cross-tabulation included at least three variables.

Information from the agency survey was used to produce an inventory of the programs and services available for clients with neuromuscular disorders in each province. The results reported in this study are based on the key informants' perceptions of clients' most pressing needs. These results were summarized in terms of frequencies of responses.

For the individual assessment, frequencies of responses and cross-tabulations were calculated in the same manner as the client survey.

The results of these analyses will be presented in chapter four and discussed in chapter five.

CHAPTER IV

PRESENTATION OF RESULTS

The results of this study are reported in four sections. The first three sections present an overview of the data generated from each of the three tools developed for the needs assessment - the client survey, the agency survey, and the individual assessment. In the last section data from this study are used to construct a hierarchy of the needs of clients with neuromuscular disorders in Manitoba and Saskatchewan.

Client Survey

Table 1 shows the number of replies received from the mailing of the client survey.

Table 1
Number of Surveys Mailed and Returned

NO. OF SURVEYS	MANITOBA	SASKATCHEWAN	TOTAL
mailed	97	126	223
returned	60	93	153
completed	54	52	106
excluded	6	41	47

"Excluded" surveys refer to those surveys returned by the postmaster or next-of-kin marked "deceased", "unknown address", or "moved out of province". The difference between the number of returned and the number of completed surveys equals the number of excluded surveys.

As noted in the methodology section, return and response rates were separate calculations suggested to reduce the effects of an inaccurate mailing list. The "return" rate was calculated using the following equation:

$$\text{Return rate} = \frac{\text{No. of surveys returned}}{\text{No. of surveys mailed}} \times 100;$$ and the

"response" rate was calculated using the following equation:

$$\text{Response rate} = \frac{\text{No. of surveys completed}}{\text{No. of surveys mailed} - \text{No. excluded}} \times 100$$

Table 2 presents the return and response rates for the client survey.

Table 2
Return and Response Rates for Client Survey

	MANITOBA %	SASKATCHEWAN %	TOTAL %
RETURN RATE	61.9	73.8	68.6
RESPONSE RATE	59.3	61.2	60.2

<u>"Section I: Background Information".</u> Table 3 presents the age ranges of the clients who responded to the client survey. Age categories were selected to correspond to significant transition periods in the lifespan of a disabled

respondent population (i.e., 5 to 6 years represents the transition from special preschool programs for orthopedically disabled children to integrated elementary school programs; 18 to 19 years represents the commencement of eligibility for provincial disability allowance and the cut-off age for pediatric treatment facilities; 64 to 65 years represents termination of diability allowance payments and the commencement of old age pensions); these categories also correspond closely to those which have been used by The MDAC in recording statistics about its registered clients.

Table 3
Age and Province of Residence of Total Respondents
N=106

AGE IN YEARS	MANITOBA		SASKATCHEWAN		TOTAL		CUMULATIVE
	#	%	#	%	#	%	%
0 - 5	4	7.4	3	5.8	7	6.6	6.6
6 - 12	5	9.3	11	21.1	16	15.1	21.7
13 - 18	4	7.4	9	17.3	13	12.3	34.0
19 - 24	6	11.1	8	15.4	14	13.2	47.2
25 - 44	24	44.4	9	17.3	33	31.1	78.3
45 - 64	6	11.1	8	15.4	14	13.2	91.5
65+	5	9.3	4	7.7	9	8.5	100.0
TOTAL	54	100.0	52	100.0	106	100.0	

Table 4 shows the distribution of the respondents by sex and province. Table 5 presents the data generated from the question that asked clients whether there are other members of their family who have a neuromuscular disorder. Table 6 presents the distribution of the respondents by diagnosis and province of residence.

Table 4
Sex and Province of Residence of Total Respondents
(N=106)

SEX	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
male	36	66.7	37	71.2	73	68.9
female	18	33.3	15	28.8	33	31.1
TOTAL	54	100.0	52	100.0	106	100.0

Table 5
Relatives with Neuromuscular Disorders and Province of Residence of Total Respondents
(N=106)

RELATIVES WITH NEUROMUSCULAR DISORDERS	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
yes	25	46.3	25	48.1	50	47.2
no	29	53.7	27	51.9	56	52.8
TOTAL	54	100.0	52	100.0	106	100.0

Table 6
Diagnosis and Province of Residence of Total Respondents
(N=106)

DIAGNOSIS	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
<u>MUSCULAR DYSTROPHIES:</u>						
Duchenne	10	18.5	11	21.2	21	19.8
Beckers	3	5.5	2	3.8	5	4.7
Fascioscapulo-humeral	0	0.0	4	7.7	4	3.8
Limb Girdle	12	22.2	5	9.6	17	16.0
Myotonic	10	18.5	4	7.7	14	13.2
Congenital	0	0.0	2	3.8	2	1.9
Type Unknown	1	1.9	3	5.8	4	3.8
<u>SPINAL MUSCULAR ATROPHIES:</u>						
Amyotrophic Lateral Sclerosis	3	5.5	0	0.0	3	2.8
Werdnig-Hoffman	2	3.7	2	3.8	4	3.8
Type Unknown	6	11.1	3	5.8	9	8.5
<u>INFLAMMATORY MYOPATHIES:</u>						
Polymyositis	1	1.9	0	0.0	1	.9
Dermatomyositis	1	1.9	0	0.0	1	.9
<u>DISEASES OF PERIPHERAL NERVE:</u>						
Charcot-Marie-Tooth Disease	2	3.7	1	1.9	3	2.8
Friedreich's Ataxia	2	3.7	2	3.8	4	3.8
Guillain-Barre	0	0.0	2	3.8	2	1.9
<u>DISEASES OF NEUROMUSCULAR JUNCTION:</u>						
Myasthenia Gravis	0	0.0	1	1.9	1	.9
<u>LESS COMMON MYOPATHIES:</u>						
Malignant Hyperthermia	0	0.0	2	3.8	2	1.9
<u>OTHER:</u>						
Type 1 Fibre Atrophy	0	0.0	2	3.8	2	1.9
Emery-Dreifus	1	1.9	0	0.0	1	.9
Arthrogryposis	0	0.0	1	1.9	1	.9
Type Unknown	0	0.0	5	9.6	5	4.7
TOTAL	54	100.0	52	100.0	106	100.0

"Section II: Need for Information". The number of respondents who reported an inability to obtain information related to their disorder is outlined in Table 7.

Table 7
Inability to Obtain Information and Province of Residence of Total Respondents (N=106)

UNABLE TO GET INFORMATION ABOUT	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
disorder	11	20.4	19	36.5	30	28.3
treatment	18	33.3	19	36.5	37	34.9
where to go for treatment	21	38.9	17	32.7	38	35.8
genetics of disorder	17	31.5	15	28.8	32	30.2

A crosstabulation of two variables showed that 13% of the respondents in Manitoba and 13% of the respondents in Saskatchewan reported having relatives with neuromuscular disorders and also reported having been unable to obtain information they have needed or wanted about whether their disorder was inheritied (i.e., the genetic implications of their disorder). However when asked in an open-ended question whether there was any information about their disorder that they had been unable to find, 73.3% of the respondents did not answer this question at all and the 26.7% who did respond primarily identified issues about prognosis or "what to expect in the future". Clients located information about, or related to their disorder from the sources shown in Table 8.

Table 8
Source of Disorder Related Information and Province of Residence of Total Respondents (N=98)

SOURCE OF INFORMATION	MANITOBA (3 Non-Respondents)		SASKATCHEWAN (5 Non-Respondents)		TOTAL	
	#	%	#	%	#	%
Doctor(s)	45	83.3	43	82.7	88	89.8
Neuromuscular Clinic	16	29.6	28	53.8	44	44.9
MDAC	21	38.9	20	38.5	41	41.8
Others with Neuromuscular Disorders	10	18.5	6	11.5	16	16.3
Library	6	11.1	4	7.7	10	10.2
Telethon	16	29.6	4	7.7	20	20.4
Physiotherapist	16	29.6	9	17.3	25	25.5
Occupational Therapist(s)	11	20.4	6	11.5	17	17.3
Nurse(s)	2	3.7	7	7.7	9	9.2
Other	7	13.0	2	3.8	9	9.2

Respondents were asked whether or not they or their families would be interested in attending large group, small group, or individual sessions to learn more about their disorder and the services available to help them. The number of clients who expressed interest in attending the suggested session formats are presented in Table 9.

Table 9
Interest in Attending Meetings and Province of Residence of Total Respondents (N=106)

INTEREST IN ATTENDING	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
workshops or lectures	27	50.0	23	44.2	50	47.2
small group meetings with other clients	26	48.1	26	50.0	52	49.1
individual meetings with a knowledgeable person	35	64.8	28	53.8	63	59.4
other	4	7.4	2	3.8	6	5.7

"Section III: Need for Medical Services". Respondents were asked if they had ever attended a neuromuscular disorder clinic; their responses are presented in Table 10. If clients reported that they did not attend a neuromuscular disorder clinic, they were asked to indicate the reasons why they did not attend. This information is presented in Table 11.

Of the clients who have attended a clinic 52.2% in Manitoba and 43.8% in Saskatchewan reported dissatisfaction with the services they have received. The primary sources of dissatisfaction were lack of practical advice for coping with day-to-day functional and psychosocial problems, lack of knowledge about community services and programs available for social and medical follow-up between clinic appointments, amount of time spent at clinic versus amount of time actually spent in consultation with professionals, waiting time between consultations, and lack of consideration for the work and school schedules of the client and family when arranging appointments. The primary positive comment about clinics concerned the ability to see a medical team of professionals in one location on the same day, instead of the alternative of scheduling appointments with each professional such that appointments occurred on different days and at different locations. Twenty-five point five per cent of the respondents who have attended a clinic report attending once a year, 21.8% attend every six months, 3.6% attend every month, 27.3% attend as needed, and 21.8% attend according to some other schedule.

Of those respondents who attend a clinic 49.0% travel less than 25 kilometres one way, while 6.6% travel between 25 and 50 kilometres one way, 10.4% travel between 51 and 120 kilometres one way, and 34.0% travel greater than 120 kilometres one way. Broken down by province 20.4% of Manitobans who attend clinic travel greater than 120 kilometres one way, while 48.1% of the respondents who attend a clinic in Saskatchewan travel this distance.

In response to the question, "Do you have a family doctor who understands the problems of your condition?", 31.4% of the respondents in Manitoba and 14.3% of the respndents in Saskatchewan responded negatively.

Table 10
Attendance at a Neuromuscular Disorder Clinic and Province Residence of Total Respondents (N=106)

ATTEND A NEUROMUSCULAR DISEASE CLINIC	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
yes	23	42.6	32	61.5	55	51.9
no	31	57.4	20	38.5	51	48.1
TOTAL	54	100.0	52	100.0	106	100.0

Table 11
Reasons for Not Attending A Neuromuscular Disorder Clinic and Province of Residence of Total Respondents (N=51)*

REASONS FOR NOT ATTENDING A CLINIC	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
not aware of a clinic	22	71.0	13	65.0	35	68.6
no clinic available	7	22.6	6	30.0	13	25.5
clinic too far	6	19.4	3	15.0	9	17.6
not satisfied with services and staff	1	3.2	3	15.0	4	7.8
other	3	9.7	5	25.0	8	15.7

* N=31 for Manitoba (see Table 10)
N=20 for Saskatchewan (see Table 10)

Respondents in Manitoba and Saskatchewan expressed a slight preference for receiving services in their home setting (57.7%) as compared to outside of the home (42.3%).

Tables 12 and 13 outline the types of medical services being received by the respondent population both in- and outside of their home setting and Table 14 indicates the sources of funding clients are receiving for their home based services.

Respondents were asked about their perceptions of services that they need, but do not receive. Responses were coded into categories, which are presented in Table 15. The results show that 30.2% of the respondents believe they require services they do not receive. Although this question was presented in the "need for medical services" section of the questionnaire, respondents also indicated a need for non-medical services, when answering this open-ended question; these responses were coded as "other". Services deemed to be needed in this category included financial assistance, transportation, physical assistance for transfers and lifting, home and yard maintenace, employment training and placement services, and flexible attendant care services.

Table 12
Medical Professionals Being Seen Now and Province of Residence of Total Population (N=106)

MEDICAL PROFESSIONALS BEING SEEN NOW	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
neurologist	30	55.6	25	48.1	55	51.9
physiatrist	6	11.1	10	19.2	16	15.1
orthopedic surgeon	6	11.1	10	19.2	16	15.1
pediatrician	7	13.0	14	26.9	21	19.8
nurse	5	9.3	6	11.5	11	10.4
physiotherapist	16	29.6	14	26.9	30	28.3
occupational	14	25.9	9	17.3	23	21.7
social worker	12	22.2	15	28.8	27	25.5
orthotist	13	24.1	8	15.4	21	19.8
respiratory therapist	10	18.5	5	9.6	15	14.2
speech therapist	5	9.3	7	13.5	12	11.3
other	2	3.7	2	3.8	4	3.8
none	9	16.7	10	19.2	19	17.9

Table 13
Home Care Services Being Received Now and Province of Residence of Total Respondents (N=99)

HOME CARE SERVICES BEING RECEIVED NOW	MANITOBA (4 Non-Respondents)		SASKATCHEWAN (3 Non-Respondents)		TOTAL	
	#	%	#	%	#	%
nurse	6	12.0	2	4.1	8	8.1
orderly/attendant	11	22.0	1	2.0	12	12.1
homemaker	10	20.0	5	10.2	15	15.2
physiotherapist	3	6.0	1	2.0	4	4.0
occupational therapist	3	6.0	2	4.1	5	5.1
speech therapist	1	2.0	0	0.0	1	1.0
social worker	5	10.0	1	2.0	6	6.1
doctor	4	8.0	3	6.1	7	7.1
other	2	4.0	2	4.1	4	4.0
none	28	56.0	37	75.5	65	65.7

Table 14
Source of Funding for Home Care Services and Province of Residence of Total Respondents (N=37)*

SOURCE OF FUNDING FOR HOME CARE SERVICES	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
I pay for some	1	4.5	3	20.0	4	10.8
I pay for all	1	4.5	0	0.0	1	2.7
My family pays for some	0	0.0	2	13.3	2	5.4
My family pays for all	0	0.0	4	26.7	4	10.8
Partially paid for by outside agency	1	4.5	4	26.7	5	13.5
Totally paid for by outside agency	20	90.9	7	46.7	27	73.0

* N=22 in Manitoba (see Table 13, where N=50 minus 28 respondents who are receiving no home care services = 22)

N=15 in Saskatchewan (see Table 13, where N=49 minus 37 respondents who are receiving no home care services = 12; the discrepancy of 3 respondents is unclear)

Table 15
Respondents' Perceptions of Services Needed and Province of Residence of Total Respondents (N=106)

SERVICES NEEDED	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
nurse	4	7.4	0	0.0	4	3.7
attendant	4	7.4	5	9.6	9	8.5
homemaker	2	3.7	1	1.9	3	2.8
physiotherapist	3	5.6	4	7.7	7	6.6
occupational therapist	2	3.7	2	3.8	4	3.7
speech therapist	0	0.0	1	1.9	1	.9
social worker	1	1.9	0	0.0	1	.9
other	6	11.1	3	5.8	9	8.5
none *	36	66.7	38	73.1	74	69.8

*the "none" category was derived from those respondents who answered "no" to the question, "do you feel you need any services that you do not receive?"

"Section IV: Need for Help with Daily Activities". A total of sixteen activity of daily living items were scored for each respondent, according to the following five-point scale: easily, with difficulty but without help, with special aids but no help, with help from someone, unable. Table 16 presents a functional profile of the respondents. The results show that 43.2% of the respondents consider themselves as dependent (i.e., requiring the aid of an assistance device or another person) in self-care tasks.

Dependency upon a wheelchair or other mobility device for mobility both indoors and outdoors is the case for 66.1% of the respondent population (see Table 17). Results from section six of the questionnaire show that 48.1% of the respondents use a power mobility device, while 43.4% use a manual wheelchair of some type. Some clients may have and use both a manual and a power mobility device (i.e., may have a manual wheelchair as a backup for when the electric mobility device requires servicing or repair; or may use a manual wheelchair over short distances or indoors and a power mobility device for longer distances or outdoors). The data on mobility indicate that 84% of the respondents use a mobility device; this gives an indication of the level of handicap amongst the respondent population and serves as confirmation of the level of disability shown in the functional profile of independence in activities of daily living.

Table 16
Ability to Perform Activities of Daily Living
(Manitoba and Saskatchewan Results Combined)

ACTIVITIES OF DAILY LIVING	N*	ABILITY TO PERFORM ACTIVITIES									
		EASILY		NO HELP		WITH AIDS		WITH HELP		UNABLE	
		#	%	#	%	#	%	#	%	#	%
<u>SELF-CARE</u>											
feeding	104	64	61.5	22	21.2	2	1.9	12	11.5	4	3.8
dressing	103	36	35.0	14	13.6	0	0.0	14	13.6	39	37.9
bathing	101	35	34.7	9	8.9	2	2.0	16	15.8	39	38.6
toileting	104	40	38.5	14	13.5	6	5.8	8	7.7	36	34.6
<u>MOBILITY</u>											
turning	104	40	38.5	23	22.1	1	1.0	13	12.5	27	26.0
transfers	103	38	36.9	18	17.5	6	5.8	2	1.9	39	37.9
walk on level	104	33	31.7	8	7.7	5	4.8	5	4.8	53	51.0
climb stairs	104	15	14.4	20	19.2	0	0.0	6	5.8	63	50.6
drive car	94	26	27.7	4	4.3	5	5.3	2	2.1	57	60.6
bus/taxi	98	16	16.3	7	7.1	2	2.0	6	6.1	67	68.4
<u>HOME-MAKING</u>											
shopping	101	31	30.7	14	13.9	4	4.0	35	34.7	17	16.8
cooking	95	33	34.7	11	11.6	1	1.1	9	9.5	41	43.2
housework	99	27	27.3	17	17.2	4	4.0	7	7.1	44	44.4
laundry	96	23	24.0	11	11.5	2	2.1	11	11.5	49	51.0
<u>MISC.</u>											
banking	96	36	37.5	5	5.2	4	4.2	17	17.7	34	35.4
use a phone	101	60	59.4	10	9.9	6	5.9	20	19.8	5	5.0

* N = number of respondents; the variability in the number of respondents per activity is due to questions that were left out by parents or caregivers representing infants and young children with neuromuscular disorders for whom all or parts of the question were not applicable

Table 17
Use of a Mobility Device and Province of Residence of Total Respondents (N=106)

USE OF A WHEEL-CHAIR OR OTHER MOBILITY DEVICE	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
outside only	12	22.2	7	13.5	19	17.9
inside & outside	32	59.3	38	73.0	70	66.1
none	10	18.5	7	13.5	17	16.0
TOTAL	54	100.0	52	100.0	106	100.0

To permit determination of whether clients and their caregivers are receiving sufficient help with daily living activities respondents were asked to choose one of four statements that best described their situation (see Table 18). Although the majority of clients (45.1%) indicated that they were receiving all the help that they require, the next largest category, chosen by 29.7% of respondents, indicated that families and friends need more assistance to meet the daily living needs of the respondents.

In order to ascertain the general level of understanding that clients have about the prognosis of their disorder respondents were asked to indicate whether they felt they would likely need more or less help in the next five years. This information is presented in Table 19.

Table 18
Perceptions of Help Needed Now and Province of Residence of Total Respondents (N=91)

CLIENTS' PERCEPTIONS OF HELP NEEDED NOW	MANITOBA (6 Non-Respondents)		SASKATCHEWAN (9 Non-Respondents)		TOTAL	
	#	%	#	%	#	%
I receive all the help I need	21	43.8	20	46.5	41	45.1
I need a little more help	7	14.6	8	18.6	15	16.5
I need a lot more help	5	10.4	3	7.0	8	8.8
I do not need help; my family and friends need help helping me	15	31.2	12	27.9	27	29.7
TOTAL	48	100.0	43	100.0	91	100.0

Table 19
Respondents' Perceptions of Help that they will Need in Five Years and Province of Residence of Respondents (N=104)

CLIENTS' PERCEPTIONS OF HELP NEEDED IN FIVE YEARS	MANITOBA (1 Non-Respondent)		SASKATCHEWAN (1 Non-Respondent)		TOTAL	
	#	%	#	%	#	%
a great deal more	22	41.5	19	37.2	41	39.4
a little more	8	15.1	6	11.8	14	13.5
same amount	2	3.8	11	21.6	13	12.5
less help	1	1.9	3	5.9	4	3.8
can't say	20	37.7	12	23.5	32	30.8
TOTAL	53	100.0	51	100.0	104	100.0

To determine the need for relief for caregivers, respondents were asked to indicate whether they were using or aware of respite care type services. This information is presented in Table 20. Because respondents were specifically asked to specify that they did not require this type of service, if this was the case in their situation, it can be said with certainty that the remaining 43.5% of the respondents feel that they do need respite care.

Table 20
Need for Respite Care and Province of Residence of Respondents (N=99)

RESPITE CARE	MANITOBA (2 Non-Respondents)		SASKATCHEWAN (5 Non-Respondents)		TOTAL	
	#	%	#	%	#	%
using	11	21.2	6	12.8	17	17.2
do not need	30	57.7	26	55.3	56	56.6
not available	1	1.9	6	12.8	7	7.1
not aware of this service	10	19.2	9	19.1	19	19.2
TOTAL	52	100.0	47	100.0	99	100.0

"Section V: Need for Specialized Housing". As indicated in the methodology section results from this section of the questionnnaire are not reported on in this paper.

"Section VI: Need for Health-Care Equipment". Table 21 presents a profile of the assistive devices being used by the respondents. Table 22 outlines the devices that the respondents feel they need. Because most medical equipment items in both Manitoba and Saskatchewan are provided by provincially funded universal equipment programs, clients who had accessed these programs were asked to indicate their level of satisfaction with various aspects of the programs (see Table 23) and whether they had experienced any difficulty in obtaining their equipment (see Table 24) or in arranging repairs (see Table 25).

Table 21
Assistive Devices Being Used and Province of Residence of Total Respondents (N=106)

ASSISTIVE DEVICES BEING USED NOW	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
MOBILITY AIDS:						
electric w/c	22	40.7	20	38.5	42	39.6
manual w/c	16	29.6	24	46.2	40	37.7
lightweight w/c	3	5.5	1	1.9	4	3.8
reclining w/c	2	3.7	0	0.0	2	1.9
scooter	2	3.7	5	9.6	7	6.6
power pak	1	1.9	1	1.9	2	1.9
AMBULATION AIDS:						
walker	0	0.0	3	5.8	3	2.8
cane	7	13.0	2	3.8	9	8.5
ORTHOPEDIC DEVICES:						
seating insert	9	16.7	13	25.0	22	20.8
standing frame	3	5.5	1	1.9	4	3.8
back brace	1	1.9	2	3.8	3	2.8
orthopedic equip.	3	5.5	5	9.6	8	7.5
BATHROOM AIDS:						
bathseat	9	16.7	5	9.6	14	13.2
commode	10	18.5	7	13.5	17	16.0
hydraulic tublift	2	3.7	11	21.2	13	12.3
raised toilet	9	16.7	5	9.6	14	13.2
grab bars	12	22.2	10	19.2	22	20.8
BEDS, MATTRESSES, CUSHIONS:						
electric hospital bed	1	1.9	1	1.9	2	1.9
manual hospital	3	5.5	2	3.8	5	4.7
waterbed	7	13.0	4	7.7	11	10.4
other type of bed	2	3.7	4	7.7	6	5.7
T-foam mattress	1	1.9	0	0.0	1	.9
alternating pressure pad	1	1.9	2	3.8	3	2.8
sheepskin pad	7	13.0	7	13.5	14	13.2
other mattress	1	1.9	3	5.8	4	3.8
bed rails	2	3.7	2	3.8	4	3.8
w/c cushion	8	14.8	9	17.3	17	16.0
LIFTS & RAMPS:						
Hoyer lift	8	14.8	1	1.9	9	8.5
other lift	4	7.4	2	3.8	6	5.7
porch lift	1	1.9	6	11.1	7	6.6
elevator	3	5.5	1	1.9	4	3.8
van lift	5	9.3	4	7.7	9	8.5
RESPIRATORY AIDS:						
respirator	2	3.7	2	3.8	4	3.8
chest percussor	4	7.4	0	0.0	4	3.8
suction machine	4	7.4	2	3.8	6	5.7
TECHNICAL AIDS:						
computer	3	5.5	5	9.6	8	7.5
environmental control system	0	0.0	3	5.8	3	2.8
protect-alert	3	5.5	3	5.8	6	5.7
communication aid	1	1.9	1	1.9	2	1.9

Table 22
Assistive Devices Needed and Province of Residence of Total Respondents (N=106)

ASSISTIVE DEVICES NEEDED	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
<u>MOBILITY AIDS:</u>						
electric w/c	5	9.3	2	3.8	7	6.6
manual w/c	1	1.9	0	0.0	1	.9
ultralight w/c	1	1.9	2	3.8	3	2.8
scooter	2	3.7	1	1.9	3	2.8
power pak	2	3.7	1	1.9	3	2.8
<u>AMBULATION AIDS:</u>						
walker	1	1.9	0	0.0	1	.9
cane	1	1.9	0	0.0	1	.9
<u>ORTHOPEDIC DEVICES:</u>						
seating insert	1	1.9	2	3.8	3	2.8
standing frame	1	1.9	0	0.0	1	.9
<u>BATHROOM AIDS:</u>						
bathseat	2	3.7	2	3.8	4	3.8
commode	2	3.7	0	0.0	2	1.9
hydraulic tublift	6	11.1	1	1.9	7	6.6
raised toilet seat	2	3.7	3	5.8	5	4.7
grab bars	2	3.7	2	3.8	4	3.8
<u>BEDS, MATTRESSES, CUSHIONS:</u>						
electric hospital bed	4	7.4	2	3.8	6	5.7
waterbed	3	5.5	2	3.8	5	4.7
other type of bed	2	3.7	0	0.0	2	1.9
T-foam mattress	0	0.0	2	3.8	2	1.9
alternating pressure pad	3	5.5	0	0.0	3	2.8
sheepskin pad	4	7.4	2	3.8	6	5.7
bed rails	1	1.9	0	0.0	1	.9
w/c cushion	2	3.7	0	0.0	2	1.9
<u>LIFTS & RAMPS:</u>						
portable aluminum ramps	3	5.5	7	13.5	10	9.4
Hoyer lift	3	5.5	0	0.0	3	2.8
other lift	2	3.7	1	1.9	3	2.8
porch lift	1	1.9	0	0.0	1	.9
elevator	3	5.5	3	5.8	6	5.7
van lift	5	9.3	4	7.7	9	8.5
<u>RESPIRATORY AIDS:</u>						
respirator	0	0.0	1	1.9	1	.9
<u>TECHNICAL AIDS:</u>						
protect-alert	9	16.7	7	13.5	16	15.1
communication aid	2	3.7	5	9.6	7	6.6

Table 23
Dissatisfaction with Government Equipment Program and Province of Residence of Total Respondents

DISSATISFIED WITH GOVERNMENT EQUIPMENT PROGRAM	MANITOBA #	MANITOBA %	SASKATCHEWAN #	SASKATCHEWAN %	TOTAL #	TOTAL %
range of equipment available	5	15.2	4	13.8	9	14.5
assessment	4	12.5	7	25.0	11	18.3
servicing	3	9.4	4	13.8	7	11.5
replacement	6	20.0	8	30.8	14	25.0

Table 24
Difficulty Obtaining Equipment and Province of Residence of Respondents (N=70)

DIFFICULT TO OBTAIN EQUIPMENT	MANITOBA #	MANITOBA %	SASKATCHEWAN #	SASKATCHEWAN %	TOTAL #	TOTAL %
yes	16	42.1	19	59.4	35	50.0
no	22	57.9	13	40.6	35	50.0
TOTAL	38	100.0	32	100.0	70	100.0

Table 25
Difficulty Arranging Repairs to Equipment and Province of Residence of Respondents (N=64)

DIFFICULT TO ARRANGE EQUIPMENT REPAIRS	MANITOBA #	MANITOBA %	SASKATCHEWAN #	SASKATCHEWAN %	TOTAL #	TOTAL %
yes	7	20.6	7	23.3	14	21.9
no	27	79.4	23	76.7	50	78.1
TOTAL	34	100.0	30	100.0	64	100.0

"<u>Section VII: Need for Emotional Support.</u> Table 26 presents a breakdown of the people to whom the respondents and their families turn when they have difficulty coping. The majority (53.8%) report that "we deal with it on our own". This is consistent with the responses of the only 10.4% of the respondents who report that they are presently involved with any client, parent, or family support groups. There is, however, obvious interest in joining group functions; 72.6% of the respondents indicated that they would attend group meetings for social and recreational, educational, and mutual support purposes (see Table 27).

Clients were asked to rank the importance of a list of 25 psychosocial issues on a four-point scale (great need, some need, no need, don't know) in terms of whether these were pressing needs for themselves and their families. The large number of items combined with the choice of four ranks per item produced data that were difficult to interpret and not meaningful for the purpose of determining clients' perceptions of their most pressing needs. Ranked importance of the items was determined instead from the question that asked clients to rank their three most pressing needs. Even here it was necessary to exclude all but the highest ranked need. The results of this question are presented in Tables 28 to 31.

Table 26
Resources Available During Difficult Times and Province of Residence of Total Respondents (N=106)

RESOURCE	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
friends	26	48.1	15	28.8	41	38.7
relatives	13	24.1	16	30.8	29	27.4
social worker	13	24.1	5	9.6	18	17.0
doctor	13	24.1	8	15.4	21	19.8
psychologist	3	5.6	0	0.0	3	2.8
marriage counsellor	2	3.7	0	0.0	2	1.9
others with disorder	4	7.4	1	1.9	5	4.7
clergy	5	9.3	6	11.5	11	10.4
MDAC staff	9	16.7	1	1.9	10	9.4
deal with it on our own	30	55.6	27	51.9	57	53.8
other	5	9.3	6	11.5	11	10.4

Table 27
Interest in Attending Group Meetings and Province of Residence of Total Respondents (N=106)

INTEREST IN ATTENDING	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
social & recreational events	23	42.6	23	44.2	46	43.4
information sessions on MD	30	55.6	30	57.7	60	56.6
support meetings with a professional person	21	38.9	24	46.2	45	42.5
other	1	1.9	4	7.7	5	4.7
none	17	31.5	12	23.1	29	27.4

Table 28
Respondents' Perceptions of their Most Pressing Needs and Province of Residence of Total Respondents (N=90)

MOST PRESSING NEEDS	MANITOBA (6 Non-Respondents)		SASKATCHEWAN (10 Non-Respondents)		TOTAL	
	#	%	#	%	#	%
respite care	8	16.7	6	14.3	14	15.6
daycare	1	2.1	1	2.4	2	2.2
attendant care	3	6.3	3	7.1	6	6.7
family to be paid as attendants	4	8.3	4	9.5	8	8.9
better coord. of health & social services	2	4.2	3	7.1	5	5.6
accessible transportation systems	7	14.6	6	14.3	13	14.4
accessible public buildings	11	22.9	11	26.2	22	24.4
parent/client support groups	6	12.5	7	16.7	13	14.4
advocacy to government	6	12.5	4	9.5	10	11.1
visits by a professional	5	10.4	3	7.1	8	8.9
coord. of hospital & home care	1	2.1	1	2.4	2	2.2
buddy system	8	16.7	6	14.3	14	15.6
funding for home modifications	9	18.8	7	16.7	16	17.8
funding for equip.	7	14.6	6	14.3	13	14.4
death counselling	1	2.1	2	4.8	3	3.3
increased social opportunities	6	12.5	9	21.4	15	16.7
educational & job training	7	14.6	4	9.5	11	12.2
job opportunities	12	25.0	5	11.9	17	18.9
better attitudes	8	16.7	9	21.4	17	18.9
accessible housing	6	12.5	7	16.7	13	14.4
educate employers about workplace accessibility	3	6.3	1	2.4	4	4.4
educate teachers	5	10.4	5	11.9	10	11.1
liaison with school	1	2.1	1	2.4	2	2.2
expand genetics services	4	8.3	1	2.4	5	5.6
other	2	4.2	2	4.8	4	4.4

Table 29
Ranking of Manitoba Respondents' Perceptions of Their Most Pressing Needs

RANK	NEED	%
1.	-improved job opportunities for the disabled	25.0
2.	-universal accessibility of public buildings	22.9
3.	-more funding for home modifications	18.8
4.	-family respite (relief) care	16.7
	-a buddy system with clients and families to share problems	16.7
	-better public attitudes towards disabled people	16.7
5.	-more funding for equipment	14.6
	-improved accessible transportation systems for the disabled	14.6
	-improved educational and job training	14.6
6.	-a network of parent or client suppport groups	12.5
	-someone to represent the concerns of the disabled to government	12.5
	-more social and recreational opportunities designed for the disabled	12.5
	-more accessible housing options	12.5
7.	-someone to educate teachers about the abilities of children with neuromuscular disorders	10.4
	-regular visits by a professional knowledgeable about neuromuscular disorders	10.4
8.	-expansion of genetic counselling services	8.3
	-subsidies for family members to be paid as attendants	8.3
9.	-someone to educate employers about workplace accessibility	6.3
10.	-subsidies for attendant care	6.3
11.	-better coordination of existing health and social services	4.2
	-other	4.2
12.	-specialized daycare facilities for children and adults	2.1
	-someone to coordinate hospital and home care	2.1
	-death and grieving counselling	2.1
	-someone to be liaison between the client and the school or workplace	2.1

Table 30
Ranking of Saskatchewan Respondents' Perceptions of Their Most Pressing Needs

RANK	NEED	%
1.	-universal accessibility of public buildings	26.2
2.	-more social and recreational opportunities designed for the disabled	21.4
	-better public attitudes towards disabled people	21.4
3.	-more accessible housing options	16.7
	-more funding for home modifications	16.7
	-a network of parent or client support groups	16.7
4.	-more funding for equipment	14.3
	-a buddy system with clients and families to share problems	14.3
	-improved accessible transportation systems for the disabled	14.3
	-family respite (relief) care	14.3
5.	-someone to educate teachers about the abilities of children with neuromuscular disorders	11.9
	-improved job opportunities for the disabled	11.9
6.	-improved educational and job training	9.5
	-someone to represent the concerns of the disabled to government	9.5
	-subsidies for family members to be paid as attendants	9.5
7.	-subsidies for attendant care	7.1
	-better coordination of existing health and social services	7.1
	-regular visits by a professional knowledgeable about neuromuscular disorders	7.1
8.	-other	4.8
	-death and grieving counselling	4.8
9.	-expansion of genetic counselling services	2.4
	-someone to be liaison between the client and the school or workplace	2.4
	-someone to educate employers about workplace accessibility	2.4
	-better coordination of hospital and home care	2.4
	-specialized daycare facilities for children or adults	2.4

Table 31
Ranking of The Total Respondents' Perceptions of Their Most Pressing Needs

RANK	NEED	%
1.	-universal accessibility of public buildings	24.4
2.	-improved job opportunities for the disabled	18.9
	-better public attitudes towards the disabled	18.9
3.	-more funding for home modifications	17.8
4.	-more social and recreational opportunities for the disabled	16.7
5.	-a buddy system with clients and families to share problems	15.6
	-family respite (relief) care	15.6
6.	-a network of parent or client support groups	14.4
	-more funding for equipment	14.4
	-improved accessible transportation systems for the disabled	14.4
	-more accessible housing options	14.4
7.	-improved educational and job training	12.2
8.	-someone to represent the concerns of the disabled to government	11.1
	-someone to educate teachers about the abilities of children with neuromuscular disorders	11.1
9.	-subsidies for family members to be paid as attendants	8.9
	-regular visits by a professional knowledgeable about neuromuscular disorders	8.9
10.	-subsidies for attendant care	6.7
11.	-expansion of genetic counselling services	5.6
	-better coordination of existing health and social services	5.6
12.	-someone to educate employers about workplace accessibility	4.4
	-other	4.4
13.	-death and grieving counselling	3.3
14.	-someone to be liaison between the client and the school or workplace	2.2
	-specialized daycare facilities for children and adults	2.2
	-someone to coordinate hospital and home care programs	2.2

Agency Survey

Thirty-three individual and small group interviews were conducted with health-care, voluntary agency, and government representatives in Manitoba and Saskatchewan (see Table 32). An inventory of the programs and services available to persons with neuromuscular disorders in Manitoba and Saskatchewan was compiled with the information gained from the interviews. Detailed profiles of each service were produced, resulting in the development of a comprehensive directory of services for individuals with neuromuscular disorders specifically, and individuals with physical disabilities generally.

Each interview with a key informant was concluded by asking the question, "Based on your experience what are the greatest problems, barriers, and/or difficulties facing clients with neuromuscular disorders living in Manitoba (in Saskatchewan)?". If respondents had no experience with clients having neuromuscular disorders, then the question was worded, "Based on your experience what are the greatest problems, barriers, and/or difficulties facing clients with physical disabilities living in Manitoba (in Saskatchewan)?". These responses were recored in interview notes as they were articulated. Over 100 problems were recorded (see Appendix 10 and 11). From these lists those problems that were mentioned by more than three individuals or groups were extracted. These problems are listed in

Tables 33 and 34 with the frequency of mention noted in brackets afterward. The purpose of this procedure was to reduce the overall number of problems to a more manageable size and to categorize the problems under general headings. Although the wording of these problems has been condensed and modified, their original meaning was preserved.

Table 32
Key Informants for Agency Survey

MANITOBA	SASKATCHEWAN
Department of Education for Manitoba -Special Educational Consultant	Saskatchewan Department of Education -Educational Consultant, Special Education Branch
Vocational Rehabilitation Program -Chief Program Consultant	Advanced Education and Manpower Department, Vocational Rehabilitation for Disabled Persons Program -Program Manager
Rehabilitation Centre for Children, Winnipeg -Pediatric Neuromuscular Team (Neurologist, Orthopedic Surgeon, Physiotherapist, Occupational Therapist, Nurse, Biomedical Engineer) -separate meetings with -Neurologist -Occupational & Physio-Therapist	Children's Rehabilitation Centre, University Hospital Saskatoon -Pediatric Neuromuscular Team (Neurologist, Social Worker, Physiotherapist, Nurse, Occupational Therapist) -Medical Director of Centre -separate meetings with -Neurologist -Physiotherapist
Children's Hospital, Winnipeg -Director and Assistant Director of Rehabilitation Services	Wascana Rehabilitation Centre, Regina -Senior Occupational Therapists, Adult Neurology Team -Occupational Therapist & Social Worker, Pediatric Neuromuscular Team
Rehabilitation Hospital for for Adults, Health Sciences Centre, Winnipeg -Assistant Director of Occupational Therapy Services & Senior Therapist, Neurology Team	Saskatchewan Aids to Independent Living (SAIL) Program -Director -Depot Coordinator
Manitoba Health, Home Care Program -Program Specialist	Saskatchewan Health -Director of Community Therapy Programs -Manager of Policy Unit for Continuing (Home) Care Programs
Society for Manitobans with Disabilities -Senior Supervisor of Childrens' Programs -Senior Supervisor of Adult Progams -Director of Preschool -Director of Wheelchair Services	Saskatchewan Abilities Council -Program Manager, Vocational Programs -Manager, Orthopedic and Technical Aids Programs -Manager of Training Centre -Manager of Special Needs Transportation (Saskatoon) -Director of Handicapped Farmers Program
Manitoba League of the Physically Handicapped -Provincial Coordinator	Saskatchewan Voice of the Handicapped -Communications & Advocacy Officer
Community Respite Service -Coordinator & Assistant Coordinator	
Independent Living Resource Centre -Managing Director	

Table 33
Categories of Problems from Agency Contacts in Manitoba

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1. Clients experience numerous problems in the provision, assessment, choice, availability and maintenance of medical equipment (9)

2. Families and clients need self-help, peer support type groups, as well as opportunities for counselling from qualified professionals (7)

3. Services available to disabled Manitobans living in rural and northern areas of the province are poor in comparison to those available in urban areas (6)

4. There is a shortage of occupational and physiotherapists with pediatric expertise in Manitoba (5)

5. Medical care in the community, as opposed to an institution, is underfunded, complex and lacks coordination (5)

6. Professionals foster dependency amongst their clients and establish a bureaucratic system of service delivery that meets their own needs, rather than the needs of the clients and their families (4)

The remainder of the problems raised by the professional contacts interviewed focused on the following issues:

-housing (3)
-workplace (3)
-limited programs and services for adolescents (3)
-transportation (3)
-financial hardship related to disorder (2)
-no adult-oriented neuromuscular services and expertise (2)
-education (2)
-recreation/leisure (1)
-respite (1)

Table 34
Categories of Problems from Agency Contacts in Saskatchewan

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1. Clients experience numerous problems in the provision, assessment, choice, availability and maintenance of medical equipment (18)

2. Services available to disabled Saskatchewan residents living in rural and northern areas of the province are poor in comparison to those available in urban areas (7)

3. There is a serious manpower shortage of occupational, physical and speech therapy personnel in Saskatchewan (5)

4. Provincial legislation dictates physician domination. Assessment and intervention by allied health professionals require a medical doctor's referral (5)

5. Medical and supportive care in the community is underfunded, understaffed, complex and lacks coordination (4)

6. Clients experience financial hardship as a result of the higher daily living costs related to their disability (e.g., travel costs related to medical appointments; need for costly specialized equipment, daily living and medical care, transportation, etc.) (4)

The remainder of the problems raised by the professional contacts interviewed focused on the following issues:

-need for emotional support for clients and families (3)
-transportation costs (3)
-need for an equipment and information resource centre (3)
-gaps in the system (3)
-attendant care (3)
-accessibility (2)
-education (2)
-employment (2)
-housing (1)
-staffing/manpower (1)

Individual Assessments

The results of the individual assessments are presented in sections which correspond to the sections of the client survey.

Background information. Table 35 presents the age ranges of the clients who participated in the individual assessments. The age categories in this table correspond to the categories used to report data from the client survey. Table 36 presents the distribution of the participants by sex and province. Of the 16 Manitoba clients who participated in the individual assessments 14 resided in the Winnipeg catchment area; the remaining two resided in the Central and Eastman regions (regional boundaries correspond to provincial health unit boundaries; see Appendix 12) of Manitoba. Of the 17 Saskatchewan clients who participated in the individual assessments seven resided in the Saskatoon catchment area and five resided in the Regina catchment area; the remaining five clients resided in the Rosetown-Biggar- Kindersley region (1) and the North Battleford region (4) of Saskatchewan (regional boundaries correspond to provincial health unit boundaries; see Appendix 13). Table 37 presents the distribution of diagnoses amongst the participants.

Table 35
Age and Province of Residence of Participants
in the Individual Assessments (N=33)

AGE IN YEARS	MANITOBA		SASKATCHEWAN		TOTAL		CUMULATIVE
	#	%	#	%	#	%	%
0 - 5	1	6.2	1	5.9	2	6.1	6.1
6 - 12	3	18.8	6	35.3	9	27.3	33.4
13 - 18	1	6.2	3	17.6	4	12.1	45.5
19 - 24	4	25.0	3	17.6	7	21.2	66.7
25 - 44	4	25.0	4	23.6	8	24.2	90.9
45 - 64	2	12.5	0	0.0	2	6.1	97.0
65+	1	6.2	0	0.0	1	3.0	100.0
TOTAL	16	100.0	17	100.0	33	100.0	

Table 36
Sex and Province of Residence of Participants
in the Individual Assessments (N=33)

SEX	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
male	12	75.0	12	70.6	24	72.7
female	4	25.0	5	29.4	9	27.3
TOTAL	16	100.0	17	100.0	33	100.0

Table 37
Diagnosis and Province of Residence of Participants in the Individual Assessments (N=33)

DIAGNOSIS	MANITOBA		SASKATCHEWAN		TOTAL	
	#	%	#	%	#	%
MUSCULAR DYSTROPHIES:						
Duchenne	5	31.2	5	29.4	10	30.3
Beckers	1	6.3	0	0.0	1	3.0
Fascioscapulo-humeral	0	0.0	1	5.9	1	3.0
Limb Girdle	2	12.5	1	5.9	3	9.1
Myotonic	1	6.3	0	0.0	1	3.0
Congenital	0	0.0	2	11.8	2	6.1
Type Unknown	0	0.0	1	5.9	1	3.0
SPINAL MUSCULAR ATROPHIES:						
Amyotrophic Lateral Sclerosis	1	6.3	0	0.0	1	3.0
Werdnig-Hoffman	5	31.2	1	5.9	6	18.2
Kugelberg-Wellander	0	0.0	2	11.8	2	6.1
Type Unknown	0	0.0	1	5.9	1	3.0
DISEASES OF PERIPHERAL NERVE:						
Charcot-Marie-Tooth Disease	0	0.0	1	5.9	1	3.0
Friedreich's Ataxia	1	6.3	2	11.8	3	9.1
TOTAL	16	100.0	17	100.0	33	100.0

Need for information. Clients were asked to specify their diagnosis and to describe what they knew about the disorder. Parents or caregivers were asked these questions, if the client was a young child. Responses were scored according to the following criteria:

1 point = knowledge of the name of their disorder

2 points = above plus knowledge of etiology (cause)

3 points = above plus knowledge of primary involvement of voluntary muscles

4 points = above plus knowledge of prognosis of progressive weakness, severity, and lifespan.

Of the thirty-three clients who participated in the individual assessments, 11 scored four points, 18 scored three points, 3 scored two points and one scored one point. In some cases clients and caregivers who had limited knowledge about the disorder indicated that they would be interested in learning more about the disorder; in other cases clients specifically remarked that they had no desire to know about their prognosis and that they were taking "one day at a time".

Need for Medical Services. Vignos' (1959; Siegel, 1977) stages of muscular dystrophy were used to determine the functional ability of the patient. Table 38 describes each of Vignos' stages and indicates the functional level of the thirty-three clients assessed.

Table 38
Physical/Functional Level of the Participants in the Individual Assessments (N=33)

NO. OF CLIENTS	% OF RESPONDENT POPULATION	VIGNOS STAGE & DESCRIPTION
0	0.0	1. Walks and climbs stairs without assistance.
2	6.1	2. Walks and climbs stairs with aid of railing.
3	9.1	3. Walks and climbs stairs slowly with aid of railing.
1	3.0	4. Walks but cannot climb stairs.
0	0.0	5. Walks unassisted but cannot climb stairs or get out of a chair.
0	0.0	6. Walks only with assistance or with braces.
6	18.2	7. In wheelchair. Sits erect, can roll chair and perform bed and wheelchair activities of daily living.
7	21.2	8. In wheelchair. Sits erect. Unable to perform bed and chair activities without assistance.
14	42.4	9. In wheelchair. Sits erect only with support. Able to do only minimal activities of daily living.
0	0.0	10. In bed. Cannot perform activities of daily living without assistance.

All clients under the age of 18 were attending a neuromuscular disease clinic at least once per year. Not one client over the age of 18 was attending a formal neuromuscular clinic or receiving ongoing medical follow-up for their disorder. Most clients had a family doctor who was available for emergencies and common illnesses. There was generally poor utilization of available community rehabilitation services either on an outpatient basis in a local treatment facility, or in the home setting. The assessing therapist's perception of gaps in services included the need for adult neuromuscular clinics and liaison between pediatric and adult facilities, as well as improved vocational rehabilitation, counselling, and placement services.

<u>Need for help with daily activities.</u> Twenty-one of the 33 participants (63.6%) required assistance with transfers (bed/wheelchair and in/out of the bathtub). None of these clients were able to weight-bear and pivot on their lower extremities; hence, transfers required a full lift. In Manitoba most families had the assistance of attendants or orderlies, who visited the home and/or work setting throughout the day to assist with transfers, dressing, and other activities of daily living. Because orderly service was not a provincially funded service in Saskatchewan, caregivers in this province experienced significant physical

and emotional difficulties in coping with the needs of the affected family member for assistance with daily activities.

Need for health-care equipment. In both Manitoba and Saskatchewan clients and their caregivers had few complaints concerning the level of service or the availability of medical equipment from the provincially funded universal equipment programs. In several cases clients were surprised that questions about their satisfaction with the government equipment programs were being asked and wondered whether they "should" be dissatisfied. Clients who had visited provinces where greater selection of equipment is available expressed frustration with the lack of choice available from their provincial programs. In Saskatchewan several clients indicated concern about pending changes to the universal equipment program that would result in service charges for delivery of equipment and reduced equipment budgets. In both provinces the failure of the equipment programs to provide lightweight manual wheelchairs was seen by the assessing therapist as a disadvantage to the population of clients under study, for whom lighter wheelchairs serve as a form of therapy as well as a form of mobility and for whom the alternative to manual wheelchairs, which are too heavy to push, is a power mobility device.

Need for emotional support. Thirty of the 33 clients assessed (90 %) expressed feelings of isolation from friends and social activities in their communities. Reasons for this isolation were inability to participate in social events due to wheelchair inaccessibility of facilities or friends' homes, no time or energy left after dealing with the routine imposed by the disability, difficulty in arranging respite or relief care, and impatience with the "trivialness" of the social scene in comparison to the tragedy and hardship of their own lives. Most clients indicated that they would find it helpful to have a professional working in the province, who was knowledgeable about neuromuscular disorders, who could be available as a support and a resource, and who could arrange or facilitate group sessions with other clients and parents.

Each individual interview was concluded by asking clients or their caregivers to describe their most pressing needs, their biggest problems, and their greatest barriers. In every situation clients expressed the need for concrete items, such as equipment and physical assistance. Needs were described in terms of problems of the "here and now", rather than in terms of both present and future needs. In most cases clients and their families presented family coping and emotional difficulties and poor knowledge of their disorder, but they did not identify these issues as problems or needs. The assessing therapist's perceptions of the clients' most pressing needs, biggest problems and greatest barriers included the need for family and parent counselling on stress and grief, disorder information, for equipment information, respite, and mutual support from other clients and families. The assessing therapist's perceptions are presented in the next section.

Hierarchy of the Needs of Clients with Neuromuscular Disorders

Each of the three tools used in this study concluded by asking respondents to specify their perceptions of their own or their clients' most pressing needs. In Table 39 a hierarchy of the most pressing needs of clients with neuromuscular disorders has been constructed taking into consideration three perspectives: one, the perspective of clients who have reported on their own situation; two, the perspective of agency representatives who have reported on their impressions of the needs of clients with neuromuscular disorders in general; and three, from the perspective of the health-care professional who has reported on her impressions of the needs of the sample of clients with neuromuscular disorders. The heirarchy is based upon the frequency of mention of each issue. Examination of the needs presented in each of the lists shows that, although the priority assigned to each item is different for each of the three groups, there is considerable overlap.

Table 39

Hierarchy of Needs According to the Perceptions of Clients, Key Informants, & a Health-care Professional

CLIENTS (N=106)	KEY INFORMANTS (N=33)	PROFESSIONAL (N=33)
1. accessibility* (56.6%)	1. provision, assessment, choice, availability of equipment (81.8%)	1. social isolation (90.0%)
2. parent/client support** (30.0%)	2. poor services for clients in rural & Northern regions (39.4%)	2. disorder information (72.7%)
3. improved job opportunities for the disabled (18.9%)	3. shortage of rehabilitation personnel (speech, occupational, & physiotherapists) (30.3%) self-help, emotional support, & counselling (30.3%)	3. parent, client, family support (48.5%)
4. better public attitudes towards disabled people (18.9%)	4. poor medical & support services in the community (27.3%)	4. client & family counselling about stress, grief, & acceptance of disorder (45.5%) respite care (45.5%) accessibility (45.5%) adult & transition clinic (45.5%)
5. more social & recreational opportunities for disabled (16.7)		5. (a) vocational counselling & placement (36.4%)
6. family respite care (15.6%)		6. information on & assessment for equipment (33.3%) attendant care (33.3%)
7. more funding for equipment (14.4%)		7. better coordination of local services (12.1%) funding for home renovations (12.1%) lack of peer relationships (12.1%) accessible transportation (12.1%)
8. improved accessible transportation (14.4%)		8. life skills training (9.1%)

*combines need for accessibility to public buildings, need for funding for home modifications, & need for more accessible housing

** combines need for a buddy system for clients & families to share problems & need for a network of client or parent support groups

CHAPTER V

DISCUSSION OF THE RESULTS

A major objective of this study was to compare information about the needs of clients with neuromuscular disorders elicited from different perspectives. In this section the results of the study will form the basis for discussion of possible reasons for the similarities and differences of the perceptions of need obtained from clients, agency representatives, and professionals. Because the measurement tools and procedures developed for this study were intended to serve as a prototype for the needs assessment of clients with neuromuscular disorders in other provinces and regions, suggestions will be made in this section for revisions to both content and procedure. Finally, this section will examine the study results in an attempt to offer recommendations to assist The Muscular Dystrophy Association of Canada in formulating program plans, undertaking advocacy projects, and determining staffing requirements on behalf of registered and eligible clients in the provinces of Manitoba and Saskatchewan.

Varying Perspectives on a Multidimensional Problem

The hierarchy of needs presented in Table 39 of the results section shows that there is definite congruence in the perceptions of the three respondent groups in this study about the needs of clients with neuromuscular disorders. Results from the client survey and from the individual assessment show the greatest agreement, although even here the priority of the needs identified is different.

Several explanations can be postulated for the different weighting of the perceptions of needs between the three respondent groups in this study. Firstly, although the final question posed to each group asked respondents to identify their most pressing needs, the respondents in the client survey ranked items in a checklist, which was developed by and known to the health-care professional performing the individual assessments; only the key informants of the agency survey were required to respond to this question with no cues. This may account for the greater agreement between the ranked needs of the client survey and the individual assessments. In addition, the greater discrepancy between the results of the agency survey and the other two tools may be accounted for by the fact that in some cases the key informants of the agency survey identified the needs of persons with neuromuscular disorders only through extrapolation from their knowledge of the general needs of persons with physical disabilities.

Although the clients represented in the client survey were persons with neuromuscular disorders of all ages, all the respondents of the client survey were, however, adults. Adult clients completed the client survey on behalf of themselves, and adult respondents completed the client survey on behalf of, or together with their children, who are registered clients. Represented in the responses of the client survey are, therefore, the life issues or adaptive tasks that have become internalized and that have become priorities of concern to the adults who completed the survey. Each adult respondent completed the client survey on the basis of his life's situation, incorporating his own unique needs and goals as a client, parent or caregiver. An examination of adult learning and the influence of developmental stages may offer additional insight into the needs identified from the client survey.

The literature on lifelong learning suggests that past experiences are a factor in learning and that learning occurs throughout life in response to experiences that encourage further development; it also suggests that learning is necessary for responding to the internal and external pressures of experience, and that experience is the essential component in the learning an adult does (Brundage & MacKeracher, 1980). The implication is that the most effective learning content and processes are ones which are consistent with and supportive of the individual's current roles, problems, or needs. The process of learning is dependent upon whether the learner is able to accept responsibility for his own learning through self-reflection and self-direction or whether the learner relies on an external change agent.

The medical model has traditionally viewed the patient as a passive recipient of health-care services or treatment. More recently the concept of "patient" has been transformed into the concept of "client", implying a more proactive than reactive relationship with health-care providers. The trend towards deinstitutionalization and community living for the disabled has made obsolete the traditional concept of the passive patient and family in the hands of the hospital or institution being shaped by the medical community; what has emerged instead is the notion of the family and client on their own "turf", directing their own care and advocating for their own needs. Adopting terminology from the field of education, it would not be difficult to envision the characteristics of the "self-directed" patient or client. The suggestion is that the respondents of the client survey in this study have by the nature of their roles as caregivers and advocates, by the nature of these experiences, and by the nature of their close liason with the health-care community identified needs that are similar to those identified by professionals.

Another factor that may have affected on the results of the client survey is the impression given to the respondents that their input would have a direct bearing on the planning and implementation of programs to meet their needs. This message was clearly communicated in the cover letter included in the mailing of the client survey. Since the first step in the planning process requires an awareness of the need to change something (Brundage & MacKeracher, 1980), respondents were likely determined to seize the opportunity given to them to express their views about their own and their family's needs. Completion of the survey was probably seen as a rare chance for clients to participate in the shaping and development of programs and services that would help address their unmet needs.

The discrepancy in the ranking of needs identified by survey respondents and by professionals may be the result of respondents' identification of felt needs, as opposed to real needs. In presenting the results of the individual assessment the tendency of clients to identify tangible items and immediate concerns as their most pressing needs was noted. These needs, although accurate representations of need at one level, were in some cases seen by the professional as symptoms of more significant, underlying, or real needs; the real needs were, however, not apparent to the clients, who were, in the health-care professional's estimation, overwhelmed by the emotional and the physical demands of their situation. Agency representatives and the health-care professional were, perhaps, able to differentiate between real and symptomatic needs more objectively and, consequently, rated these differently on the hierarchy than the symptomatic needs identified and ranked by the clients themselves.

Finally, the design of the client questionnaire may have contributed both to the needs identified by clients and to the variation seen in the weighting of needs between this tool and the other two tools; this will be discussed in the next section.

Suggested Revisions to Needs Assessment Tools & Procedure

The process of undertaking this needs assessment project has suggested revisions to the content of the tools developed and to the procedure employed in administering each tool. The following suggestions are offered should a similar or larger assessment of the needs of a population of persons with neuromuscular disorders be undertaken.

The client survey. A major error in the wording of the client survey was found in the question concerning attendance at a neuromuscular disorder clinic. This question asked, "Have you ever attended a neuromuscular disorder clinic?"; the response choices provided were either "yes" or "no". If clients chose the "no" response, they answered the question, "Why do you not attend a clinic?". Unfortunately, these questions fail to provide information that differentiates between the number of clients who have attended a neuromuscular disorder clinic in the past, but do not attend now, and the number of clients who continue to attend a clinic. In addition the questions in their present format do not provide insight into the reasons why the former group no longer attend a clinic. The solution to this oversight would be to include two separate questions in the questionnaire: one, that elicits information about whether people have ever attended a clinic; and a second, that indicates whether they attend now. All clients who do not presently attend a clinic would be asked to indicate why they do not attend.

The final section of the survey asked clients to rate a list of 24 issues (plus spaces for "other" issues not covered by the list) as pressing needs for themselves and their families. Rating involved determining whether each item on the list was an issue of great need, some need, no need, or unknown need (don't know). Having completed this task, clients were then asked to choose their three most pressing needs from the list and to rank them from highest to lowest. Given the size of the sample only the second part of the task yielded meaningful data that could be used to draw conclusions about the needs of the respondents. It is possible that a larger sample would generate useful data from the question in its present format; however, the question is complex and may yield an improved response rate, if reduced to only the second portion of its current format. In addition, several of the issues could be combined to reduce the overall length of the list (e.g. subsidies for attendant care and subsidies for family members to be paid as attendants; a network of parent or client support groups and a buddy system with clients and families to share problems; universal accessibility of public buildings, more funding for home renovations, and more accessible housing options). A dilemma regarding this question concerns its structure. A question that provides respondents with issues and instructs them to rank these issues may preclude the generation of issues not on the list; it may restrict creativity or contemplation of issues that better reflect the respondents true problems and needs; and it may be "the easy way out". On the other hand a question that is completely open-ended may generate very little data, if respondents are unwilling or unable to undertake the contemplation necessary to respond to such a question. This was borne out by the structure of this question, which was partially open-ended, allowing clients to generate issues beyond the 24 offered; however, the majority of respondents did not add to the 24 issues listed. Although other questions embedded in the survey also provide an indication of the respondents' needs, this question presented the best avenue of comparison of clients' self-perceived needs with information about needs generated by the other tools.

The agency survey. The agency survey was developed to yield information that would serve three purposes in the needs assessment process: firstly, to generate information about the services available to clients and the utilization of these services in each province; secondly, to elicit information from agency representatives about the needs of clients with neuromuscular disorders; and thirdly, to allow for comparison of available services with clients' perceptions of gaps in service or services not available to meet their needs.

Problems associated with the agency survey were that most of the agencies surveyed did not maintain statistics that reflected the number of clients with neuromuscular disorders covered by The MDAC and that many did not have sufficient experience serving this client group to provide information about specific needs beyond those obvious for any group of clients with physical disabilities. It is likely that the former problem would be true in any area of the country; the latter problem may, however, have been specific to the region under study, because of the historically low profile of The MDAC and the lack of MDAC health-care professional staff in these provinces to provide public and professional education about neuromuscular disorders.

Administration of the agency survey phase of the needs assessment was both costly and labour intensive, requiring travel by the primary researcher to each province in order to meet with the agency representatives. Consideration should be given to a mailed survey or telephone interview format, should a study of this type be undertaken again. Clearly either alternative has its own advantages and disadvantages that would require deliberation before choosing one or the other format.

The Individual Assessment. Administration of the individual assessments was also a costly and labour intensive endeavour; however, these assessments provided very important data about real needs that could not have been ascertained through a more indirect process.

Several problems with the individual assessment phase of the needs assessment should be examined before undertaking future studies using this tool. Firstly, the size of this sample of 33 clients was manageable for one assessor; should this project be undertaken on a national scale, it may be necessary to employ several assessors and to undertake training to ensure interrater reliability.

The participation of parents or caregivers during the assessments proved to be a problem that was not anticipated. It had been decided that input from family members and caregivers affected by the client's disorder was desirable, but in several instances the issues raised by the assessment and interview were beyond the scope of the task and time available for each assessment. For example, in response to the question, "What is the impact on your family of having to help you with your daily living tasks? Is it hard on them physically? Emotionally?" several clients indicated that there was "no problem" in this area, while parents or caregivers in the room during the assessment rolled their eyes and shook their heads, giving non-verbal cues that the nature of the problem was much more complex than the client had indicated. Where possible these issues were explored during the interview; however, in some instances the dynamics of the interview were so complex that it was not possible to come to a good understanding of the needs of the family unit. A procedural suggestion would be to structure the individual assessments into three phases: part one, a physical/functional examination and discussion with the client only present; part two, a separate discussion with parents or caregivers; and part three, a discussion and wrap-up with both client and caregivers present. The individual assessments performed for this study took on average one to one and a half hours; an additional half hour for the suggested format would probably be required.

A final recommendation for revision of the individual assessment tool concerns new information available about the relationship between upper and lower extremity strength and functional grade in patients with neuromuscular disease. Lord, Portwood, Fowler, Lieberman and Carson (1987) have reported that measures of lower body function or strength may be used as a substitute for upper extremity measurements in drug trials in which global effects are expected, but that the two measurements are not equivalent when evaluating an individual's clinical status. They suggest the use of both the Vignos' lower extremity functional scale (used in the individual assessment) and Brooke's upper extremity functional rating scale (see Figure 7) for evaluation of the functional abilities of patients with Duchenne Muscular Dystrophy and other neuromuscular disorders. Inclusion of the Brooke upper extremity scale in the individual assessment procedure is recommended.

GRADE	DESCRIPTION OF BROOKE UPPER EXTREMITY SCALE
1	Starting with arms at the sides, the patient can abduct the arms in a full circle until they touch above the head.
2	Can raise arms above head only by flexing the elbow (shortening the circumference of the movement) or using accessory muscles.
3	Cannot raise hands above head but can raise an 8-oz. glass of water to mouth.
4	Can raise hands to mouth but cannot raise an 8-oz. glass of water to mouth.
5	Cannot raise hand to mouth but can use hands to hold pen or pick up pennies from the table.
6	Cannot raise hands to mouth and has no useful function of hands.

Figure 7. Grading criteria for Brooke's upper extremity scale (Lord et al., 1987, p. 9)

Recommendations for Determining Priorities for Program Planning

The results of this study point to three major conclusions that will require consideration in the planning and development of programs and services for clients with neuromuscular disorders in Manitoba and Saskatchewan. These conclusions are presented in a format that addresses the real needs identified, as well as the underlying symptomatic needs. It is important to remember that the purpose of this study was not to make recommendations about specific programs and services that should be developed, rather to present the conclusions of this study in a format that identifies the priorities that should be addressed in the planning of programs for this population.

Conclusion #1 -- need for pediatric transition and adult neuromuscular disorder clinics. Examination of the age ranges of the client population studied shows that although only one-third of the respondents are under the age of 19, services for persons with neuromuscular disorders in both Manitoba and Saskatchewan are primarily oriented to a pediatric population. Formal clinics for clients with neuromuscular disorders over 18 years of age do not exist in either province, resulting in clients over the age of 18 being followed in pediatric facilities, or, more commonly, not receiving any medical follow-up at all. As a result the needs of the adult population for assessment of their physical, functional, and medical equipment needs are not addressed in a coordinated fashion. In addition, because referrals for vocational counselling, life skills training, equipment assessment, home care services, and community rehabilitation services must all be initiated by a medical practitioner, usually a physician in these provinces, clients not attending clinics generally are not able to access these services. In contrast clients who do attend a clinic have a forum to express their needs and they can expect to be referred to appropriate services that will attempt to address these needs. Because the majority of young adult and adult clients in Manitoba and Saskatchewan do not regularly attend a clinic or other rehabilitation facility, they have, on the whole, not accessed the range of programs available to them and are, in fact, not aware that these programs are even accessible to them.

<u>Conclusion # 2 -- need to overcome the barriers to normal social experiences.</u> The degree of isolation of clients and their families in both provinces from typical social activities is extremely high. Problems of accessibility of homes, public buildings, and transportation systems all contribute to the development and fostering of isolation. With the increasing physical care demands imposed by progressive muscle diseases parents and caregivers find themselves unable to recruit relief help for

even intermittent outings. This is a more serious problem in Saskatchewan than in Manitoba, where a respite care program is available to provide a limited service to families. The need to address the problem of social isolation is supported by the interest expressed by 72.6% of the respondents of the client survey to attending group meetings that would focus on social and recreational events, information sessions on neuromuscular disorders, and support meetings with a professional; this is further supported by the 30.0% of the client survey respondents who ranked the need for a buddy system with clients and families to share problems and the need for a network of client or parent support groups as their most pressing need.

The distribution of clients in Manitoba (see Appendix 12) is such that 57.4% of the clients reside in the Winnipeg catchment area and the remaining 42.5% reside throughout the remainder of the rural and Northern regions of the province. The distribution of clients in Saskatchewan (see Appendix 13) is such that 15.4% of the clients reside in Saskatoon, 23.1% reside in Regina, and the remaining 61.5% of the clients reside throughout the remainder of the rural and Northern regions of the province. Because of the wide regional distribution of clients outside of the major centres in each province, it will be necessary to adopt innovative approaches to facilitate total client participation in social and educational activities and to ensure that clients already isolated by virtue of their place of residence are not excluded from future programs and services developed.

Conclusion # 3 -- need for information about neuromuscular disorders. There is a need for information about neuromuscular disorders amongst clients, health-care professionals, and the general public. Clients and their families require both information and counselling to deal with the stress and grief of living with a family member with a progressive, often terminal condition. Crucial concerns, such as prognosis, need to be addressed so that the client and the family can adopt a lifestyle and an expectation of life that takes into account the disease process. Health-care professionals require information about the management and treatment of neuromuscular disorders in order to develop meaningful rehabilitation programs, to assess for appropriate medical equipment items, and to initiate appropriate referrals for clients for social, educational, career counselling, and other services. The general public requires knowledge of the abilities of the physically disabled, neuromuscular disease client in order to foster improved public attitudes towards the disabled and in order to offer their support in lobbying efforts for accessible transportation systems, accessible public buildings, et cetera.

In summary, the results of this needs assessment have identified three areas of priority for program planning; the scope of the needs of the clients with neuromuscular disorders represented by this study should in turn suggest human resource needs necessary to implement and administer programs that focus upon the areas of priority identified.

Limitations of the Study

This study has examined the needs of a group of MDAC registered clients with neuromuscular disorders residing in the prairie provinces of Manitoba and Saskatchewan. The group of MDAC clients represented a sample of the actual population that exists in these two provinces. Although caution should always be exercised when extrapolating the results obtained from a study such as this to the whole population, there is no reason to suspect that the characteristics of the non-respondents or the non-surveyed population of clients with neuromuscular disorders in these provinces would be different from the sample studied. Generalization of the results to clients in other provinces is, however, not advisable on account of the different programs and services available in different regions that would have a direct bearing on the needs of clients in these other areas.

The fact that needs are constantly changing suggests that the results of this study should only be considered as a snapshot that portrays the needs of the population under study at a particular point in time. The changing nature of needs stresses the importance of constant re-evaluation to ensure that the programs and services developed continue to address needs that actually exist. This has particular relevance to a population of people whose needs are changing due to the progressive and often terminal nature of their disorders.

Implications for Further Research

The scope of the present study could be expanded to examine subpopulations of the original population of clients with neuromuscular disorders. Examination of the clients by age, diagnosis, number of affected persons per family, and region of residence would yield interesting information and relationships.

A disappointing consequence of this study was the limited use by respondents of the open-ended questions. Because of criticism that the orientation of questionnaires concerning needs tend to define need in terms of the perceptions of the providers of services, rather than the consumers, considerable emphasis was placed on providing respondents with space to express their own views. Although it is possible that the questionnaire offered respondents with all the options needed for most of the questions, it is more likely that since people respond to questions out of their fund of experiences, that the population surveyed did not offer additional comments, because they had no knowledge of alternative programs or services needed or wanted. If the goal of the needs assessment process is to generate information about needs from those in need, it would be advisable to examine whether the expectations and demands placed upon respondents to identify and evaluate (i.e., rank) their own needs is realistic. Research is necessary to determine whether prerequisite knowledge in an area under study is required before adults can be considered competent to identify and rank their own needs.

Finally, examination of the developmental stages of a physically disabled, terminally ill population is an area of theory development suggested by the results of this study. Questions to be addressed include whether the developmental stages of a special population are different from the stages of a normal population; whether transition from one developmental stage to the next is accelerated by knowledge of a fatal prognosis; and whether the self-perceived needs of clients with progressive or terminal disorders are consistent with their chronological age or consistent with their developmental stage.

Summary

It was the purpose of the present study to develop methodology for assessing the needs of persons with neuromuscular disorders and to utilize the needs assessment measures developed in order to assess the needs of a population of clients with neuromuscular disorders residing in the provinces of Manitoba and Saskatchewan. Three separate assessment tools were developed to generate data from different perspectives about the nature and magnitude of the human service needs of persons with neuromuscular disorders. The findings of this study are based on a comparison of the self-perceived needs of clients themselves, the needs of persons with neuromuscular disorders as perceived by representatives of human service agencies, and the needs of persons with neuromuscular disorders as perceived by a health-care professional.

The findings indicated that the perspectives of need identified by each of the three respondent groups exhibit definite congruence, although the priority of the needs identified is different. The results of the client survey and the individual assessments showed the greatest agreement. It is suggested that the variation in the weighting of the needs identified by each of the respondent groups is based upon the identification of felt needs, or symptomatic needs, by the clients and the identification of real needs by health-care professionals.

The results of the study point to three major conclusions that suggest changes to the current service delivery system. Neuromuscular disease clinics might be restructured or expanded to increase availability of medical and supportive services to clients over the age of 18 years. Facilitation of liasons between families and between families and professionals might be encouraged to provide a network of supportive services within the client's community and to facilitate overcoming the barriers that interfere with participation by the client and family in normal social experiences. This is especially important because as clients' disorders progress, they become more debilitated, and the families' burden of physical care increases. Lastly, more systematic provision of information and counselling about the disease process might be offered to all clients and their families, health-care professionals, and the general public; it is anticipated that this would foster positive adjustment by clients and their families to the demands of the disease process and improved public attitudes towards the disabled through accurate understanding of the disabilities and the capabilities of persons with neuromuscular disorders.

Based on the findings and experiences of this study, it would be recommended that similar or larger assessments of a population of clients with neuromuscular disorders could be undertaken using the tools developed for the purposes of this study with only minor revisions to content and procedure.

BIBLIOGRAPHY

Atwood, H. M., & Ellis, J. (1971). The concept of need: an analysis for adult education, Adult Leadership, 19 (7), 210-212, 244.

Baker, H. R. (1976a). Teaching adults in the context of community development, in H.R. Baker (Ed.), The Teaching of Adults Series. (pp.1-6). Saskatoon: The University of Saskatchewan, Extension Division. Publication No. 273C.

Baker, H. R. (1976b). Identifying the learner's needs and priorities, in H.R. Baker (Ed.), The Teaching of Adults Series. (pp. 1-6). Saskatoon: The University of Saskatchewan, Extension Division. Publication No. 280.

Barbulesco, C. W. (1980). Components of a major needs assessment study, in F.C. Pennington (Ed.), Assessing Educational needs of Adults (pp. 73-82). New Directions for Continuing Education, 7. San Francisco: Jossey-Bass.

Bell, R. A., Nguyen, T. D., Warheit, G. J. & Buhl, J. M. (1978). Service utilization, social indicator, and citizen survey approaches to human service need assessment, in C. G. Attkisson, W. A. Hargreaves, M. J. Horowitz, & J. E. Sorensen (Eds.), Evaluation of Human Service Programs. (pp. 253-300). New York: Academic Press.

Brackhaus, B. (1984). Needs assessment in adult education: its problems and prospects, Adult Education Quarterly, 34 (4), 233-239.

Brookfield, S. (1985). A critical definition of adult education, Adult Education Quarterly, 36 (1), 44-49.

Brundage, Donald H. & MacKeracher, Dorothy. (1980). Adult Learning Principles and their Application to Program Planning. Toronto: Ministry of Education, Ontario.

Bullard, M. (1983). A needs assessment strategy for educational planning, The American Journal of Occupational Therapy, 37 (9), 624-629.

Chambers, Larry W., Woodward, Christel A., & Dok, Caroline M. (1983). *Guide to Health Needs Assessment: A Critique of Avaialable Sources of Health and Health Care Information*. Ottawa: Canadian Public Health Association.

Clark, M. (1959). *Health in the Mexican-American Culture*. Berkeley: University of California Press.

Colvez, A. & Robine, J. M. (1986). Problems encountered in using the concepts of impairment, disability, and handicap in a health assessment survey of the elderly in Upper Normandy, *International Rehabilitation Medicine*, *8* (1), 18-22.

Falk, Isadore S., Klein, Margaret C., & Sinai, Nathan. (1933). *The Incidence of Illness and the Receipt and Cost of Medical Care Among Representative Families: Experiences in Twenty Consecutive Months During 1928-31*. Committee on the Cost of Medical Care Report, No. 26. Chicago: University of Chicago Press.

Fitzpatrick, Carol, Barry, Ciaron, & Garvey, Criona. (1986). Psychiatric disorder among boys with Duchenne Muscular Dystrophy, *Developmental Medicine and Child Neurology*, *28*, 589-595.

Freire, Paulo. (1970). *Pedagogy of the Oppressed*. New York: Herder and Herder.

Friedman, Gary D. (1980). *Primer of Epidemiology*, Second Edition. New York: McGraw-Hill Book Company.

Gilson, Betty S., Gilson, John S., Bergner, Marilyn, Bobbitt, Ruth A., Kressel, Shirley, Pollard, William E., & Vesselago, Michael. (1975). The Sickness Impact Profile: development of an outcome measure of health care, *American Journal of Public Health*, *65* (12), 1304-1310.

Granger, Carl V. (1985). Outcome of comprehensive medical rehabilitation: an analysis based upon the impairment, disability, and handicap model, *International Rehabilitation Medicine*, *7*, 45-50.

Greenley, James R. (1980). Sociocultural and psychological aspects of the utilization of health services, in M.H. Brenner, A. Mooney, & T.J. Nagy, (Ed.), *Assessing the Contributions of the Social Sciences to Health* (pp. 169 -207). Boulder: Westview Press, Inc.

Greenwood, J. G. (1985). Disability dilemmas and rehabilitation tensions: a twentieth century inheritance, Social Science and Medicine, 20 (12), 1241-1252.

Hansluwka, Harald, E. (1985). Measuring the health of populations, indicators and interpretations, Social Science and Medicine, 20 (12), 1207-1224.

Horne, Sylvia. (1982). A Survey of the Needs of Children and Adults with Muscular Dystrophy in the Province of British Columbia. Unpublished manuscript.

Hough, Evelyn & Torrance, George M. (1984). Final Report of the Accommodation and Support Care Needs of the Severely Physically Disabled Aged 0-64 in Ottawa- Carleton. Ottawa: Ottawa-Carleton Regional District Health Council.

Illsley, R. (1980). Professional or Public Health? : Sociology in Health and Medicine. London: The Nuffield Provincial Hospitals Trust.

Katz, Sidney, Downs, Thomas D., Cash, Helen R., & Grotz, Robert C. (1970). Progress in development of the Index of ADL, The Gerontologist, 10 (1), 20-30.

Keith, Robert Allen. (1984). Functional assessment measures in medical rehabilitation: current status, Archives of Physical Medicine and Rehabilitation, 65, 74-78.

Kilburg, Richard. (1978). Consumer survey as needs assessment method: a case study, Evaluation and Program Planning, 1, 285-292.

Knowles, M. (1970). The Modern Practice of Adult Education. New York: Association Press.

Lord, Janet P., Portwood, Margaret M, Fowler, William M., Lieberman, James S., & Carson, Richard. (1987). Upper vs lower extremity functional loss in neuromuscular disease, Archives of Physical Medicine and Rehabilitation, 68, 8-9.

McMahon, E. E. (1970). Needs -- of People and Their Communities -- and the Adult Educator. Washington, D.C.: Adult Education Association of the U.S.A.. ED 038 551.

Madorsky, Julie G. Botvin, Radford, Linda M., & Neumann, Elizabeth M. (1984). Psychosocial aspects of death and dying in Duchenne Muscular Dystrophy, Archives of Physical Medicine and Rehabilitation, 65, 79-82.

Monette, M. (1977). The concept of educational need: an analysis of selected literature, Adult Education, 27 (2), 116-127.

Monette, M. (1979). Need assessment: a critique of philosophical assumptions, Adult Education, 29 (2), 83-95.

Moore, Donald E. (1980). Assessing the needs of adults for continuing education: a model, in F.C. Pennington (Ed.), Assessing Educational Needs of Adults (pp. 91-97). New Directions for Continuing Education, 7. San Francisco: Jossey-Bass.

Mootz, Marijke. (1986). Health Indicators, Social Science and Medicine, 22 (2), 255-263.

Muscular Dystrophy Association of Canada. (1984). MDAC The Facts. Toronto: Muscular Dystrophy Association of Canada.

Orthner, Dennis K. & Smith, Suzanna. (1986). Measuring progaram needs: a strategic design, Evaluation and Program Planning. 9, 199-207.

Pennington, F. C. (1980a). Needs assessment: concepts, models, and characteristics, in F.C. Pennington (Ed.), Assessing Educational Needs of Adults (pp. 1-14). New Directions for Continuing Education, 7. San Francisco: Jossey-Bass.

Pennington, F. C. (1980b). Educational needs assessment: conclusion, in F.C. Pennington (Ed.), Assessing Educational Needs of Adults (pp. 99-103). New Directions for Continuing Education, 7. San Francisco: Jossey-Bass.

Satin, Maurice S. & Monetti, Charlotte H. (1985). Census tract predictors of physical, psychological, and social functioning for needs assessments, Health Services Research, 20 (3), 341-357.

Saunders, L. (1954). Cultural Differences and Medical Care. New York: Russell Sage Foundation.

Scissons, E. H. (1982). A typology of needs assessment definitions in adult education, Adult Education, 33 (1), 20-28.

Scissons, E. H. (1985). Needs assessment in adult education (Brackhaus, 1984): a reaction, Adult Education Quarterly, 35 (2), 105-108.

Siegel, Irwin M. (1977). The Clinical Management of Muscle Disease: A Practical Manual of Diagnosis and Treatment. London: William Heinemann Medical Books Limited.

Siegel, L. M., Attkisson, C. C., & Carson L. G. (1978). Need identification and program planning in the community context, in C. G. Attkisson, W. A. Hargreaves, M. J. Horowitz, & J. E. Sorensen (Eds.), Evaluation of Human Service Programs. (pp. 215-251). New York: Academic Press.

Stewart, Anita L., Ware, John E., Brook, Robert H., & Davies-Avery, Allyson. (1978). Conceptualization and Measurement of Health for Adults in the Health Insurance Study: Vol. II, Physical Health in Terms of Functioning. Santa Monica, Ca.: The Rand Corporation.

Taylor, R. (1979). Self-reports and self-estimates of health, in J. Brotherston (Ed.), Planning and Provision of Services for the Elderly. Edinburgh: Churchill-Livingstone.

Vignos, P. J., Jr., & Archibald, K. C. (1959). A Study of contractures in Muscular Dystrophy, Archives of Physical Medicine and Rehabilitation, 40, 150-157.

Vignos, P, J., Jr., & Archibald, K. C. (1960). Maintenance of ambulation in childhood Muscular Dystrophy, Journal of Chronic Diseases, 12, 273-290.

Vignos, P. J., Jr., Spencer, G. E., Jr., & Archibald, K. C. (1963). Management of progressive Muscular Dystrophy in childhood, Journal of the American Medical Association, 184, 89-96.

Warren, M. D. (1985). The Canterbury studies of disablement in the community: prevalence, needs, and attitudes, International Journal of Rehabilitation Research, 8 (1), 3-18.

WHO (World Health Organization). (1980). International Classification of Impairments, Disabilities, & Handicaps: A Manual of Classification Relating to the Consequences of Disease. Geneva: World Health Organization.

Woodward, Christel A., & Chambers, Larry W. (1983). Guide to Questionnaire Construction and Question Writing. Ottawa: The Canadian Public Health Association.

Woodward, Christel A., Chambers, Larry W., & Smith, Kimberly D. (1982). Guide to Improved Data Collection in Health and Health Care Surveys. Ottawa: The Canadian Public Health Association.

Zborowski, M. (1952). Cultural components in response to pain, _Journal of Social Issues_, _8_ (4), 16-30.

Appendix 1

Categories of Neuromuscular Disorders

MUSCULAR DYSTROPHY ASSOCIATION OF CANADA

REFERENCE FOR CATEGORY - "NEUROMUSCULAR DISORDERS"

MUSCULAR DYSTROPHIES

Duchenne Muscular Dystrophy
    (Pseudohypertrophic)
Becker Muscular Dystrophy
Facioscapulohumeral Muscular Dystrophy
    (Landouzy-Dejerine)
Limb-Girdle Muscular Dystrophy
    (including Juvenile Dystrophy of Erb)
Myotnic Dystrophy
    (Steinert's Disease)
Congenital Muscular Dystrophy
Opthalmoplegic Muscular Dystrophy
Distal Muscular Dystrophy
Muscular Dystrophy of Late Onset

SPINAL MUSCULAR ATROPHIES

Amyotrophic Lateral Sclerosis (ALS) Motor Neuron Disease
Infantile Progressive Spinal Muscular Atrophy
    (Werdnig-Hoffmann Disease)
Juvenile Progressive Spinal Muscular Atrophy
    (Kugelberg-Welander Disease)
Benign Congenital Hypotonia
    (formerly called Amyotonia Congenita)
Adult Progressive Spinal Muscular Atrophy
    (Aran-Duchenne Type)

INFLAMMATORY MYOPATHIES

Polymyositis
Dermatomyositis
Myositis Ossificans

DISEASES OF PERIPHERAL NERVE

Peroneal Muscular Atrophy
    (Charcot-Marie-Tooth Disease)
Friedreich's Ataxia
Dejerine-Sottas Disease
Guillain-Barre Syndrome

DISEASES OF NEUROMUSCULAR JUNCTION

Myasthenia Gravis

MYOTONIAS

Myotonia Congenita
    (Thomsen's Disease)
Paramyotonia Congenita

METABOLIC DISEASES OF MUSCLE*

Phosphorylase Deficiency
    (McArdle's Disease)
Acid Maltase Deficiency
    (Pompe's Disease)
Phosphofrucktokinase Deficiency
    (Tarui's Disease)
Debrancher Enzyme Deficiency
    (Cori's or Forbes' Disease)
Carnitine Deficiency
Periodic Paralysis

*Glygocen storage diseases

MYOPATHIES DUE TO ENDOCRINE ABNORMALITIES

Hyperthyroid Myopathy
Hypothyroid Myopathy
Myopathies Secondary to Disorders
    of Adrenal Corticosteroids

LESS COMMON MYOPATHIES

Central Core Disease
Nemaline Myopathy
Mitochondrial Disease
Myotubular Myopathy
Malignant Hyperthermia

OTHER APPROVED DISORDERS

Infantile Metachromatic Leukodystrophy
    (or Sulphatide Lipidosis)
Agenesis of the Curpus Callousum
Anterior Horn Cell Disease woth Progressive Dementia
Spinal Cerebellar Degeneration
Isaac Syndrome (Neuromyotonia)
Chronic Relapsing Neuropathy
Familial Ataxia
Disproportion Congenitale des Fibres
Multicore Myopathy
Lipid Myopathy
Type 1 Muscle Fibre Atrophy and Central Nuclei
Syndrome Charlevoix-Saguenay
Atypical Glycogen Storage Disease of Muscle
Oculopharyneal dystrophy with distal weakness
Amyotrophic spinale intermediarie - severe
Myopathie Syndrome Schwarts-Jumpel
Syndrome Eaton-Lambert
Cerebellar Tremor & Familial Ataxia
Minicore Disease
Emery-Dreifuss Muscular Dystrophy
Fingerprint Myopathy
Fukuyama Type Muscular Dystrophy

3/9/87

Appendix 2
Cover Letter and Client Survey

L'ASSOCIATION CANADIENNE DE LA DYSTROPHIE MUSCULAIRE

MUSCULAR
Dystrophy
ASSOCIATION
OF CANADA

April 16, 1987

Dear Client,

The attached questionnaire has been developed to help **THE MUSCULAR DYSTROPHY ASSOCIATION OF CANADA** learn from you, our clients, what people with neuromuscular disorders need. The information which we gain will be used by the The Association to plan services for clients and their families living in Manitoba or Saskatchewan.

Your answers are the key to ensuring that the views of you and your family are included in our final results. All the information you give will be kept in strict confidence.

Completing the questionnaire will take about one hour of your time. If you are an adult client and are unable to complete the questionnaire personally, please have a relative or friend help you. If you are a parent or guardian, please complete the questionnaire for your child. If there is more than one person in your household registered as a client, please see that one questionnaire is completed for each person.

Please try to answer all the questions. Throughout the questionnaire there is space to add comments of your own. If you have more to say than we have provided space for, you may attach a separate piece of paper and label each answer by section and number. When you are finished, please put the questionnaire in the envelope provided and drop in the mail by April 30, 1987. If you have any questions or if you would like more information, please call collect to the Prairies office of the Muscular Dystrophy Association of Canada at 204-233-0022.

Thank-you for contributing your time and experience to this important study that will, in turn, help determine new services to be made available to you and your family through The Muscular Dystrophy Association of Canada. It is our hope that this study will serve to reinforce The Association's motto that **"ONE STEP AT A TIME, TOGETHER WE CAN MAKE IT!"**.

Sincerely,

L. N. Cuthbertson

Lena N. Cuthbertson
Client Services Research Coordinator

Patron
Her Excellency the Right Honourable Jeanne Sauvé, P.C., C.C., C.M.M., C.D., Governor General of Canada
Son Excellence la très honorable Jeanne Sauvé, C.P., C.C., C.M.M., C.D., Gouverneur général du Canada
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SURVEY OF THE NEEDS OF PEOPLE
With Muscular Dystrophy and Related Neuromuscular Disorders Living in Manitoba or Saskatchewan

L'ASSOCIATION CANADIENNE DE LA
Dystrophie
MUSCULAIRE
MUSCULAR
Dystrophy
ASSOCIATION OF CANADA

Who will be completing this questionnaire?
(check box)

1. Client ☐
2. Other ☐

Please specify relationship
to client: ______________________________
____

SECTION I: **BACKGROUND INFORMATION**

The questions in this section will give us information on your background and how it compares to other clients.

1. **WHAT CITY OR TOWN AND PROVINCE DO YOU LIVE IN?**

City/town: ______________________________

Province: ______________________________

2. **WHAT IS YOUR BIRTHDATE?**

_____ / _____ / _____

WHAT IS YOUR SEX: (check box)

1. Male ☐
2. Female ☐

4. **DO YOU LIVE ON YOUR OWN:** (check box)

1. Yes ☐ → PLEASE GO TO QUESTION # 5.
2. No ☐ → Please list below the relationship of everyone living with you.

RELATIONSHIP (eg. husband, wife, sister, mother, etc.)	**AGE**

5. **DO YOU KNOW WHAT TYPE OF MUSCULAR DYSTROPHY OR NEUROMUSCULAR DISORDER YOU HAVE?** (check box)

1. Yes ☐ → Please specify type: ______________________________
2. No ☐

6. **DO YOU KNOW WHEN YOUR DIAGNOSIS WAS MADE?** (check box)

1. Yes ☐ → Please specify year: ______________________________
2. No ☐

7. ARE THERE OTHER MEMBERS OF YOUR FAMILY WHO HAVE MUSCULAR DYSTROPHY OR A NEUROMUSCULAR DISORDER? (check box)

1. Yes ☐ → Please list below their relationship to you and their ages.

RELATIONSHIP	AGE	LIVING WITH YOU	NOT LIVING WITH YOU
________________	____	☐	☐
________________	____	☐	☐
________________	____	☐	☐
________________	____	☐	☐
________________	____	☐	☐

2. No ☐

8. ARE YOU THE PRINCIPAL WAGE EARNER IN YOUR HOUSEHOLD? (check box)

1. Yes ☐
2. No ☐

9. WHAT ARE YOUR SOURCES OF INCOME? (check box)

1. Salary or Wages ☐
2. Long Term Disability Pension ☐
3. Federal Disability Allowance (Canada Pension) ☐
4. Provincial Disability Allowance ☐
5. Worker's Compensation ☐
6. Social Assistance ☐
7. Unemployment Insurance ☐
8. Private Retirement Pension ☐
9. Other ☐

SECTION II: **NEED FOR INFORMATION**

The questions in this section will tell us how easy or difficult it has been for you to get information related to your condition.

1. HAVE YOU BEEN ABLE TO GET THE INFORMATION YOU HAVE NEEDED OR WANTED ABOUT: (check boxes)

	Yes	No
1. Your disorder	☐	☐
2. Treatment for your disorder	☐	☐
3. Where to go for treatment	☐	☐
4. Whether your disorder was inherited	☐	☐

2. WHERE DID YOU GET THIS INFORMATION? (check boxes)

1. Doctor(s) ☐
2. Neuromuscular Clinic(s) ☐
3. The Muscular Dystrophy Association of Canada ☐
4. Other People with the Same Disorder ☐
5. Library ☐
6. Jerry Lewis Telethon ☐
7. Physiotherapist(s) ☐
8. Occupational Therapist(s) ☐
9. Nurse(s) ☐
10. Others, please specify: ☐

____

____

____

3. IS THERE ANY INFORMATION ABOUT YOUR DISORDER THAT YOU HAVE BEEN UNABLE TO FIND? PLEASE SPECIFY.

____

____

____

____

____

4. TO LEARN MORE ABOUT YOUR DISORDER AND THE SERVICES AVAILABLE TO HELP YOU, WOULD YOU AND/OR YOUR FAMILY BE INTERESTED IN ATTENDING: (check boxes)

		Yes	No
1.	Workshops or Lectures	☐	☐
2.	Small Group Meetings with other Clients and Families	☐	☐
3.	Individual Meetings with a Knowledgeable Person	☐	☐

4. Other ☐, Please specify: ______________________________

____

____

SECTION III: **NEED FOR MEDICAL SERVICES**

The questions in this section are about the medical services you are receiving, as well as those services that you feel you need.

1. **HAVE YOU EVER ATTENDED A NEUROMUSCULAR DISORDER CLINIC?** (check box)
   1. Yes ☐
   2. No ☐ ⟶ PLEASE GO TO QUESTION # 7.

2. **WHERE IS THE CLINIC?**

   Name of City: ______________________________

3. **WHAT IS THE NAME OF THE CLINIC?**

   Name of the clinic: ______________________________

4. **HOW OFTEN DO YOU ATTEND THE CLINIC?**(check boxes)
   1. Every month ☐
   2. Every 6 months ☐
   3. Once a year ☐
   4. As needed ☐
   5. Other ☐, Please specify: ______________________________

   ____

5. **PLEASE EXPLAIN WHY YOU ATTEND THE CLINIC?**

   ____

   ____

   ____

   ____

6. **ARE YOU SATISFIED WITH THE SERVICES YOU HAVE RECEIVED AT THE CLINIC?** (check box)
   1. Yes ☐, Please explain why: ______________________________

   ____

   ____

   ____

   ____

6 continued on next page . . .

6 continued from previous page

2. No ☐, Please explain why: ______________________________

____

____

____

____

____

What suggestions do you have for improving the clinic?

____

____

____

____

____

____

____

PLEASE PROCEED TO QUESTION # 8.

7. WHY DO YOU NOT ATTEND A CLINIC? (check boxes)

1. I am not aware of a clinic. ☐
2. There is no clinic available. ☐
3. The clinic is too far away. ☐
4. I am not satisfied with the services and professionals at the clinic. Please explain why: ☐

____

____

____

____

5. Other ☐, please specify: ☐

____

____

8. HAVE YOU SEEN ANY OF THE FOLLOWING MEDICAL PROFESSIONALS REGARDING YOUR DISORDER?

	SAW IN THE PAST	STILL SEE
1. Doctor specializing in nerves and muscles (Neurologist)	☐	☐
2. Doctor specializing in rehabilitation (Physiatrist)	☐	☐
3. Doctor specializing in bones (Orthopedic surgeon)	☐	☐
4. Doctor specializing in children (Pediatrician)	☐	☐
5. Nurse	☐	☐
6. Physiotherapist	☐	☐
7. Occupational Therapist	☐	☐
8. Social Worker	☐	☐
9. Person who makes braces and casts (Orthotist)	☐	☐
10. Respiratory Therapist	☐	☐
11. Speech Therapist	☐	☐
12. Others, please specify:		
____________________	☐	☐
____________________	☐	☐
____________________	☐	☐
____________________	☐	☐

9. HOW DO YOU TRAVEL TO MEDICAL APPOINTMENTS RELATED TO YOUR DISORDER? (check box)

1. Car ☐
2. Bus ☐
3. Air ☐
4. Other ☐, Please specify: ____________________

____

10. HOW FAR MUST YOU TRAVEL TO GET MEDICAL ATTENTION FOR YOUR DISORDER? (check box)

1. less than 25 kilometres one way ☐
2. between 25 and 50 kilometres one way ☐
3. between 51 and 120 kilometres one way ☐
4. greater than 120 kilometres one way ☐

11. WHO ACCOMPANIES YOU TO MEDICAL APPOINTMENTS? (check boxes)

1. A family member ☐
2. An attendant ☐
3. No one ☐
4. Other ☐, Please specify: ____________________

____

12. DO YOU HAVE A FAMILY DOCTOR WHO UNDERSTANDS THE PROBLEMS OF YOUR CONDITION? (check box)

1. Yes ☐
2. No ☐

13. WHICH OF THE FOLLOWING HOME SERVICES DO YOU RECEIVE? (check box)

		NUMBER OF DAYS PER WEEK
1.	Visiting Nurse	☐ ____________
2.	Orderly or Attendant	☐ ____________
3.	Visiting Homemaker	☐ ____________
4.	Visiting Physiotherapist	☐ ____________
5.	Visiting Occupational Therapist	☐ ____________
6.	Visiting Speech Therapist	☐ ____________
7.	Visiting Social Worker	☐ ____________
8.	Doctor who makes house calls	☐ ____________
9.	Other	☐
	Please specify: __________________________	____________
	__________________________	____________

10. None ☐ ——→ PLEASE GO TO QUESTION # 15.

14. WHO PAYS FOR ANY OF THE HELP YOU GET FROM A NURSE, A HOMEMAKER, OR AN ATTENDANT? (check boxes)

1. I pay for some of it myself. ☐
2. I pay for all of it myself. ☐
3. My family pays for some of it. ☐
4. My family pays for all of it. ☐
5. Partially paid for by an outside agency. ☐
   Please specify: ____________________
6. Totally paid for by an outside agency. ☐
   Please specify: ____________________

15. DO YOU FEEL YOU NEED ANY SERVICES THAT YOU DO NOT RECEIVE? (check box)

1. Yes ☐

What services?	Why do you feel you need these services?
____________________	____________________
____________________	____________________

2. No ☐

16. WHERE DO YOU PREFER TO RECEIVE SERVICES? (check box)

1. In my home ☐ ——→ PLEASE GO TO QUESTION # 17
2. Outside my home ☐, Please specify place, eg. hospital, treatment centre, school, work, doctor's office, etc.

____

17. HAVE ANY MEMBERS OF YOUR FAMILY OR ANY OF YOUR FRIENDS BEEN TRAINED TO DO ANY OF THE MEDICAL PROCEDURES, WHICH YOU NEED, SUCH AS EXERCISES, SUCTIONING, ETC.? (check box)

1. Yes ☐, Please indicate which procedures and how often they assist you with these procedures.

PROCEDURES	**HOW OFTEN?**
____________________	__________
____________________	__________
____________________	__________

2. No ☐

SECTION IV: **NEED FOR HELP WITH DAILY ACTIVITIES**

The questions in this section are about your daily activities and whether you have any difficulty with them.

1. ARE YOU ABLE TO DO THE FOLLOWING ACTIVITIES? (check boxes)

	EASILY	WITH DIFFICULTY BUT WITHOUT HELP	WITH SPECIAL AIDS BUT NO HELP	WITH HELP FROM SOMEONE	UNABLE
1. Feed yourself	☐	☐	☐	☐	☐
2. Dress yourself	☐	☐	☐	☐	☐
3. Bathe yourself	☐	☐	☐	☐	☐
4. Turn yourself	☐	☐	☐	☐	☐
5. Move from a chair to a bed	☐	☐	☐	☐	☐
6. Toilet yourself	☐	☐	☐	☐	☐
7. Walk on a level surface	☐	☐	☐	☐	☐
8. Climb stairs	☐	☐	☐	☐	☐
9. Go shopping	☐	☐	☐	☐	☐
10. Cook a meal	☐	☐	☐	☐	☐
11. Do light housework	☐	☐	☐	☐	☐
12. Do laundry	☐	☐	☐	☐	☐
13. Do your own banking	☐	☐	☐	☐	☐
14. Drive a car	☐	☐	☐	☐	☐
15. Use a telephone	☐	☐	☐	☐	☐
16. Use **PUBLIC** transportation (not special transport for the disabled	☐	☐	☐	☐	☐

2. DO YOU USE A WHEELCHAIR OR OTHER MOBILITY DEVICE? (check box)

1. Yes ☐ ⟶ Outside only ☐
Inside and Outside ☐

2. No ☐

3. **WHO ASSISTS YOU, WHEN YOU NEED HELP WITH YOUR DAILY ACTIVITIES?** (check boxes)

	LIVING WITH YOU	NOT LIVING WITH YOU	DURING THE DAY	DURING THE NIGHT
1. Family	☐	☐	☐	☐
2. Friends	☐	☐	☐	☐
3. Visiting Nurse	☐	☐	☐	☐
4. A Homemaker or Housekeeper	☐	☐	☐	☐
5. An Attendant or Orderly	☐	☐	☐	☐
6. Others, please specify:				
______________________	☐	☐	☐	☐
______________________	☐	☐	☐	☐

7. Not applicable, I do not need help. PLEASE GO TO QUESTION # 8.

4. **IF YOU ARE HELPED BY FAMILY OR FRIENDS, HOW WOULD YOU DESCRIBE THE EFFECT ON THEM?** (check boxes)

	PHYSICALLY	EMOTIONALLY
1. It is not too hard on them.	☐	☐
2. It is fairly hard on them.	☐	☐
3. It is very hard on them.	☐	☐

5. **PLEASE DESCRIBE THE DIFFICULTIES FACED BY YOU AND YOUR FAMILY OR FRIENDS IN MEETING YOUR DAILY NEEDS?**

6. **PLEASE OUTLINE ANY IDEAS YOU HAVE FOR HOW THESE DIFFICULTIES COULD BE OVERCOME.**

7. WHICH STATEMENT BELOW APPLIES TO YOU? (check box)

1. I receive all the help I need. ☐
2. I need a little more help. ☐
3. I need a lot more help. ☐
4. I do not need help, but my family and friends need help helping me. ☐

8. DO YOU THINK YOU WILL LIKELY NEED MORE OR LESS HELP IN THE NEXT 5 YEARS?
(check box)

1. I will probably need a great deal more help. ☐
2. I will need a little more help. ☐
3. I will need about the same amount of help. ☐
4. I will probably need less help. ☐
5. I can't say. ☐

9. DURING THE PAST YEAR, HAVE YOU UTILIZED ANY RELIEF OR RESPITE TYPE OF SERVICE THAT ALLOWS YOUR FAMILY OR OTHER CAREGIVERS TO HAVE A REST OR VACATION?
(check box)

1. Yes ☐, Please specify where this relief was provided, how many times during the year you used it, and for how long.

WHERE?	HOW MANY TIMES?	HOW LONG?
________________________	________________	__________
________________________	________________	__________
________________________	________________	__________

2. No, I/we do not need this. ☐
3. No, this is not available in my area. ☐
4. No, I have not been aware that this type of service exists. ☐

SECTION V: **NEED FOR SPECIALIZED HOUSING**

The following questions are about your housing needs now and in the future.

1. **ARE YOU CURRENTLY LIVING IN:** (check box)

1.	A house?	☐
2.	An apartment?	☐
3.	An apartment in a special integrated housing project?	☐
4.	A rooming house?	☐
5.	A group home for disabled tenants?	☐
6.	A student residence?	☐
7.	A cooperative?	☐
8.	A hospital or extended care facility?	☐

9. Other ☐, Please specify: ______________________

2. **DO YOU NEED ANY OF THE FOLLOWING MODIFICATIONS TO THE PLACE WHERE YOU NOW LIVE?** (check boxes)

	NOT NEEDED	DONE	NEEDED NOW	WILL NEED
1. Ramps constructed	☐	☐	☐	☐
2. Handrails installed	☐	☐	☐	☐
3. Doorways widened	☐	☐	☐	☐
4. Elevators or lifts installed	☐	☐	☐	☐
5. Special bath or showers installed	☐	☐	☐	☐
6. Kitchen modified	☐	☐	☐	☐
7. Light switches or outlets relocated	☐	☐	☐	☐
8. Others, please specify: ______________________	☐	☐	☐	☐
______________________	☐	☐	☐	☐
______________________	☐	☐	☐	☐

3. **HOW SATISFIED ARE YOU WITH YOUR CURRENT LIVING SITUATION?** (check box)

1.	Very satisfied	☐
2.	Fairly satisfied	☐
3.	Neither satisfied or dissatisfied	☐
4.	Somewhat dissatisfied	☐
5.	Very dissatisfied	☐

4. **ASSUMING THAT YOU COULD GET ALL THE ASSISTANCE YOU NEED, WHICH OF THE FOLLOWING WOULD YOU CONSIDER TO BE THE MOST ACCEPTABLE TYPE OF ACCOMMODATION FOR YOU?** (check box)

1. To live alone in my own apartment or home ☐
2. To live with family or friends in a private home or apartment ☐
3. To live with other disabled people in shared accommodation of 4 to 6 individuals ☐
4. To live in specially constructed housing with on-site attendant care ☐
5. To live with other disabled people in shared accommodation of approximately 30 people ☐
6. To live in a nursing home ☐
7. To live in a long-term care hospital ☐
8. Other ☐, Please specify: ______________________

Which would be your second choice? (write in number) ______

Which would be your third choice? (write in number) ______

SECTION VI: **NEED FOR HEALTH CARE EQUIPMENT**

The following questions are about the equipment that you use and need.

1. **PLEASE INDICATE, IF YOU USE OR NEED ANY OF THE ITEMS BELOW AND WHO PAID FOR EACH.** (check boxes)

	NOW USING	NEED BUT DON'T HAVE	HAVE BUT DON'T USE	PAID FOR MYSELF	GOVERNMENT FUNDING	MUSCULAR DYSTROPHY ASSOCIATION	INSURANCE COMPANY	OTHER	**PLEASE SPECIFY:**
1. Electric wheelchair	☐	☐	☐	☐	☐	☐	☐	☐	
2. Regular manual wheelchair	☐	☐	☐	☐	☐	☐	☐	☐	
3. Lighweight manual wheelchair	☐	☐	☐	☐	☐	☐	☐	☐	
4. Ultralight manual wheelchair	☐	☐	☐	☐	☐	☐	☐	☐	
5. Reclining manual wheelchair	☐	☐	☐	☐	☐	☐	☐	☐	
6. 3-wheeler or scooter	☐	☐	☐	☐	☐	☐	☐	☐	
7. Power pak on a manual wheelchair	☐	☐	☐	☐	☐	☐	☐	☐	
8. Seating insert for wheelchair, Please describe type: ______	☐	☐	☐	☐	☐	☐	☐	☐	
9. Walker	☐	☐	☐	☐	☐	☐	☐	☐	
10. Cane	☐	☐	☐	☐	☐	☐	☐	☐	
11. Standing frame	☐	☐	☐	☐	☐	☐	☐	☐	
12. Back brace	☐	☐	☐	☐	☐	☐	☐	☐	
13. Other orthopedic equipment, Please specify: ______	☐	☐	☐	☐	☐	☐	☐	☐	
14. Grab bars	☐	☐	☐	☐	☐	☐	☐	☐	
15. Bath or shower seat	☐	☐	☐	☐	☐	☐	☐	☐	
16. Commode	☐	☐	☐	☐	☐	☐	☐	☐	
17. Hydraulic bath lift	☐	☐	☐	☐	☐	☐	☐	☐	
18. Raised toilet seat	☐	☐	☐	☐	☐	☐	☐	☐	
19. Manual hospital bed	☐	☐	☐	☐	☐	☐	☐	☐	
20. Electric hospital bed	☐	☐	☐	☐	☐	☐	☐	☐	
21. Waterbed	☐	☐	☐	☐	☐	☐	☐	☐	
22. Other type of bed, please specify: ______	☐	☐	☐	☐	☐	☐	☐	☐	
23. T-foam mattress	☐	☐	☐	☐	☐	☐	☐	☐	
24. Alternating pressure mattress	☐	☐	☐	☐	☐	☐	☐	☐	
25. Sheepskin pad	☐	☐	☐	☐	☐	☐	☐	☐	

1 Continued on next page . . .

1 Continued from previous page

	NOW USING	NEED BUT DON'T HAVE	HAVE BUT DON'T USE	PAID FOR MYSELF	GOVERNMENT FUNDING	MUSCULAR DYSTROPHY ASSOCIATION	INSURANCE COMPANY	OTHER	PLEASE SPECIFY:
26. Other type of mattress, please specify:	☐	☐	☐	☐	☐	☐	☐	☐	
27. Bed rails	☐	☐	☐	☐	☐	☐	☐	☐	
28. Wheelchair cushion, please specify:	☐	☐	☐	☐	☐	☐	☐	☐	
29. Portable Aluminum Ramps	☐	☐	☐	☐	☐	☐	☐	☐	
30. Hoyer lift	☐	☐	☐	☐	☐	☐	☐	☐	
31. Other type of lift, please specify type:	☐	☐	☐	☐	☐	☐	☐	☐	
32. Outside porch lift	☐	☐	☐	☐	☐	☐	☐	☐	
33. Elevator	☐	☐	☐	☐	☐	☐	☐	☐	
34. Van lift	☐	☐	☐	☐	☐	☐	☐	☐	
35. Respirator	☐	☐	☐	☐	☐	☐	☐	☐	
36. Chest percussor	☐	☐	☐	☐	☐	☐	☐	☐	
37. Suction machine	☐	☐	☐	☐	☐	☐	☐	☐	
38. Computer	☐	☐	☐	☐	☐	☐	☐	☐	
39. Environmental control system	☐	☐	☐	☐	☐	☐	☐	☐	
40. Device to signal for help, eg. Protect-alert	☐	☐	☐	☐	☐	☐	☐	☐	
41. Communication device	☐	☐	☐	☐	☐	☐	☐	☐	
42. Other equipment, please specify									
	☐	☐	☐	☐	☐	☐	☐	☐	
	☐	☐	☐	☐	☐	☐	☐	☐	
	☐	☐	☐	☐	☐	☐	☐	☐	
	☐	☐	☐	☐	☐	☐	☐	☐	

2. **IS OBTAINING EQUIPMENT DIFFICULT?** (check box)

1. Yes ☐, Please explain why.
2. No ☐
3. I don't know. ☐
   I have not needed any equipment.

3. **IS IT DIFFICULT TO ARRANGE FOR REPAIRS TO YOUR EQUIPMENT?** (check box)

1. Yes ☐, Please explain why. ______________________

____

____

____

2. No ☐
3. Not applicable. ☐
   I do not have equipment.

4. **HAVE YOU EVER REQUESTED FINANCIAL ASSISTANCE FOR EQUIPMENT FROM THE MUSCULAR DYSTROPHY ASSOCIATION OF CANADA?** (check box)

1. Yes ☐ ——→ PLEASE GO TO QUESTION # 6.
2. No ☐

5. **WHY HAVE YOU NOT REQUESTED EQUIPMENT FROM THE MUSCULAR DYSTROPHY ASSOCIATION OF CANADA?** (check boxes)

1. I was not aware of this program. ☐
2. I have received all of my equipment from other sources. ☐
3. Other ☐, Please specify reason: ______________________

____

6. **HAVE YOU RECEIVED ANY EQUIPMENT THROUGH FUNDING FROM GOVERNMENT PROGRAMS?** (check boxes)

1. Yes ☐
2. No ☐ ——→ PLEASE PROCEED TO SECTION VII ON PAGE # 19.

7. PLEASE INDICATE HOW SATISFIED YOU WERE WITH THE FOLLOWING ASPECTS OF THE GOVERNMENT EQUIPMENT PROGRAM. (check boxes)

	VERY SATISFIED	FAIRLY SATISFIED	NEITHER SATISFIED NOR DISSATISFIED	SOMEWHAT DISSATISFIED	VERY DISSATISFIE
1. The range of equipment available.	☐	☐	☐	☐	☐
2. The assessment process to determine your need for equipment.	☐	☐	☐	☐	☐
3. The servicing of equipment	☐	☐	☐	☐	☐
4. The length of time before you become eligible for replacement of equipment.	☐	☐	☐	☐	☐
5. Other, please specify:					
________________________	☐	☐	☐	☐	☐
________________________	☐	☐	☐	☐	☐
________________________	☐	☐	☐	☐	☐

SECTION VII: **NEED FOR EMOTIONAL SUPPORT**

The questions in this section are about how you and your family manage and what your most pressing needs are.

1. **WHOM DO YOU AND/OR YOUR FAMILY TURN TO, WHEN YOU HAVE TROUBLE MANAGING OR COPING?** (check boxes)

   1. Friends ☐
   2. Other relatives ☐
   3. A social worker ☐
   4. A doctor ☐
   5. A psychologist ☐
   6. A marriage or family counsellor ☐
   7. Other people with the same condition and their families ☐
   8. Clergy ☐
   9. Staff of The Muscular Dystrophy Association of Canada ☐
   10. We deal with it on our own. ☐
   11. Other ☐, Please specify: ______________________________

   ____

2. **ARE YOU INVOLVED WITH ANY CLIENT, PARENT, OR FAMILY SUPPORT GROUPS?** (check box)

   1. Yes ☐, Please specify: ______________________________

   ____

   ____

   2. No ☐

3. **WOULD BE INTERESTED IN ATTENDING GROUP MEETINGS THAT FOCUSED ON:** (check boxes)

	YES	NO
1. Social and recreational events with other clients and their families	☐	☐
2. Information sessions regarding Muscular Dystrophy and other Neuromuscular Conditions	☐	☐
3. Support meetings with a professional to guide discussion on feelings and problems	☐	☐

4. Other ☐, Please specify: ______________________________

____

____

4. **HOW WOULD YOU RATE THE IMPORTANCE OF EACH OF THE FOLLOWING AS PRESSING NEEDS FOR YOU AND YOUR FAMILY?** (check boxes)

	GREAT NEED	SOME NEED	NO NEED	DON'T KNO
1. Family respite (relief) care	☐	☐	☐	☐
2. Specialized daycare facilities for children and adults	☐	☐	☐	☐
3. Subsidies for attendant care	☐	☐	☐	☐
4. Subsidies for family members to be paid as attendants	☐	☐	☐	☐
5. Better coordination of existing health and social services	☐	☐	☐	☐
6. Improved accessible transportation systems for the disabled	☐	☐	☐	☐
7. Universal accessibility of public buildings	☐	☐	☐	☐
8. A network of parent or client support groups	☐	☐	☐	☐
9. Someone to represent the concerns of the disabled to government	☐	☐	☐	☐
10. Regular visits by a professional knowledgeable about neuromuscular disorders	☐	☐	☐	☐
11. Someone to coordinate hospital and home care programs	☐	☐	☐	☐
12. A buddy system with clients and families to share problems	☐	☐	☐	☐
13. More funding for home modifications	☐	☐	☐	☐
14. More funding for equipment	☐	☐	☐	☐
15. Death and grieving counselling	☐	☐	☐	☐
16. More social and recreational opportunities designed for the disabled	☐	☐	☐	☐
17. Improved educational and job training	☐	☐	☐	☐
18. Improved job opportunities for the disabled	☐	☐	☐	☐
19. Better public attitudes towards disabled people	☐	☐	☐	☐
20. More accessible housing options	☐	☐	☐	☐
21. Someone to educate employers about workplace accessibility	☐	☐	☐	☐
22. Someone to educate teachers about the abilities of children with neuromuscular disorders	☐	☐	☐	☐
23. Someone to be liason between the client and the school or workplace	☐	☐	☐	☐

4 Continued on next page . . .

4 Continued from previous page

	GREAT NEED	SOME NEED	NO NEED	DON'T KNOW
24. Expansion of genetic counselling services	☐	☐	☐	☐
25. Other, please specify:				
____________________	☐	☐	☐	☐
____________________	☐	☐	☐	☐
____________________	☐	☐	☐	☐

5. WHICH OF THE 25 ITEMS FROM THE PREVIOUS PAGE (QUESTION # 4) ARE YOUR THREE MOST PRESSING NEEDS? RANK THEM FROM 1 (HIGHEST) TO 3 (LOWEST).

Please record the number of your choice 1. __________

2. __________

3. __________

6. FOR EACH OF THE NEEDS YOU HAVE IDENTIFIED IN QUESTION # 5, PLEASE DESCRIBE WHY THESE ARE NEEDS FOR YOU AND YOUR FAMILY.

1. ____

____

____

____

2. ____

____

____

____

3. ____

____

____

____

SECTION VIII: **COMPLETING THE QUESTIONNAIRE**

Please use the space below to elaborate on any additional needs or concerns you or your family have that you would like to bring to our attention.

THANK YOU FOR YOUR HELP IN COMPLETING THIS QUESTIONNAIRE.

PLEASE RETURN THIS QUESTIONNAIRE TO THE MUSCULAR DYSTROPHY ASSOCIATION OF CANADA IN THE ENVELOPE PROVIDED.

Appendix 3
Agency Survey Form

THE MUSCULAR DYSTROPHY ASSOCIATION OF CANADA
AGENCY NEEDS ASSESSMENT SURVEY

NAME OF ORGANIZATION:____________________________________

CONTACT PERSON:____

ADDRESS:____

____

TELEPHONE NUMBER:______________________________________

DATE:____

....

1. <u>TYPES/RANGE OF SERVICES PROVIDED</u>:

2. <u>ELIGIBILITY FOR SERVICE</u>:

   AGE

   SEX

   FINANCIAL (ie. NEEDS TEST)

   GEOGRAPHIC CATCHMENT AREA

   TARGET POPULATION

3. <u>SERVICE PROVIDERS</u>:

TRAINING/CREDENTIALS

NUMBER OF STAFF

AVERAGE CASELOAD PER STAFF MEMBER

TREATMENT MODALITIES PROVIDED

CONTINUING EDUCATION OPPORTUNITIES FOR STAFF

4. <u>FINANCIAL CHARACTERISTICS</u>:

CHARGE FOR SERVICE:

FEE SCHEDULE

ELIGIBILITY FOR THIRD PARTY REIMBURSEMENT

SLIDING SCALE PROVISIONS

AGENCY FUNDING SOURCES:

GOVERNMENT FUNDING

PRIVATE FUNDING

CHARITABLE FUNDING

OTHER FUNDING

5. <u>ACCESSIBILITY, AVAILABILITY AND AWARENESS OF SERVICES</u>:

LOCATION OF FACILITY

TRANSPORTATION SERVICES TO FACILITY

INTAKE PROCEDURE:

  AMOUNT OF INFORMATION REQUIRED

  HOURS OF SERVICE

  PUBLICITY OF AVAILABLE SERVICES

6. <u>REFERRALS</u>:

NUMBER (within standardized time frame)

SOURCE

REASONS

GEOGRAPHIC ORIGIN OF REFERRING AGENTS

GEOGRAPHIC ORIGIN OF CLIENTS REFERRED

TEMPORAL PATTERNS OF REFERRALS

7. <u>CLIENTS ACCEPTED FOR SERVICE</u>:

NUMBER (within specified time frame)

DIAGNOSES

SOCIODEMOGRAPHIC CHARACTERISTICS (age, sex, economic status)

REFUSALS (why service refused)

8. <u>WAITING LIST</u>:

NUMBER ON WAITING LIST

REASONS FOR WAITING LIST

PROPORTION OF THOSE ON LIST WHO NEVER RECEIVE SERVICE

9. <u>REFERRALS INITIATED</u>:

REFERRALS MADE TO OTHER AGENCIES

PROBLEMS MAKING REFERRALS (ie. transportation, finances, language, cultural barriers, accessibility)

10. <u>PROBLEM AREAS</u>:

PROBLEM AREAS THOUGHT TO BE OF HIGHEST PRIORITY

SERVICES INCREASING IN DEMAND

11. <u>OTHER INFORMATION</u>:

Appendix 4

Individual Assessment Form

SURVEY OF THE NEEDS OF PEOPLE WITH MUSCULAR DYSTROPHY AND RELATED NEUROMUSCULAR DISORDERS

INDIVIDUAL ASSESSMENT FORM

INTERVIEW DATE: ______________________________

NAME OF REGISTERED CLIENT: ______________________________

DIAGNOSIS ON MDAC REGISTRY: ______________________________

DATE OF BIRTH ON REGISTRY: _______________ AGE: _______

NAME/RELATIONSHIP OF OTHERS PRESENT AT INTERVIEW:

____

____

____

1. WHAT IS YOUR DIAGNOSIS? ______________________________
2. WHAT DO YOU KNOW ABOUT YOUR DISORDER? _______________

   ____

   ____

   ____

3. WHAT WAS THE SCENARIO LEADING TO YOUR DIAGNOSIS? (EG. WHEN WERE DEVELOPMENTAL MILESTONES ACHIEVED?, WHAT SPECIALISTS WERE SEEN?, DID YOU HAVE AN EMG?, A BIOPSY?, WHAT WERE YOUR MAJOR DIFFICULTIES?, ETC.)

   ----

4. WHERE DID YOU/DO YOU GET INFORMATION ABOUT YOUR DISORDER?

   ____

   ____

5. HAVE YOU OR YOUR FAMILY RECEIVED ANY GENETIC COUNSELLING?; WHEN?; WHERE?; FROM WHOM?

6. WHAT MEDICAL FOLLOW-UP DO YOU RECEIVE IN THE COMMUNITY? (EG. GP, THERAPISTS, RN, ATTENDANT, ETC.)

7. DO YOU ATTEND A NEUROMUSCULAR CLINIC?; WHERE?; HOW OFTEN?

8. WHY DO YOU ATTEND CLINIC?

9. IN WHAT WAYS HAS THE CLINIC BEEN HELPFUL?

10. IN WHAT WAYS COULD THE CLINIC HAVE BEEN MORE HELPFUL?

MORE TIME TO ASK QUESTIONS	Y/N
MORE TIME WITH STAFF	Y/N
MORE FREQUENT VISITS	Y/N
LESS FREQUENT VISITS	Y/N
BETTER FOLLOW-UP IN THE COMMUNITY	Y/N
BETTER TRANSPORTATION TO CLINIC	Y/N

OTHER: ____________________

11. WAS IT PRACTICAL TO FOLLOW THROUGH AT HOME ON THE ADVICE GIVEN BY THE STAFF MEMBERS OF THE CLINIC?

YES

NO, WHY?: ____________________

12. VIGNOS STAGE OF MUSCULAR DYSTROPHY (ASSESSED BY OT)

STAGE #: _____ DESCRIPTION: ______________________________

____

13. DO YOU CONSIDER THE FOLLOWING TO BE DIFFICULTIES FOR YOU?

	CLIENT'S	OT'S
	PERCEPTION	
IMPAIRED AMBULATION	Y/N	Y/N
MUSCULAR WEAKNESS SHOULDER GIRDLE	Y/N	Y/N
MUSCULAR WEAKNESS HIPS AND PELVIS	Y/N	Y/N
POOR HAND FUNCTION	Y/N	Y/N
POSTURE	Y/N	Y/N
RESTRICTED ENERGY AND PHYSICAL TOLERANCE (COMPARED TO 1 YR. AGO)	Y/N	Y/N
SKIN BREAKDOWN	Y/N	Y/N
RESPIRATORY PROBLEMS / SHORTNESS OF BREATH	Y/N	Y/N
SWELLING	Y/N	Y/N
PAIN	Y/N	Y/N

WHERE? ____

____

14. DO YOU REQUIRE HELP WITH DRESSING? Y/N
WHO HELPS YOU? ____________________

15. DO YOU REQUIRE HELP MOVING FROM YOUR BED TO A CHAIR OR YOUR WHEELCHAIR? Y/N
WHO HELPS YOU? ____________________

16. IF YOU ANSWERED "YES" TO #11, PLEASE DESCRIBE YOUR TRANSFERS OR DEMONSTRATE A TRANSFER TO ME.

____

____

17. DO YOU REQUIRE HELP GETTING IN AND OUT OF THE BATHTUB? Y/N
WHO HELPS YOU? ____________________

18. IF YOU ANSWERED "YES" TO # 13, PLEASE DESCRIBE YOUR TUB TRANSFERS OR DEMONSTRATE A TRANSFER TO ME.

19. WHAT IS THE IMPACT ON YOUR FAMILY OF HAVING TO HELP YOU WITH YOUR DAILY LIVING TASKS? IS IT HARD ON THEM PHYSICALLY? EMOTIONALLY?

CLIENT'S PERCEPTION:

OT'S PERCEPTION:

20. DO YOU THINK YOU WILL NEED MORE OR LESS HELP IN THE NEXT 5 YEARS?

CLIENT'S PERCEPTION: MORE/LESS
OT'S PERCEPTION: MORE/LESS

21. HAVE YOU EXPERIENCED ANY DIFFICULTIES GETTING MEDICAL EQUIPMENT? GETTING EQUIPMENT REPAIRED? REPLACED?

22. DO YOU CONSIDER ANY OF THE FOLLOWING TO BE DIFFICULTIES FOR YOU?

	CLIENT'S PERCEPTION	OT'S PERCEPTION
RESTRICTED AMBULATION	Y/N	Y/N
STAIRS	Y/N	Y/N
USING PUBLIC TRANSPORTATION	Y/N	Y/N
TRANSFERS	Y/N	Y/N
LOW ENERGY LEVEL	Y/N	Y/N
ACCESS TO COMMUNITY FACILITIES	Y/N	Y/N
LACK OF FAMILY SUPPORT	Y/N	Y/N

23. DO YOU EVER FEEL FRUSTRATED AS A RESULT OF THE LIMITATIONS IMPOSED BY YOUR DISABILITY? Y/N

24. HOW DO YOU DEAL WITH THESE FEELINGS?

____

____

25. DO YOUR FAMILY OR CAREGIVERS EVER FEEL OVERWHELMED OR FRUSTRATED BY THE CONSTANT NEED TO HELP YOU?

CLIENT'S PERCEPTION: Y/N

FAMILY'S/CAREGIVERS' PERCEPTION: Y/N

OT'S PERCEPTION: Y/N

26. HOW DO THEY DEAL WITH THESE FEELINGS?

____

____

27. DO YOU OR YOUR FAMILY FEEL ISOLATED FROM OTHER PEOPLE? EG. UNABLE TO PARTICIPATE IN SOCIAL ACTIVITIES DUE TO ACCESSIBILITY FOR A WHEELCHAIR, THE ROUTINE IMPOSED BY YOUR DISABILITY, INABILITY TO GET KNOWLEDGEABLE BABYSITTERS, ETC.)

____

____

____

____

____

28. WHAT RECREATIONAL ACTIVITIES DO YOU PARTICIPATE IN OUTSIDE OF THE HOME? YOUR FAMILY?

____

____

29. WOULD YOU BE INTERESTED IN MEETING OTHER CLIENTS WITH THE SAME DISORDER TO COMPARE NOTES ABOUT COMMON PROBLEMS AND SOLUTIONS?

YES, WHY?: ______________________________

____

NO, WHY?: ______________________________

____

30. WOULD YOU BE INTERESTED IN MEETING WITH A KNOWLEDGABLE PERSON TO LEARN MORE ABOUT YOUR DISORDER?

YES, INDIVIDUALLY OR WITH MY FAMILY

YES, WITH OTHER CLIENTS IN A WORKSHOP SESSION

NO

31. WOULD YOU FIND IT HELPFUL TO HAVE A KNOWLEGEABLE PERSON WORKING IN YOUR PROVINCE AND AVAILABLE BY TELEPHONE TO BE A RESOURCE ABOUT YOUR DISORDER, YOUR EQUIPMENT NEEDS AND TO TALK ABOUT ANY DIFFICULTIES YOU MIGHT HAVE?

YES, GIVE AN EXAMPLE OF WHEN YOU MIGHT CONTACT THIS PERSON: ______________________________

____

NO

32. HOW DO YOU DEAL WITH QUESTIONS ABOUT YOUR / YOUR CHILD'S DISORDER?

____

____

____

<u>THE NEXT SECTION APPLIES TO PEDIATRIC CLIENTS ONLY</u>

(PARENTS OR OLDER CHILDREN MAY RESPOND)

33. IS YOUR SCHOOL FULLY WHEELCHAIR ACCESSIBLE?

Y/N, COMMENTS: ______________________________

____

34. WHO HELPS YOU AT SCHOOL? ______________________________

35. HOW DO YOU GET TO SCHOOL? ______________________________

36. IS THE ACADEMIC PROGRAM SATISFACTORY? Y/N, COMMENTS:

____

37. DO THE SCHOOL STAFF KNOW ENOUGH ABOUT MUSCULAR DYSTROPHY AND YOUR SPECIAL NEEDS? Y/N

38. HOW DOES THE SCHOOL VIEW YOUR PROBLEMS?

EASY / MANAGEABLE / DIFFICULT / OTHER: ______________

39. DO YOU HAVE FRIENDS AT SCHOOL? Y/N

40. DO FRIENDS COME TO VISIT YOU AT HOME? Y/N

41. DO YOU VISIT FRIENDS IN THEIR HOMES? Y/N

42. HAS THE EXTRA TIME SPENT WITH YOUR DISABLED CHILD AFFECTED YOUR RELATIONSHIP WITH YOUR OTHER CHILDREN? PLEASE EXPLAIN: ______________________________________

____

____

<u>THE NEXT SECTION APPLIES TO ADULT CLIENTS ONLY</u>

43. ARE YOU PRESENTLY WORKING? Y/N

44. IF YOU ANSWERED "YES" TO #43,

ARE YOU SATISFIED WITH YOUR WORK? Y/N

IS YOUR WORKPLACE ACCESSIBLE? Y/N

WHO HELPS YOU AT WORK, IF YOU NEED ASSISTANCE?

____

WHAT MEANS OF TRANSPORTATION DO YOU USE TO GET TO WORK?

____

DOES YOUR EMPLOYER KNOW ENOUGH ABOUT MUSCULAR DYSTROPHY AND YOUR SPECIAL NEEDS? Y/N

45. IF YOU ARE NOT WORKING, COULD YOU PLEASE EXPLAIN WHY?

____

____

____

____

____

THE NEXT SECTION APPLIES TO ALL CLIENTS

46. PLEASE DESCRIBE YOUR MOST PRESSING NEEDS, YOUR BIGGEST PROBLEMS AND YOUR GREATEST BARRIERS.

CLIENT'S PERCEPTION: ______________________________

____

____

____

____

____

OT'S PERCEPTION: ______________________________

____

____

____

____

____

47. DO YOU HAVE ANY OTHER ISSUES THAT YOU WOULD LIKE TO BRING TO MY ATTENTION OR ANY QUESTIONS?

____

____

____

____

____

____

____

____

____

____

Appendix 5

Letter Confirming Appointments with Key Informants of Agency Survey

December 29, 1986.

Dear

The intent of this letter is twofold: firstly, I would like to thank you for agreeing to meet with me on January   , 1987 at   ; secondly, I would like to briefly review the purpose of the needs assessment research project presently being undertaken by The Muscular Dystrophy Association of Canada and the reason why input from government, health-care and voluntary agency representatives is being sought.

The Muscular Dystrophy Association of Canada is a national, voluntary, health-care organization. The goals of the Association are to provide medical and supportive services to clients with neuromuscular disorders and to finance medical research into the causes and the treatments for muscular dystrophy and over 40 related neuromuscular disorders. In order to gain information about the total needs of clients with neuromuscular disorders and their families a research project is presently underway in the Prairie provinces of Manitoba and Saskatchewan. The information gained from this study will be used by the Association to plan for the development of services and programs specifically tailored to clients living in Manitoba and Saskatchewan.

The Muscular Dystrophy Association of Canada presently provides only very limited services to registered clients in the Prairies. This study will develop a strategy to address the unmet needs identified by clients, themselves, in their responses to mailed surveys, by professionals in their assessments of client needs, by interviews with service providers, by analysis of resources available to clients, and via public meetings with clients.

L'ASSOCIATION
CANADIENNE DE LA
Dystrophie
MUSCULAIRE
MUSCULAR
Dystrophy
ASSOCIATION
OF CANADA

The survey to be mailed to registered clients is currently in the draft stage and is being tested and revised for distribution in late January. Individual assessments will be arranged with a small sample of clients once the completed surveys have been returned. Interviews with service providers and agency representatives, such as yourself, are presently being conducted in order to determine what services are currently available to our clients, what services are being accessed by our clients, and what is the relationship between our organization and these other programs.

Once again I would like to thank you for taking time from your busy schedule to meet with me. I have enclosed some additional reading material about the study and The Muscular Dystrophy Association of Canada, should you care to review this prior to our meeting. I am looking forward to our meeting and sharing information about our respective programs and services.

Sincerely,

Lena N. Cuthbertson, BHSc. O.T.; Dip. O.T.
Personal Support Services Department
Epidemiology Research Coordinator

LNC/

L'ASSOCIATION CANADIENNE DE LA DYSTROPHIE MUSCULAIRE

MUSCULAR Dystrophy
ASSOCIATION OF CANADA

Thank you for agreeing to participate in an evaluation of a survey type questionnaire that is being developed to help The Muscular Dystrophy Association of Canada gain knowledge about the needs of clients with neuromuscular disorders throughout Canada. The survey in its present form is a draft. With your help the survey will be tested. It will then be revised for distribution to clients in Manitoba and Saskatchewan. Based on the results of the Prairies trial, the survey will again be revised for distribution to other regions across Canada.

Your help is required at this stage to assist us in evaluating the questionnaire and in deciding if each of the questions is measuring what it is intended to measure. We want your comments and general impressions on everything from the cover letter, to the specific questions, the format, the sequence, and the instructions.

Please read through the questionnaire and attempt to answer all the questions. When reading and answering questions, please keep the following checklist in mind:

1. are the instructions clearly worded?
2. are the questions clearly worded?
3. are any of the words objectionable?
4. how do you feel about the length of the survey?
5. is sufficient space provided to answer all questions?
6. is the order of items/sections satisfactory?
7. does the questionnaire and cover letter motivate you to complete the survey?

.../2

Her Excellency the Right Honourable Jeanne Sauvé, P.C., C.C., C.M.M., C.D., Governor General of Canada
Son Excellence la très honorable Jeanne Sauvé, C.P., C.C., C.M.M., C.D., Gouverneur général du Canada

National Office (#0043307-11-13) Siège Social
150 Eglinton Avenue East, Suite 400, Toronto, Ontario M4P 1E8 Tel. (416) 488-0030

Your comments can be noted directly on the survey and/or on a separate sheet of paper. When completed please return the questionnaire and your comments in the envelope provided by January 6, 1987.

Once again, thank you for your help in testing the enclosed questionnaire. Your help at this busy time of year is especially appreciated.

Sincerely,

Lena N. Cuthbertson, Dip.O.T.; BHSc.O.T.
Personal Support Services Department
Epidemiology Research Co-ordinator

LNC/mrf

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Appendix 7

Letter to Parents Regarding Individual Assessments at The Rehabilitation Centre for Children Winnipeg

L'ASSOCIATION CANADIENNE DE LA DYSTROPHIE MUSCULAIRE

MUSCULAR
Dystrophy
ASSOCIATION
OF CANADA

May 21, 1987

Dear Parent:

The MUSCULAR DYSTROPHY ASSOCIATION OF CANADA provides services to persons with neuromuscular disorders throughout Canada. In Manitoba our services have overlapped with government funded services, such as The Society for Manitobans, Wheelchair Services program. The Muscular Dystrophy Association of Canada has, therefore, provided only limited services to our registered clients who live in Manitoba. We do recognize, however, that you and your child may still have needs that are not being met. For this reason The Muscular Dystrophy Association of Canada has undertaken a research project to study your needs. The information gained from this study will be used by The Association to plan services for our clients and their families, who live in Manitoba.

The first part of the research project involves a questionnaire that will be sent to all our clients registered in Manitoba. You have probably already received this questionnaire in the mail. The second part of our research project involves meeting with a small number of our clients to confirm the results of the questionnaire. The staff of The Rehabilitation Centre for Children in Winnipeg have kindly agreed to allow me to hold these meetings during their June 2nd, 1987 Muscular Dystrophy Clinic. As you and your child are scheduled to attend this clinic, Mrs. Olga Honeybun has offered to schedule about 30 to 45 minutes of time during this clinic for me to meet with you. I am interested in hearing your views about the needs of your child and your family and any suggestions you may have for meeting these needs. Your involvement will ensure that your views are included in the final results of our research. All personal information will, of course, be kept in strict confidence.

Please contact Mrs. Olga Honeybun at The Rehabilitation Centre for Children at 452-4311, should you be unable to attend this clinic. If you have any questions about the session with me, please call collect at 604-732-8799.

I look forward to meeting with you on June 2nd.

Sincerely,

Lena N. Cuthbertson
Client Services Research Coordinator

Appendix 8

Letter to Parents Regarding Individual Assessments at The Children's Rehabilitation Centre, Saskatoon

April 13, 1987

Dear Parent:

The MUSCULAR DYSTROPHY ASSOCIATION OF CANADA provides services to persons with neuromuscular disorders throughout Canada. In Saskatchewan our services have overlapped with government services, such as the SAIL equipment program. The MUSCULAR DYSTROPHY ASSOCIATION OF CANADA has, therefore, provided only limited services to our registered clients who live in Saskatchewan. We do recognize, however, that you and your child may still have needs that are not being met. For this reason The MUSCULAR DYSTROPHY ASSOCIATION OF CANADA has undertaken a research project to study your needs. The information gained from this study will be used by The Association to plan services for our clients and their families, who live in Saskatchewan.

The first part of the research project involves a questionnaire that will be sent to all our clients registered in Saskatchewan. You will receive this questionnaire in the mail within the next two weeks. The second part of our research project involves meeting with a small number of our clients to confirm the results of the questionnaire. The staff of The Children's Rehabilitation Centre in Saskatoon have kindly agreed to allow me to hold these meetings during their May 11th, 1987 Muscular Dystrophy Clinic. As you and your child are scheduled to attend this clinic, Mrs. Mardell Wolfrom has offered to allow me to meet with you for about 30 to 45 minutes in lieu of your regularly scheduled social work session with her. I am interested in hearing your views about the needs of your child and your family and any suggestions you may have for meeting these needs. Your involvement will ensure that your views are included in the final results of our research. All personal information will, of course, be kept in strict confidence.

Please contact Mrs. Mardell Wolfrom at The Children's Rehabilitation Centre at 966-1257, should you be unable to attend this clinic. If you have any questions about the session with me, please call collect at 604-732-8799.

I look forward to meeting with you on May 11th.

Sincerely,

Lena N. Cuthbertson
Client Services Research Coordinator

L'ASSOCIATION CANADIENNE DE LA
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ASSOCIATION OF CANADA

Appendix 9

Follow-up Letter to Non-respondents of Client Survey

L'ASSOCIATION CANADIENNE DE LA DYSTROPHIE MUSCULAIRE

MUSCULAR
Dystrophy
ASSOCIATION
OF CANADA

May 26, 1987

Dear Client,

Last month a questionnaire was sent to you. This questionnaire was developed to gather information about the needs of people, like you, living in Manitoba or Saskatchewan, who have Muscular Dystrophy or one of the related neuromuscular disorders. So far about 50% of these questionnaires have been returned to us.

If you have already returned the questionnaire, then let me take this opportunity to thank you for your input. If, however, you have not yet returned the questionnaire, please consider the loss of important information that you and your family will not have contributed towards helping to shape the direction of services to be offered in your province by THE MUSCULAR DYSTROPHY ASSOCIATION OF CANADA.

Luckily, the schedule for this project will allow us to use the information from all questionnaires returned to us before June 19th, 1987. So --- if you have not yet completed the questionnaire, we encourage you to please do so as soon as possible. You may contact me at (604) 732-8799 (collect), if you have any questions or concerns.

Please remember your input is the key to ensuring that the views of you and your family are included in our final results. THE MUSCULAR DYSTROPHY ASSOCIATION OF CANADA is committed to improving services in your province, but we can't do it without your help. Remember -- "One step at a time, TOGETHER we can make it!".

Sincerely,

L. N. Cuthbertson
Lena N. Cuthbertson
Client Services Research Coordinator

Appendix 10

Problem Lists Generated from Agency Surveys in Manitoba

PROBLEM LISTS GENERATED FROM AGENCY CONTACTS IN MANITOBA

1. O.T/P.T. in the community are generalists with no pediatric experience
2. O.T./P.T./S.T. not readily available; if available lack confidence and expertise in pediatrics
3. inconsistent service provision in rural areas
4. majority of therapists working in the community have adult and geriatric experience with no pediatric O.T/P.T./S.T. training
5. services for disabled adolescents are lacking
6. avocational programming is lacking
7. accessible and low cost housing is lacking
8. technical aids -- lifts, environmental controls, computers -- are not available
9. leisure transportation services for disabled clients 13 to 18 years of age are not available
10. waiting for equipment has been frustrating for parents
11. parents of older children are resistant to joining or forming support groups, but are the clients in most need of such psychosocial support
12. social workers have been unsuccessful in bringing together parents of Duchenne Muscular Dystrophy kids due to small numbers and distribution over large areas
13. financial restraint limits the expansion of a government funded universal equipment program to include all items needed by the disabled
14. workload for equipment repair staff of the government equipment program is too heavy
15. inability to supply different models and high technology wheelchairs due to limited nature of the universal equipment program (limited number of dollars)

16. requests for wheelchair products other than the Everest & Jennings models supplied through the universal equipment program

17. difficulty to access specialty clinicians (psychologists, O.T., P.T., S.T.) in isolated rural and northern areas of the province

18. specialized services and technical expertise is lacking outside of Winnipeg in the provision and maintenance of respirators, environmental control units, etc.

19. services for young adults (who do not want services as developed for the elderly) are lacking

20. lack of back-up services, such as respite; this lack places tremendous emotional and physical strain and responsibility on family and primary caregivers who enable disabled clients to live in the community

21. delivery of medical service in the community is subject to limitations in service, such as home care nurses who are not available during the night, weekends, etc.

22. insufficient funds to maintain adequate staffing levels, resulting in delays and reduced service

23. clients with increasingly complex medical problems are being referred for care in the community

24. adult clients are frustrated with medical services and provision of equipment

25. no central coordination of services, information and education exists

26. adult clients are not attending clinics as no neuromuscular specialty service with experienced staff exists

27. clients reaching 16 to 18 years of age are not being referred from pediatric settings to the adult rehabilitation centre due to lack of coordinated services and expertise with neuromuscular disorders

28. public attitudes towards the disabled in the workplace are incorrect and restrict access of the disabled to gainful employment

29. specialty services are limited to Winnipeg and Brandon

30. service providers create needs and thereby create their own jobs

31. medical and technical aspects of clients with neuromuscular disorders are well cared for, but family coping is very poor

32. need for patient and parent self-help

33. funding needed for home modifications

34. funding needed for adapted transportation for the disabled

35. funding needed to assist with attendance at clinic to compensate for parental lost wages

36. acceptance of diagnosis

37. working parents have no time or money (lost time at work) to attend appointments

38. peer relationships of children with neuromuscular disorders are poor; children need counselling and groups

39. equipment is available for clients in the home setting, but not in acute care hospitals

40. shortage of O.T./P.T. manpower to serve the special program needs of disabled children

41. bureaucratic system of professionals meets needs of professionals, rather than the needs of the special children and their families

42. programs provided to disabled children in the school are educational programs, but not necessarily "appropriate" educational programs

43. clients need help in sorting out avenues to approach the complex system of the school board

44. large geographic area of Manitoba and manpower shortages of clinicians (therapists, educational consultants, psychologists, etc.) dictates a consultative, rather than a direct service model

45. personal and family counselling is being done by unqualified workers (vocational rehabilitation counsellors) because no other resources are available

46. adult services of The Society for Manitobans with Disabilities has a mandate that only deals with employment; no other needs of disabled adults are addressed

47. there is a lack of transportation and attendant care services during and after the pre-vocationional training phase

48. vocational rehabilitation is more successful in urban than in rural areas when clients won't or can't relocate

49. attendant care services vary across the province; clients experience great difficulty accessing services in remote areas

50. dependency of disabled persons on professionals; failure to assume responsibility to direct own care plan; professionals encourage dependency

51. lack of choice in equipment needs; only certain products are available from the provincial universal equipment program

52. equipment provision and selection requires professional input (assessment and prescription); disabled clients are not permitted to make their own choices or identify their own needs

53. need for self-directed attendant care

54. lack of appropriate housing to meet the needs of the disabled

Appendix 11

Problem Lists Generated from Agency Surveys in Saskatchewan

PROBLEM LISTS GENERATED FROM AGENCY CONTACTS IN SASKATCHEWAN

1. equipment choices are limited to models and products purchased by bulk tender

2. there are long delays in providing specialty equipment

3. there are delays of up to several months in providing power wheelchairs

4. equipment can only be replaced, when it can no longer be repaired

5. power wheelchairs must be shipped by truck (buses will not carry power chairs and batteries) to the SAIL repair depot; in remote areas trucking companies travel to Saskatoon or Regina not more than once per week or once every two weeks

6. the teen, young adult and adult programs of the Saskatchewan Abilities Council are unable to serve rural and even satellite towns greater than 10 miles outside of Saskatoon or Regina; this limits the avocational programs available to these clients

7. programs receive funding to carry out assessments, but not to provide the assistive devices determined via the assessment to be needed (eg. technical aids such as computers and environmental control units)

8. the technology of equipment, such as mobility devices and technical aids, changes rapidly; there is a dilemma concerning who should fund what, when and whether all available options have been considered

9. there is a lack of funding for staff and equipment; ie. voluntary and government funds are more frequently given for the construction of new and fancy buildings, but no consideration is given for the funds required to adequately staff these buildings and to provided the equipment necessary to do the work

10. there is a lack of rehabilitation manpower in Saskatchewan -- O.T., P.T., S.T.

11. vocational rehabilitation programs are only successful, if rural and Northern Saskatchewan clients relocate to Saskatoon or Regina for training and ultimate work

12. the Saskatchewan Abilities Council branch in Saskatoon is the only provider of adapted seating in the entire province; all clients living outside of Saskatoon must travel to this centre several times for measurements, fittings and alterations of custom-seating inserts

13. SAIL does not provide funding for the transportation costs of clients who must travel within the province for medical attention

14. there is a need for an information and resource centre for equipment and technical aids in Saskatchewan

15. there is a need for an assessment centre for equipment and technical aids in Saskatchewan

16. there is a need for a training centre for equipment and technical aids in Saskatchewan

17. accessibility

18. transportation for the physically disabled

19. the training allowance for disabled clients involved in vocational rehabilitiation is approximately $75.00 per month; hence, there is little incentive to work

20. there are a lack of employment opportunities for the disabled, in part due to the current employment situation in Canada and in part due to the negative attitudes of employers towards the physically disabled

21. poverty of the disabled; this is due to inadequate income maintenance

22. gaps in the "system" render disabled people ineligible for services which should be a basic right, eg. transportation services equal to those which able-bodied persons can access

23. the special needs and added costs encurred by the disabled are not reflected in disability allowances, eg. disabled people have the same flat rate as other people in receipt of social assistance, but disabled people have higher costs due to their special needs)

24. SAIL does not provide all the equipment needed by the disabled

25. Muscular Dystrophy clients do not qualify for the Para Program

26. the majority of disabled persons move to larger centres to have access to medical services and jobs

27. non-accessible housing

28. provincial legislation still does not reflect the needs of disabled people, eg. new supermailboxes are not accessible to the disabled

29. medical and allied health service referrals cannot be made by paraprofessionals, only by physicians

30. according to the definition of eligibility of the Para Program, Muscular Dystrophy clients are not eligible for funding for wheelchair van lifts, ramps or electric lifts, hand controls for motor vehicles, etc.

31. provinicial legislation discriminates against the disabled, eg. the rules of the Para Program are legislation, not policy

32. transportation costs to medical appointments are only available to social service recipients

33. SAIL does not provide a public forum for policy change; SAIL policies are based on recommendations made by a committee composed only of medical (physician) specialists

34. the vocational rehabilitation program relies on the school system to provide career counselling to disabled students; this is done satisfactorily in city schools, but not in rural schools

35. attendant care services are available to post-secondary school students or trainees only for the duration of their study/training period; these services terminate as soon as the study/training period is completed

36. referrals to a rehabilitation centre must be initiated by a community physician and be directed to a rehab centre physician; community therapists cannot refer to rehab centre therapists and vice-versa

37. receipt of equipment funded by SAIL takes a very long time

38. finding funding for equipment, if clients are not eligible for the Para Program, is a great problem

39. placement post-rehabilitation; some clients never leave the rehab centre due to insufficient community housing options and long-term care facilities

40. inadequate financial resources exist to develop educational programs for disabled students

41. inadequate financial resources exist to develop educational programs for teachers of disabled students

42. even if enough money existed for programs for the disabled, it would still not be possible to recruit the specialty clinicians (eg. therapists, psychologists, etc.) needed to staff these programs

43. a dilemma exists about when to recommend technical aids -- need vs. want vs. obsolecence

44. inability to recruit community-based therapists (O.T. and P.T.)

45. there is a critical shortage of O.T.'s in Saskatchewan (current ratio of O.T.:P.T. is 1:5

46. community therapists are not involved with rural schools

47. community therapists have virtually no skills in pediatrics

48. clients are not referred to community therapists post-discharge for follow-up and encounter difficulties as a result of this

49. therapists cannot engage in a therapy program with a client without a physician's referral

50. SAIL does not supply equipment to level 4 residents in special care homes or hospitals

51. restrictions in dollars and manpower reduce availability of attendant care services in the home

52. the home care program provides assistance for families, but necessitates strong family commitment to participation in the home program; it is not a relief program, rather a support program

53. the fee schedule for home care homemaking and personal care is $30 to $250 per month dependent on income; this is a burden or restriction to some families

54. the expansion of the home care program, although needed by clients receiving care in their homes, is not possible due to the financial limits of the program

55. home care services limit acute care to urban centres

56. emotional support is needed for parents and clients

57. even exceptional parents and clients have difficulty accepting the different stages of deterioration of a neuromuscular disorder and require more support than they currently receive from all sources

58. because Muscular Dystrophy clients do not have a support group of their own, they often are invited to attend heterogeneous support groups of parents or clients with stable conditions; these groups do not prove to be helpful, because the problems of MD clients are much more intense as a result of the constantly deteriorating nature of these conditions

Appendix 12

Distribution of Respondents by Health Unit Regions in Manitoba

REGION NUMBER	REGION NAME	NUMBER OF RESPONDENTS PER REGION	PERCENTAGE OF RESPONDENTS PER REGION
1	Winnipeg	31	57.4
2	Eastman	2	3.7
3	Central	5	9.2
4	Norman	4	7.4
5	Parklands	1	1.9
6	Interlake	3	5.6
7	Thompson	0	0.0
8	Westman	8	14.8
		54	100.0

Appendix 13

Distribution of Respondents by Health Unit Regions in Saskatchewan

REGION NUMBER	REGION NAME	NUMBER OF RESPONDENTS PER REGION	PERCENTAGE OF RESPONDENTS PER REGION
1	Swift Current	2	3.8
2	Moose Jaw-Assiniboia-Gravelbourg	2	3.8
3	Weyburn-Estevan	3	5.8
5	Regina Rural	1	1.9
6	Regina City	11	21.2
7	Rosetown-Biggar-Kindersley	5	9.6
8	Saskatoon Rural	0	0.0
9	Saskatoon City	8	15.4
10	Yorkton-Melville	6	11.5
11	Melfort-Tisdale	3	5.8
12	Prince Albert	3	5.8
13	North Battleford	5	9.6
14	Northern Saskatchewan	3	5.8
		52	100.0