

**THE ROLE OF VOLUNTEERS IN THE
CANADIAN DIABETES ASSOCIATION**

by

Patricia Gayle Redman

A Thesis

**submitted to the Faculty of Graduate Studies
in partial fulfilment of the requirement for the degree of
MASTER OF SCIENCE**

Department of Community Health Sciences

Faculty of Medicine

University of Manitoba

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ABSTRACT

This thesis describes the structure and functions of the Canadian Diabetes Association and its use of volunteers, based on a study conducted on the Brandon and District Branch of the Association, which serves Western Manitoba. The study was based on a content analysis of program documents and in depth interviews with key informants in leadership positions. These interviews were used to document the motivations of volunteers, their perceptions of barriers to participation, and their changing roles within the organization. Whereas the organization placed its primary emphasis on volunteer efforts in fundraising, the interviews found that the volunteers themselves most valued their involvement in public education and informal counselling.

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CHAPTER I

INTRODUCTION

The health care system in Canada encompasses a variety of structures and organizations whose purpose is to provide comprehensive health care to the citizens of this country. In 1994, even as provincial governments are reorganizing the health care system to place health care "closer to home", the focus of attention is still on the formal health care agencies and institutions encompassing hospitals, personal care homes, physicians and other professional health care providers. Nevertheless, side by side with the development of this complex system has been a parallel growth of what has become known as the voluntary sector, a sector that both complements and supplements the formal health care sector.

In Chapter II, formal definitions of voluntary organizations will be discussed. For the present, it is sufficient to note that voluntary health organizations have played a vital role in shaping our health, educational and welfare system in Canada. For example, as early as 1843, in Montreal, a citizen organized voluntary agency, Azile de la Providence, provided home visits to the needy sick (Shah 1987). Branches of British societies, including the Red Cross Society (1896) and the Priory of the Venerable Order of the Hospital of St. John of Jerusalem (1910) were established with each becoming independent in 1910 and 1914 respectively. The Victorian Order of Nurses was established in 1897 (Shah 1987).

Through these and many other agencies that have become established over the span of 150 years, citizens have become increasingly involved in the provision of health care. More recently, with advances in medical science, Western society has seen the

emergence of voluntary organizations whose mission is centred on one particular disease or condition. The organizations have usually been formed for the purposes of providing services that were not readily available through the formal health care system, for raising funds for research, and to act as advocates for patients and their families.

The Canadian public has demonstrated a willingness to support these many organizations by financial giving and by volunteering for various kinds of activities under the umbrella of these organizations. In fact, with the burgeoning health care needs and escalating requirements for research, the voluntary sector has become not only a partner with government in health related enterprises but has sought an active role in the determination of public policy. In a keynote address to the National Voluntary Consultation held in Ottawa in January 1990, Margaret Catley-Carson, the then Deputy Minister of Health and Welfare Canada presented her view of this relationship:

I think it is fair to say that we have seen a steady decline in the willingness and/or the ability of government to be the prime force in solving major social and economic problems. This has been accompanied by the growing expectations for direct and meaningful public participation in matters of public policy and broader social development. Much of this has been spurred by the growing involvement and sophistication of the voluntary sector. Many of you have told me of the growing burdens being placed on the voluntary sector, that "partnership" is all very welcome, but what often happens is that "partnership" is accompanied by a general shifting responsibility from government to the private and voluntary sector. I think that in the future we will need to carefully assess how far we can go with striking a new balance amongst individuals, government, private industry and the voluntary sector, to ensure that we all do our fair share and play our most effective roles (Catley-Carson 1990).

THE CANADIAN DIABETES ASSOCIATION

In this thesis, the focus of attention is the Canadian Diabetes Association (CDA), a voluntary organization that has targeted its efforts to provide services to individuals with

diabetes, to gather funds for research, education of both the public as well as the health professionals involved in the health care of these individuals, and to advocate for any individual with diabetes experiencing discrimination as a result of the disease.

The World Health Organization (WHO) has targeted diabetes as a primary health concern. On May 8, 1989, a resolution was unanimously passed by the Assembly calling on member governments to strengthen activities to prevent and control diabetes. As explained by Dr. Men Tan, President of the CDA, this resolution called on the members of WHO to "foster relations with the International Diabetes Federation and other relevant bodies with a view to expanding the scope of joint activities in the prevention and control of diabetes" (Tan 1990).

A recent endorsement and promotion of healthy public policy influencing individuals with diabetes is evident in the adoption of principles known as the San Jose Declaration by the International Diabetes Federation at the 14th International Diabetes Federation Congress International Symposium on Diabetes Education, June 20-21, 1991 in San Jose, Costa Rica. This symposium saw diabetes education as a central component of a primary health care system for diabetes management in Latin America. It was also a forum for discussing future directions for training doctors, nurses, nutritionists and other health care providers about patient education and self-monitoring in Latin America.

The San Jose Declaration asserted that:

It is the right of every person with diabetes to be fully informed on the nature and management of the disorder; and it is the obligation of communities and of nations, to supply the means for achievement of this right.

It is important and urgent that all governmental and non-governmental organizations with an interest in health and, particularly, diabetes, take responsibility for the promotion of and increase in educational activities in diabetes (The San Jose Declaration 1991).

THE PURPOSE OF THE STUDY

The purpose of the present study is to describe the structure and functions of the Canadian Diabetes Association. This organization has been chosen because of the researcher's interest as a dietitian who has been affiliated with the organization both as a volunteer and in a professional, educational and advisory role.

The organization will be described, focusing on its philosophy and objectives, its organizational structure, its activities and functions. The description will encompass an overview of the national organization and will describe the Manitoba Division and the Westman regional level of the Association. In addition, attention will be paid to the relationship between voluntary and governmental sectors. In the description of the organization at the regional level, the role, motivation and philosophy of volunteerism will be examined. A comparison of the role of the organization as mandated by the association to that perceived by the volunteers will be explored. An attempt will be made to delineate the role of both the activity of volunteering and the benefits derived from this activity in enhancing health.

METHODOLOGY

The methodology employed in this thesis included: a search of the literature concerning voluntary health organizations; review of secondary sources of published literature, administrative reports and archival documents, to describe the Canadian Diabetes Association at the national, provincial and regional level; semi-structured interviews were conducted with key informants who participate as volunteers in the Westman Branch to describe the individuals' motivations, their inputs into the organization and the benefits received.

CHAPTER II

VOLUNTARY HEALTH ORGANIZATIONS IN HEALTH: A REVIEW OF THE LITERATURE

VOLUNTARY HEALTH ORGANIZATIONS DEFINED

Voluntary health organizations are encompassed within the broad category of the nonprofit organization. The "voluntary sector" or "nonprofit sector" refers to all those persons, groups, roles, organizations and institutions in society whose goals involve primarily social action. Smith defines "voluntary action" as "an endeavour that is deliberate, intentional and performed of one's free-will, and includes what one is neither paid to do or made to do" (Smith 1989). According to Smith, voluntary action has three characteristics: legal independence from government; a non-profit status; a voluntary decision making structure.

Although voluntary associations are sometimes referred to as non-governmental organizations, the latter term fails to define their nature since it refers only to what they are not and encompasses everything from the corporate sector to local community groups. At the same time, however, there have evolved several analogous terms which purport to characterize the broad concept of voluntary organizations. A short list of such terms includes: "voluntary association", "voluntary group", "voluntary organization", "voluntary sector", "voluntarism", "volunteerism", or "voluntary action". The National Advisory Council on Voluntary Action (National Advisory Council 1977) in its report to the government in 1977 agreed that the term "voluntary association" should be used in its broadest sense to refer to "that vast array of groupings of volunteers, formal

or informal, registered or not registered, incorporated or unincorporated, which form or are set up to carry out activities in a voluntary manner" (National Advisory Council 1977). This definition encompasses both "voluntary organizations", (ie. bodies with identifiable structures and programs), and "voluntary groups", or bodies which are informal or sometimes newly created. The Council noted that though the term "voluntary organization" was often used to refer to all voluntary bodies, its preference for the term "voluntary association" was adopted because the concept of "voluntary organization" has been most often applied to voluntary groupings which have attained some form of legal status, thus excluding those formed on an informal basis.

Within this general framework, a definition has been expressed by Brown which allows for the inclusion of the full spectrum of organizational types:

A voluntary health association is an organization of long-term or brief episodic existence with a primary focus on health-related problems which exceed the potential for the individual (or family) resolution. Its membership participates of its own free will, donating its time, effort and/or financial and other resources with no expectation of material gain (Brown 1981:111).

Voluntary associations have as their primary objectives, the promotion of health, prevention of illness or disability, and the identification, treatment or rehabilitation of persons suffering from a disease or disability (Govan 1966).

There are multiple types of voluntarily organized health-related associations. They include agencies with a primary focus on health research, community service and education, organizations that represent health professionals, philanthropic foundations which fund health research and special demonstration projects, organizations sponsored by private industry which conduct extensive health education efforts, and community groups which spontaneously react to an individual or a community health concerns.

A PROFILE OF CANADIAN VOLUNTARY ACTION

In Canada, there are approximately 90,000 voluntary organizations. One in four persons is estimated to volunteer, mainly in activities such as education, health and social development (Nepean Development Consultants 1986). These voluntary organizations contribute \$6.4 billion to the economy or 2% of the GNP. While they represent an important social and economic movement in Canadian society, relatively little is known about them or the people who engage in volunteer activities (Duschesne 1989). Much of the literature in the field is of a practical, instructive nature for practitioners of volunteer management. As Ross and Shillington pointed out, "Volunteer activity as a whole is little understood beyond the anecdotes of individual efforts many of us are familiar with" (Ross and Shillington 1989:3).

In 1987, the report, the Canadian government surveyed, in depth, volunteer activity in this country. The National Survey of Volunteer Activity in Canada (Ross and Shillington 1989), documented the scale and significance of volunteering in this country. For example, according to the survey:

- 5.3 million Canadians performed some organized volunteer activity, representing over one-quarter of all working age Canadians.
- volunteers contributed an average of 3.7 hours per week or 191 hours per year, representing a total of 1.16 billion volunteer hours.
- residents of Alberta, Manitoba and Saskatchewan were more likely to volunteer than residents of other provinces.
- almost half of the 5.3 million volunteers worked for more than one organization.
- four sectors accounting for 57% of all volunteer experiences: religious organizations, 17%, leisure, recreation and sports, 16%, education and youth development, 14% and health, 10%.

A second report that describes the profiles of volunteers in health organizations was published, detailing the characteristics, motivation, activities, and needs of these volunteers (Kent 1989).

An estimated 939,000 Canadians actively volunteer for health organizations. They work in well known national voluntary organizations such as: the Victorian Order of Nurses; Canadian Cancer Society; Alzheimer Society; Canadian Cystic Fibrosis Foundation and the Canadian Heart Foundation. Volunteers worked as candy strippers in hospitals; assisted in residential treatment for the physically developmentally disabled; and provided first aid at public events. Volunteers also included many people who participated in self-help or mutual-aid groups such as Alcoholics Anonymous, weight control, drug addiction, and non-smoking groups (Ross & Shillington 1989).

An analysis of the activities of the volunteers in health organizations showed that:

- Volunteers spend an average of 92 hours per person per organization per year in providing programs and services.
- 77% of the health volunteers are female, a significantly higher percentage than for females in the workforce (55%).
- 43% of health volunteers are not in the labour force, compared to the 29% of all volunteers who are not in the labour force.
- The most common activity engaged in by volunteers in health organizations is fundraising or canvassing for funds, accounting for 55% of their activities and consuming an average of 34% of their time.
- Of the other activities performed by volunteers in health organization, 29% provide information to others; 23% counsel, adviser provide friendly support; 22% provide care or companionship and visiting; 8% recruit other volunteers; and 16% organize events, supervise, or co-ordinate activities.
- Fewer youth are involved in canvassing or fundraising, but 49% of these young volunteers provide care or companionship, which accounts for 30% of their volunteer time.

- Differences were noted in the types of activities handled by men and women. Men were more likely to become involved in recruiting, educating, speaking, and participating on boards (30%) compared to women (14%). Men spend 13.5% of their time providing counselling and advice, while women spend more time preparing food, making and selling items.
- Generally, a board of directors of health organizations is composed of 66% men and 33% women. Thus, although more than three quarters of the volunteer force is composed of women, men become more involved at the policy and decision-making level.
- More seniors make and sell things, while non-seniors become involved in teaching, counselling, providing information, promoting ideas and speaking. An equal number of seniors and non-seniors sit on the organization's board of directors or executive.
- When volunteers were asked how they first became involved with the organization, almost 50% attributed their involvement to "being asked by someone in the organization". Less frequent reasons for becoming involved in volunteering were: being asked by a friend or relative outside the organization (9%), being asked by a boss or employer (3%), and being chosen by co-workers, classmates, etc. (2%). However, another 19% of those surveyed approached the organization themselves.
- 54% of the volunteers rated their volunteer experience as "very satisfying" and 33% gave a rating of "somewhat satisfying". The rating of positive satisfaction tended to increase for seniors and be slightly lower in for youth.
- When volunteers were asked to indicate the gains in skills and knowledge resulting from participation as a volunteer, 58% felt that they did not experience any gains, while 35% thought that they did. Those who indicated a gain in skills, 39% was in interpersonal skills; 30% in general knowledge; 25% in communication skills; and 19% in organizational and management skills.

OBJECTIVES OF VOLUNTARY HEALTH ORGANIZATIONS

Objectives of voluntary health organizations range from all encompassing to very specific. However, most can be generally encapsulated in the fundamental goal of enabling its target group(s) to achieve health as defined in its most general and

encompassing sense as the "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization 1986).

As such, with the differentiation referring only to the particular disease or organ to which they are related, their primary or major objectives are the promotion of health, prevention of illness or disability, and the identification, treatment or rehabilitation of persons suffering from a disease or disability (Govan 1966).

Typically, a voluntary health organization or agency results from a concerted effort of private citizens with a special interest in a given health or health related problem. It is normally the perception of the citizen organizers that the needs associated with a particular health problem are not adequately being met through current efforts of the health care system. Govan delineates these needs as:

- (1) Research: the collection of statistics of incidence; the investigation of reported cures; surveys of facilities and needs; the encouragement, support and assistance of basic and clinical research.
- (2) Service: the establishment or provision of resources for the establishment of facilities or services for diagnosis, treatment and rehabilitation of the sufferers of the disease; service (ie. summer camps capable of coping with the juvenile diabetic).
- (3) Education: the education and dissemination of information to both lay and professional target audiences, continuing education and/or awareness programs directed toward the health professional or the general public promoting preventative health practices.
- (4) Advocacy: supporting changes in legislation and public policy to meet the needs of the individuals.
- (5) Organizational objectives: the establishment of divisions, branches, chapters, etc. to promote these objectives.
- (6) Fundraising: fundraising activities to support these objectives.

Canadian voluntary organizations today provide services in some communities which are performed by government or for-profit organizations in other communities, or

sometimes in the same community. For example, volunteer work often fulfils the functions that might be considered the legitimate role of the government, such as: preparing and delivering meals to homes of the elderly or handicapped; providing educational opportunities to the disadvantaged; helping to settle refugees; establishing recreational facilities; and providing fire fighting services to communities. In fact, some of the services now provided by the government, were first provided by volunteers. Welfare services, post secondary education and health care were once exclusively provided by voluntary organizations in some provinces (Ross & Shillington 1989).

In practice, then, the functions of the voluntary organizations and the government in the health-field are often intermingled to such an extent that differentiation in function and roles cannot easily be distinguished.

White enumerates the number of attributes of voluntary health agencies in that they represent a degree of visible public support for particular causes, and an organized response to perceived needs (White 1986). Through such organizations, objectives can be achieved on a person to person basis much more than by government agencies. Voluntary organizations have a sociology that includes a high degree of loyalty to the group, and an ability to network that cannot be achieved by governments or private enterprise because of the bureaucratic requirements of official agencies or the bottom-line of profit and loss statements. Voluntary organizations have the potential to be much more flexible than government, labour or big business. The spirit of voluntarism empowers people, gives them a sense of belonging and a purpose, and because this process is voluntary, they feel good about themselves and their contribution to society. This process is essentially spontaneous and not statutory, and represents enormous potential for the promotion of health and social development.

THE MEMBERSHIP AND ORGANIZATIONAL STRUCTURE OF VOLUNTARY ORGANIZATIONS

Various voluntary health organizations differ in the nature of their membership and have been categorized as "citizen member" and "patient member" organizations. For some disabilities and diseases, organizations include both types of membership.

Citizen-member organizations, a familiar form of philanthropy, are organized by members who are interested in community service and motivated to give time, money and thought to the organization and the achievement of its goals. Members' activity is based on their social values, and these social values are identified with good citizenship, social status and public recognition (Govan 1966). It has been hypothesised that in health organizations, the motivation of the members may be fear or anxiety created by the knowledge that anyone can become a victim of the disease.

Patient member organizations are developed by patients themselves or by their parents, family members and friends. The motivation to organize is that of mutual aid. This implies obtaining services needed by those afflicted, social action to present the case for increased services, and, in some cases, to increase public awareness of the disease and acceptance of those afflicted by the disease. This also means an emphasis on research, to both assist those with the disease as well as prevention. The concept of mutual support and sharing of similar anxiety, fears, frustrations and sufferings associated with the disease is an integral part of the patient-member organization.

FUNCTIONAL ROLES OF VOLUNTARY ORGANIZATIONS

Voluntary action in Canada has been a strong and vital component of Canadian life. Govan expands on the historical evolution of the functions of voluntary organizations:

Voluntary organizations have traditionally been associated with "charity" and service to those less fortunate groups to whom a stigma of weakness or inferiority may be attached. In the field of welfare this stigma may persist, however, in the field of health, this breaks down more readily with the reality that disease and disability are human hazards which do not recognize social and economic boundaries. Thus, the members of a voluntary health organization are not subject to the mark of the under-privileged, there is no "victim-blaming" for becoming ill, and the patient-member and citizen members alike consider their efforts as a fight against an enemy, rather than "charitable" work (Govan 1966).

However, the traditional functions of voluntary organization have been in a constant state of change, which has led to a re-assessment and re-definition of their functions and activities. There is evidence of an emergence among voluntary associations of increasing numbers of new activities and areas of concerns. The Cooperstock and the Lefebvre studies (Cooperstock 1976, Lefebvre 1977) have suggested that many of these activities are directed at newly identified or neglected community concerns, advocacy for reforms and new social innovations. These studies show that increasing numbers of associations are taking issue with more controversial concerns and directing an increasing amount of resources toward influencing social change and political decisions, rather than merely providing services.

In delineating the character, role and function of voluntary health associations in society, six themes emerge:

(A) **Service provision:** In the field of health care, voluntary associations have had a great impact on the provision of health care, preventative health activities and health-related rehabilitation. The voluntary sector, in assuming this role as service provider, often responds to the need to deliver specific services, some of which may be the responsibility that the government, is unable, unwilling or does not choose to assume at a given time. Voluntary health associations continually identify new areas of need and

provide for them to the limit of their capacity. Their capacity to meet these needs is related directly to their financial and human resources. These needs may be met in only a token fashion. In some instances, as a result of advocacy to increase public awareness and support as well as continued pressure on the government, governments have funded or assumed the responsibility for the voluntary organizations' services.

By supplementing and complementing government services, voluntary associations contribute to enhancing the life and health of Canadians. Government, with its universal standards, often cannot meet specific needs and permit a personal mode of interaction between the server and the served.

(B) **Social innovation:** A central role of the voluntary sector is to provide society with a variety of social innovations, from which business, governments, and private institutions can select and institutionalize in accordance with their own agenda. Many functions currently performed by governments were once a new social idea and the experiment of a voluntary group (Smith 1973). Governments, bureaucracies and established institutions are often inhibited by their inflexible organizational structures and their need to satisfy a broad social consensus. Voluntary associations can avoid these obstacles and, as a result, create a forum for initiating new ideas and processes. A voluntary agency has the independence to be more selective than the universal and comprehensive scope of the government. Voluntary health agencies tend to target low profile groups, or those considered to be too controversial for the government such as pregnant teenagers, runaways, the homeless, immigrants and battered women (Kramer 1989).

(C) **Countervailing force to the Government:** The needs of a specific group are often of little concern to the majority of the Canadian public and are given a low priority by

governmental bureaucracies, government itself and established social institutions. Voluntary action is an effective means of ensuring that these minority interests and concerns are not ignored. By articulating minority views, and bringing them to the attention of the government and the public, the function of a countervailing force is achieved. Voluntary organizations function as a "check and balance" system, providing moral and ideological leadership to society and often call into question the existing legitimacy of formal structures (Katz & Bender 1976).

(D) **Social integration:** Voluntary action involves people acting together to attain an objective within their community or society at large. Hence, the voluntary sector satisfies human needs for affiliation, integration and so on.

As an added benefit, voluntary action encourages Canadians to develop and express sense of responsibility for themselves, their community and their world. Through voluntary action, they learn to govern themselves and influence the conditions which affect their lives and those of their communities, and in some instances, permits Canadians to have a direct influence on the formulation and execution of public policy.

The need for people to be involved in making decisions about their own health has been accepted as fundamental principle of health promotion (World Health Organization 1986). The movement away from "victim blaming" and increasing recognition of governmental and industrial responsibility for social support and safe environments, has brought the domain of healthy communities into the arena of individual responsibility and participation in public policy.

(E) **Volunteering as a health promoting activity:** A fourth role of the voluntary sector in society is that of enhancing the health of those individuals engaging in the behaviour of volunteering. Smith asserts that volunteer activity fulfils a basic human need

for the 'play element' in society, especially in search for novelty, beauty, recreation and fun (Smith 1973).

The conclusions of a report from Volunteer Ontario, "Volunteering for the Health of It", concluded that "volunteering is a health promoting activity for those who engage in it, and that this fact is grounded not only in the day-to-day life experiences of volunteers themselves, but most recently, in medical, psychological and epidemiological research" (Graff 1991:45). The ways in which voluntary action can enhance health, increase vitality and longevity are complex. The report proposes that volunteering can have the following positive health effects:

(1) Increased self-esteem: Strong evidence of the benefits of volunteering for the volunteer is found within the fields of psychological and medical research. In the relationship between volunteering and health, the concept of self-esteem may play a key role. Similar to the "high", including a sense of self-esteem and self-discipline (Hopson 1988) that follows moderate exercise, a similar "high" and sense of heightened self-esteem have been shown to be a by-product of volunteering (Luks 1988).

(2) Increased personal empowerment: In a study by Lord and Farlow (1990) the relationship between volunteering and increased self-esteem has been linked to both greater personal empowerment and enhanced health. The authors discussed the profound sense of powerlessness experienced by people, whether poor, disabled or elderly or who had been rejected by communities and marginalized. They noted that some of these individuals were still able to experience a strong sense of personal control, or empowerment, and found that involvement in community life was the most key element to growth in their personal empowerment.

We found that the process of participation itself was both empowering and self-reinforcing. As people gained in self-confidence, they would seek more avenues for participation; their involvement in community activity would in turn, enhance their self-confidence and sense of personal control... Participation appears to contribute to empowerment because it increases social contact, reduces isolation, and enables people to take part in meaningful activity... When people feel more in control, their stress level is reduced and they are freer to make decisions that will have a healthy impact on their lives... (Lord and Farlow 1990:6-7).

(3) Reducing life's stressors: Growald and Luks have suggested that the activity of volunteering may be an effective stress-reducer. "Altruism is the currency with which we buy the social support that sustains us" (Growald & Luks 1988:2).

(4) Reduce heart rates and blood pressure: Many techniques have evolved over the centuries to decrease blood pressure, heart and metabolic rates, and to achieve the benefits which follow. Harvard cardiologist Herbert Benson states: "Altruism works this way, just as do yoga, spirituality and meditation" (Benson quoted in Growald and Luks 1988:42).

(5) Boost to the immune system and nervous system functioning: In a further extension of this relationship between volunteering and health, Growald and Luks suggest that not only doing good but even "thinking good about altruistic action may give the immune system a boost" (Growald & Luks 1988:2). Other research indicates that doing good for others may stimulate the release of endorphines into the blood stream. Endorphines are the body's natural opiates which produce good feelings (Luks 1988) and endorphines are linked to improved nervous system and immune system function (Growald & Luks 1988; Hopson 1988).

(F) Advocacy: Advocacy is a central function for voluntary organizations (Filer Commission 1975). As organizational differences between governmental, voluntary and for-profit social service organizations diminish and social services in the welfare state

become widespread, the voluntary agency assumes the mandate to advocate for those who are unable to do so for themselves. In performing this role, the voluntary agencies urge improvements in public policies and practices, and criticise as well as defend government services when they are unjustly attacked.

Voluntary health organizations have the vitally important role to identify the issues, envelope a constituency for health living, to improve the level of debate and to increase the stakes - in short, to get health on the agenda of all areas of public policy. To do this, voluntary organizations must become more politically active (White 1986).

Voluntary health organizations find an increasing need to serve as community advocates. Kramer labels this role as 'improver' or advocate, calling for the voluntary agency to act as critic or watchdog, as it pressures government to extend, improve or establish needed services (Kramer 1989).

(G) **Support of research:** The magnitude of this role certainly varies with the goals and philosophies of each organization. For many voluntary health organizations, supporting research to discover the causal relationships and treatment modalities in physical, emotional and social illness is a fundamental role. The Canadian Diabetes Association itself dedicates as its prime and major goal "to become the leading force in diabetes research in Canada" (Canadian Diabetes Association 1986).

(H) **Support for the economic system:** An analysis of the role and importance of voluntary associations must include the support given by the voluntary sector specifically to the economic system of society. Voluntary non-profit associations of many kinds provide crucial kinds of social, intellectual and technical linkages among workers in numerous occupations.

In Canada estimates of the economic contribution of voluntary organizations have been made by Ross and Shillington. Their study estimated that volunteers contributed a

combined total of 1.016 billion volunteer hours in 1986/1987. This represents approximately 625,000 person years - the equivalent number of full time paid workers in the Saskatchewan and New Brunswick labour forces combined (Ross & Shillington 1989). The value of this volunteer work, using an average service sector wage, was estimated at \$12.0 billion in 1987 (or approximately \$13.2 billion in 1990) (Ross 1990).

TRENDS AND ISSUES FOR VOLUNTARY HEALTH ORGANIZATIONS

The environment for voluntary action, like that for most other forms of endeavour has been transformed by the growing role of the government in Canadian society (Brown 1981). The increased importance of government has meant a dramatic change in public perceptions of voluntary action. Voluntary action is now generally seen as part of something called "non-governmental" activity. In short, government has become the reference point. Expansion of the government into the health and social welfare field has reduced the necessity for voluntary services for the needy. The National Advisory Council on Voluntary Action found that the public perceived that services offered by the voluntary sector were of lesser importance than those offered by the "paid professional staff" of the government. This attitude and public acceptance of the increasing role for government has meant that government has moved into areas once regarded as the responsibility of the "voluntary sector". It has become tiresomely obvious, though not entirely accurate, to say that voluntary associations create activities and services which eventually become part of the public domain (National Advisory Council 1977).

The public's misconception about the government's role in research can also weaken the position of voluntary associations in their continual appeal to the public for funding dollars to fund their research mandates. It is feasible that the taxpayer may

assume that government funding of health care precludes the need for voluntary involvement, or may fail to see the research voluntary agency as an important vehicle for opening up areas of medical research which the government may be unwilling to pursue.

Perhaps the most serious challenge facing the voluntary sector is the continuing competition for the charity dollar. Each Canadian charity competes with thousands of other Canadian charities for the public's support of their diverse and ingenious campaigns for funding.

Voluntary associations see fund-raising as one of their major problems. Results of the studies commissioned by the National Advisory Council for Voluntary Action, 1977 reported that the 58% of the local and 61% of the national organizations viewed fundraising as their major problem.

CHAPTER III

THE CANADIAN DIABETES ASSOCIATION

DIABETES IN CANADA: AN OVERVIEW

Diabetes is a major health issue affecting over one million Canadians and impacting on the social and economic conditions of Canadian society. The disease is characterized by a disturbance in blood sugar that must be controlled by a variety of treatment modalities. But even the best treatment cannot ensure complete correction of the metabolic abnormalities and the prevention of the serious complications associated with diabetes. It is these complications that are responsible for the majority of health care concerns related to diabetes (National Diabetes Task Force 1987).

The annual cost of diabetes to the publicly funded health care system is significant. An American study has reported diabetes as the most frequent single cause for physicians visits, hospital outpatient use and hospitalization (National Diabetes Data Group 1985). It is from this data that the direct and indirect cost of diabetes in Canada is estimated to be in excess of \$2.5 billion (National Diabetes Task Force 1987). The cost to every individual with diabetes averages \$2,000 annually for special products, services and treatment not covered under the provincial health care plans (McKendrey 1989).

It is within this context that the Canadian Diabetes Association (CDA) has become committed to leading Canada's response to the challenges presented by this disease and continues to dedicate its human and financial resources in support of research, increasing access to improved treatment and service, advocating for enlightened laws and policies

that provide protection from discrimination and public awareness of the risks of diabetes (Canadian Diabetes Association 1991a).

DEFINITION OF DIABETES

Diabetes mellitus is a systemic disease characterized by hyperglycaemia (fasting plasma glucose levels of > 7.8 mmol/l.) (National Diabetes Data Group 1985). Due to its chronic nature, diabetes remains a devastating disease which results in a host of vascular, neurologic and renal complications. The frequency, severity and progression of these complications appear to be related not only to the duration of the disease, but also to the severity and degree of hyperglycaemia and associated metabolic derangements. Hence, the control of hyperglycaemia and other effects of disordered metabolism, such as hyperlipidaemia, is of paramount importance in diabetes management.

Diabetes brings with it an increased vulnerability to a range of serious health problems:

- i) Diabetes doubles the chance of a heart attack or stroke;
- ii) Diabetes is the leading cause of adult blindness;
- iii) Diabetes is the leading cause of non-trauma amputation;
- iv) Diabetes increases the risk of kidney disease;
- v) Diabetes related complications are the third leading cause of death in Canada (Canadian Diabetes Association 1991a).

To achieve good control requires complex treatment regimes of self-blood monitoring, self-adjustment of insulin dosage and decisions involving various alterations in carbohydrate intake. The individual with diabetes must actively participate in the care

and management of their own disease, it is essential that they acquire certain skills and an understanding of the disease; this can be provided only through education.

These complications of diabetes are common to both insulin-dependent (IDDM) or Type I diabetes and non-insulin-dependent (NIDDM) diabetes mellitus or Type II diabetes. Type I diabetes usually develops in childhood or early adulthood, and is related to an auto immune attack on the pancreatic islets of the beta cells and a subsequent lack of insulin production (Daneman 1990). Insulin therapy therefore is required for the prevention of ketosis and the preservation of life. Combined with proper diet and exercise, it allows these individuals to manage their disease. Type II diabetes tends to develop more gradually and later in adulthood, although the onset of this type of diabetes in children and adolescents has been reported (Dean 1993). People with Type II diabetes represent between 85 and 90 percent of all Canadians with diabetes. Effective management for people with Type II diabetes is primarily focused on lifestyle, which includes a healthy diet, regular exercise and stress management. In many cases, such as an oral hypoglycaemic agent or insulin is required to enable the individual to achieve optimum metabolic control. Type II diabetic patients are usually obese and have a strong family history of diabetes.

Diabetes therefore, presents two major challenges: first, to work towards finding a cure; secondly, to assist those afflicted with diabetes to effectively manage their disease and reduce their risks.

PREVALENCE AND INCIDENCE OF DIABETES

Most of the Canadian estimates of the incidence and prevalence of diabetes in Canada are derived from studies conducted in the United States. Based on U.S data, it

is estimated that one million Canadians have diabetes and 50,000 new cases are diagnosed every year.

Canadian data is limited in the sources for epidemiologic data on which estimates of incidence and prevalence of diabetes mellitus can be made. The Canada Health Survey (Department of Health and Welfare 1981) involved a probability sample of the Canadian population, (except for the Yukon and the North West Territories) and included questions on diabetes and obtained blood samples for random blood glucose measurements. The General Social Survey (Statistics Canada 1987) included questions on diagnosed diabetes. However, the limitations of these studies for estimation of prevalence rates lie in the bias resulting from respondent recall and self-reporting as well as lack of validation of medical records (Young, Roos, and Hammerstrand 1991).

A more recent and geographically relevant study was the Manitoba Heart Health Survey, (Gelskey, MacDonald, and Young 1991), which reported the prevalence of diabetes to be 6%, more common than previously thought.

Young et al. have reported an estimation of the incidence and prevalence of diabetes mellitus in the total population of Manitoba using data from the provincial health insurance plan (Young, Roos, and Hammerstrand 1991). The study sampled 100,000 people, ages 25 and over and stratified by sex, age and Manitoba Health Services Commission health region.

The prevalence of diabetes was found to be 0.8% among those 25-44 years of age, 3.5% among those 45-64 years and 7.6% among those 65 or older. The annual incidence rate was 7.8 per 1000. The reported incidence and prevalence rates were similar to those determined on the basis of self-reports in Canadian and U.S. surveys (Department of National Health and Welfare 1981, Statistics Canada 1987, Harris et al. 1987).

The estimated 5-year period prevalence of Diabetes in Westman from 1980-1984 was 1.6% for those 25-44 years of age, 6.2% for those 45-64 years and 11.7% for those 65 years and over. These prevalence rates were similar to those of the other MHSC regions (with the exception of the Norman Region) (Young, Roos, and Hammerstrand 1991). Thus, from this data, an estimation of the number of people in the Westman region with diabetes mellitus, ages 24 and over is 4,270. Although this prevalence estimate was derived from claims data, it is recognized that the true prevalence of diabetes in a population can be determined only through oral glucose tolerance screening. Studies have shown that people with diabetes who seek care from physicians and hospitals constitute perhaps only 50% of everyone who would satisfy the biochemical criteria for diabetes had they undergone screening (Harris et. al. 1987, Zimmet 1982). However, the use of the MHSC administrative data base to estimate the prevalence of diabetes produced results similar to those based on the self reports in Canadian and US National surveys. As well, the recently completed Manitoba Heart Health survey, which examined self-reports of diabetes and actual measurements of fasting plasma glucose and glycated haemoglobin levels in representative samples of Manitobans aged 18-74 years of age served as a source of validation of the MHSC data base.

THE ORIGINS OF THE CANADIAN DIABETES ASSOCIATION

The roots of the Canadian Diabetes Association (CDA) date back to May 1949, when the Diabetic Association of Ontario held an inaugural meeting which illuminated the need for a National organization uniting people interested in diabetes across Canada. As a result of the dedication and efforts of Dr. Charles H. Best, co-discoverer of insulin, and others, a National charter was granted to the Canadian Diabetic Association in

January 1953. (In 1978, the word "Diabetic" was changed to Diabetes, and in 1984, the francophone version became ASSOCIATION CANADIENNE DU DIABETE.)

Subsequent to inauguration, activities were directed towards organizing provincial branches, with the first provincial meeting being held in Regina in 1953 (Canadian Diabetes Association 1986).

It has been four decades since the origination of the CDA and the membership today comprises over 50,000 members, it has a national office located in Toronto, and representation from ten provincial divisions and over 170 branches in communities across Canada.

PHILOSOPHY AND ORGANIZATIONAL OBJECTIVES

The Canadian Diabetes Association is a national, independent, self-financing organization whose mission statement is: "To promote the health of Canadians through research, service, professional and public education and advocacy."

The Canadian Diabetes Association is Canada's leading organization in the support of research focused on finding a cure as well as improving the needs of those with diabetes and their families. At the same time, the association recognises the need to broaden its perspective to establish relevance to all Canadians and adopt a health promotion philosophy. CDA is committed to "promoting an appreciation for the personal and social relevance of diabetes, and to fostering the knowledge, attitudes and behaviour that will result in the prevention of the onset of diabetes for many; and the early diagnosis and treatment for those who do contract it" (CDA 1991a).

MEMBERSHIP AND ORGANIZATIONAL STRUCTURE

CDA is membership based and membership driven. The membership currently encompasses 10 provincial divisions and 170 Branches representing some 50,000 members.

The Association's membership is composed of a variety of individuals, some have diabetes; some have family members affected by the disease; some are professionals working in the field of diabetes research, education or health care; others are members of corporations or service organizations that have adopted the cause of diabetes as their philanthropic endeavour. Membership requires the payment of annual dues. The membership dues in 1994/1995 ranged from \$9.00 for an individual membership to \$1,000 for a Corporate membership.

The organization is governed by its volunteers and managed by its staff. The association's objectives are client focused. All services and benefits are directed towards the membership, and the organization depends on the individual members to provide the volunteer function of the Association.

The organizational structure of CDA is that of a three level hierarchy, consisting of one national body, ten provincial assemblies or divisions and 170 local groups known as branches or chapters. Each level of the organization is composed of distinct and separate governing boards providing varying services and functions. For example, the functions of service and education are developed, coordinated, and standardized exclusively at the national level. The local of branch levels of the organization function primarily as distributors and implementors of the services.

One distinction which is frequently applied to the internal structures of voluntary organizations is that of the distinction between federated and corporate structures. The CDA is characterized by a corporate structure, since the control rests at the national level,

as opposed to federated structures where local and/or provincial structures and offices exercise control in certain areas, and the federation is all of these acting in concert under majority rule. Within corporate structures, the elected officers set the policy and the national office administers the operation, budget and staff.

THE NATIONAL BOARD OF DIRECTORS

The policies of the Association are directed by the Annual Meeting of the Association. The position of responsibility and authority resides within the National Board of Directors, with the delegation of this capacity being granted at the National Annual General Meeting. The ultimate power resides with the Annual General Meeting as this is the only body which can change the By-laws of the Association and it is at this meeting that the National Executive Committee and the National Board of Directors are elected. Legislative and executive powers are delegated to the National Board, which implements the policies of the organization. The CDA by-laws (contained in the Board Manual) describe the official duties and composition of the National Board and the National Executive Committee.

Organizational Function of the National Board

The Board of Directors at the National level governs the operations of and delegation of directives to the Provincial Divisions and 170 local branches. All legal recognition and authority as a charitable organization resides solely with the National Board. Divisions and Branches exist and function only under the auspices of the National Board, which alone can grant charters to them.

The National Board levies considerable influence on the Provincial Divisions and local branches is evidenced by in the following documentation of the Board's functions:

- To hire an Executive Director to manage the day-to-day affairs of the association.
- To develop and implement policy of the association as established by annual meetings.
- To establish, institute and carry forward Association policy and generally supervise the affairs of the association.
- To encourage and promote the formation of branches.
- To establish Standing and Ad Hoc Committees.

Organizational Structure of the National Board

The National Board is made up of seven executive members and twenty two directors. Members of the National Board of Directors may be appointed as chairpersons of one of four National Councils and two Professional Sections. As well, the National Board may establish "standing" and "ad hoc" Committees and provide for the duties and membership of them.

The 1991/1992 National Board contained fifteen standing Committees and several Ad hoc Committees.

The National Councils

The Chairpersons of the National Councils are appointed from the National Board of Directors. The four National Councils are: Advocacy, Professional Development, Research and Service. The functions of these councils are as follows:

Research Council

The Research Council functions as an advisory board to the National Board on the research policy of the Canadian Diabetes Association. In addition, it informs the CDA membership and general public of the needs of, and progress in, diabetes research. It is also charged with informing the government, the Medical Research Council of Canada, and voluntary health research granting agencies of the needs and importance of diabetes research.

It considers the recommendations of the Grants and Personnel Awards Committee of the CDA and, after review, presents them for funding to the National Board. In addition, it reviews and evaluates applications for those aspects of research such as the funding of special symposia or workshops that are not directly the responsibility of the Grants and Personnel Awards Committee.

The Advocacy Council

The primary focus of the Advocacy Council has been to increase awareness while influencing and effecting positive changes in attitudes, policies and practices of government, business and the general public on behalf of people with diabetes.

Its mandate is to ensure that diabetes is recognized as a major health problem and that individuals affected by diabetes are provided with the best medical, educational and social services possible. The Council continues to work to guarantee that each person with diabetes be treated as an individual and not be subject to any form of discrimination. The Council advocates the positions and policies of the Canadian Diabetes Association to the Canadian public on behalf of the diabetes community, identifies specific advocacy needs and recommends policies for approval by the CDA National Board.

The Professional Development Council

The mandate of the Professional Development Council (PDC) is to advocate, initiate and strengthen education programs for present and future physicians and health professionals involved in diabetes care.

The PDC publishes and distributes at no charge, "Canadian Diabetes", a CDA publication for Canadian physicians. This quarterly publication brings information on diabetes care to 12,000 family physicians in Canada.

One of its working committees, the National Nutrition Committee has developed and published many position papers targeted at keeping health professionals abreast of the latest information regarding nutritional issues affecting the individual with diabetes. These include: "The Good Health Eating Guide" book, pamphlet, poster and Guide for professional use; "Guidelines on the Dietary Management of Diabetes Mellitus for the 1990's", and "Guidelines for the Nutritional Management of Diabetes during Pregnancy".

The PDC gathers information on the undergraduate curriculum used for training of physicians, dietitians and nurses in Canada. The Council has begun collecting data for the training of specialists in Internal Medicine, Endocrinology and Paediatrics with regards to diabetes.

The PDC is collaborating with the Banting and Best Diabetes Centre, University of Toronto, in the preparation of the handbook on diabetes mellitus for medical students, interns and residents in Canada.

The National Service Council

The mandate of the National Service Council is to recommend the appropriate service policies and programs to the National Board and to monitor current service programs such as camps and stores in place in the CDA Divisions.

National Standing Committees

The National Board has the authority to establish "standing" and "ad hoc" committees and provide for their duties and membership. These committees vary from year to year according to the objectives and priorities established by the organization. Standing committees are of a permanent nature, with ad-hoc committees being established to achieve the short term objectives of the organization. While some of the committees report to the National Board through one of the National Councils, others may report directly to the National President and the National Board.

The National Standing Committees for the 1991/1992 year were:

1. Achievement Awards
2. Archives
3. Audit
4. Communications
5. Diabetes Dialogue, Editorial Advisory Board
6. National Finance Committee
7. National Office Finance
8. Fundraising
9. Grants
10. Lions Club Liaison
11. Nominating
12. Nutrition
13. Personnel Awards
14. Publications
15. Youth

THE PROFESSIONAL SECTIONS OF CDA

Although the CDA is composed mainly of lay membership, it also has two professional sections, the Clinical and Scientific Section (C&SS) and the Diabetes Educators Section (DES). These sections exist to provide services to the professional members of the association. They have independent activities and budgets. They also advise the National Board of Directors, when requested, on the scientific aspects of diabetes.

All members of the professional sections are automatically members of the Canadian Diabetes Association and their local branch.

The Clinical and Scientific Section acts as the Medical Advisory Board to the National Board of Directors.

THE NATIONAL OFFICE

The National Office of the Canadian Diabetes Association is located in Toronto and the staff is headed by a National Executive Director who plays the major coordinating function within the organization.

The National Office consists of five departments: Advocacy/Public Affairs; Communications; Finance and Administration; Research Education and Services; and Fund Development.

The National Office administers the work of the organization at the National Level, coordinating activities of, and providing services to, its members and affiliates. The office distributes CDA print materials, organizes conferences, funds or implements support services and conducts public education programs.

ORGANIZATIONAL GOALS AND FUNCTIONAL ROLES OF CDA NATIONAL

The commitment of CDA toward its goal of being the leading force in research, service, education, and advocacy is embodied in the mission statement as well as demonstrated by its proven track record as outlined in the 1991 annual report of the National President to the membership (Canadian Diabetes Association 1991a). The Canadian Diabetes Association is:

- Canada's major non-governmental source of funding diabetes research
- the leading supporter of professional education in Canada
- the primary source of Canada's public education across the country
- the national advocate for fair and just laws and policies affecting people with diabetes

The following section reviews the goal statements of the association and outlines where the responsibilities for goal implementation should be allocated. Figure 1 summarizes the goal responsibilities by organization level.

Figure 1: SUMMARY OF GOAL RESPONSIBILITIES BY ORGANIZATION LEVEL

GOAL	NATIONAL	DIVISION	BRANCHES
RESEARCH	Primary responsibility: policy, coordination & allocation.	Distribution channel for information.	Distribution channel for information.
SERVICE	Responsibility for National policy and & educational support materials.	Primary responsibility for coordination & delivery.	Primary responsibility for needs assessment & delivery.
ADVOCACY	Primary responsibility for developing policy framework. Advocacy to National organizations. Federal gov't coordination.	Advocacy to provincial government & provincial organizations.	Advocacy to local public and local & local organizations.
EDUCATING	Primary resp. for policy & Health Professional	Support to National.	Support to the National.

RESEARCH

The research goal is "... to promote research into causes, prevention, cure, management and understanding of diabetes and its effects on those affected by diabetes."

The Association believes that research will eventually lead to a cure for diabetes. Its goal, therefore is to fund research in causes, prevention, management and cure of diabetes.

The CDA is Canada's major non-governmental source of funding for diabetes research, committing \$3.23 million to 38 new operating grants and 14 personnel awards in 1990-1991.

The major vehicle for funding of research by the CDA is the Charles H. Best Fund. This fund was established in 1975 in honour of the co-discoverer of insulin, Charles H. Best and provides support for researchers conducting investigations into the causes, prevention, cure management and understanding of diabetes and its effect on those affected by diabetes (CDA 1991b).

A collaborative effort of CDA and the Juvenile Diabetes Foundation (JDF) and Association Diabete Quebec (ADQ) has resulted in the formation of Diabetes Canada. It is through Diabetes Canada that a major portion of the funds are raised through a corporate sector to support diabetes research.

CDA has established a National Research Council which is composed of representatives from DES, C & SS, the Personnel Awards committee, the Grants Committee and the National Board of Directors.

A review of the list of Research Grants and Personnel Awards for the 1990 and 1991 fiscal year shows that basic medical science is the major benefactor of funding by the

CDA. A summary of the research projects funded by CDA illustrates this focus on support of basic scientific research:

- i) Immunology and Diabetes: How diabetes starts with an attack by the body on its own insulin-producing cells. This research has been ongoing for 15 years.
- ii) Transplantation and Diabetes: The successful transplantation of islets or insulin-producing tissue into patients.
- iii) Nutrition, Metabolism and Diabetes: The consequence of diabetes in terms of disordered use of fuels which can lead to obesity and insulin resistance. This underlines the importance of diet in the management of diabetes.
- iv) Diabetes and Molecular Biology: New techniques to isolate the molecules involved in the body's metabolic response.
- v) Diabetes and Complications: Understanding how diabetes affects the eye, kidneys, nerves, heart, circulation in order to develop better treatment.
- iv) Diabetes and Therapy: Better insulin and new drugs that initiate particular functions of insulin are being developed.

It is noteworthy that there is little research support for the areas of social science, psychology and education.

The emphasis on research also extends to persuading government, pharmaceutical companies and other agencies to increase their funding of diabetes research.

In addition to research grants, the CDA provides personnel awards and traineeships through the Diabetes Educators' section and the Professional Development Council of the CDA.

The Professional Development Council of the CDA awards two \$5,000 bursaries annually to enable health professionals to pursue graduate studies in diabetes related subjects in a Canadian University. As well, six clinical traineeships are awarded to contribute to a minimum of one week of personalized professional development for diabetes educators who wish to advance their knowledge and skills.

The DES Annual Awards Program presents five annual awards: a \$5,000 bursary to provide funding for innovative education research and/or the development of educational materials that will benefit people with diabetes; a \$2,000 award in recognition of a diabetes educator who has made a special contribution to diabetes education through dedication, sensitivity and innovation in daily practice of patient and education care; a \$2,000 award to recognise an outstanding volunteer contributing to diabetes education through leadership in community service and public awareness programs; a \$1,000 manuscript award to recognize the author of an article judged to be outstanding amongst the submissions published in the DES professional journal, Beta Release; a \$1,000 grant to recognise an outstanding DES Chapter.

SERVICE

The service goal is described as "... to promote, provide and strengthen services to people affected by diabetes." It is intended that such services will enhance the quality of life of those affected by diabetes. According to the 1991 Annual Report of the CDA, it is regarded as imperative that "... people with diabetes have ready access to the services they need. Their quality of life depends on it" (CDA 1991a).

These services are delivered in a large part by volunteers at a community level and encompass programs for all ages and in all regions of the country.

CDA believes that service coordination and delivery are the primary responsibilities of the Branches and Divisions. The role of National is to establish national policies within which these programs can operate effectively and to develop supporting materials.

The National Service Council has the responsibility for monitoring the services provided by the CDA and recommending appropriate national policies and standards to

the Board of Directors. Furthermore, each Division and Branch is to establish a Service Committee to coordinate the service activities of that Division or Branch. The National service Council is composed of a representative from each of the Division Service Committees, plus representatives from the National Nutrition Committee, the National Publications Committee and the National Board. The Division Services Committee is composed of Branch representatives.

CDA provides services in four primary areas:

- education support services,
- social support services,
- economic support services,
- supplemental health care support services.

These services are described below:

i) Educational Support Services: CDA recognizes the continuing need to produce relevant, high quality, technically accurate educational information for those affected by diabetes. It does this through two national committees. Thus, the National Nutrition Committee is responsible for developing CDA's nutrition material, while the National Publications Committee is responsible for the development, regular updating and monitoring of all other non-nutrition education publications.

The CDA literature is developed, coordinated and prepared by National and sold to the Division at cost. It is a CDA policy that Branches and Divisions distribute the material at no cost to the public.

The CDA is always taking new initiatives. For example, new youth programs and materials are being developed. Publications will deal with drinking, drugs, birth control and exercise. A new computer assisted learning program has been developed entitled,

"Forward motion: a Lifestyle Program for Adolescents with Diabetes Mellitus." At a population level, through CDA efforts, hundreds of food products now carry special label information to help people with diabetes use these products appropriately.

- ii) Social Support Services: CDA National encourages opportunities for those affected by diabetes to assist, support and learn from each other how to control their condition through establishment of peer support groups. Activities targeted at of youth, young adult and senior groups, and including workshops, seminars, presentations, camps and weekend retreats, are supported by CDA National through allocation of funds to support these programs as well as establishment and coordination of standards and policies which govern these activities.

Children's summer camps have become a well recognised initiative. Like the conventional camps, campers learn about the outdoors and develop a range of camping skills. In addition, they learn how to better understand and manage their condition in association with other children who have diabetes. The experience also benefits the parents since it is reassuring for them to know that their children are in a safe and controlled environment.

The major responsibility of funding, promotion and implementation of the member services is that of the Divisions and Branches.

- iii) Economic Support Services: In parts of Canada, CDA-managed stores provide diabetic health supplies and services at the lowest possible cost to the consumer along with informed service and in a non-commercial atmosphere. The establishment and management of these stores has been the responsibility of Divisions and Branches although National has been primarily responsible for the establishment of policies.

iv) Supportive Health Care Services: CDA is not a direct provider of health care services. However, the association attempts to play a leadership role in identifying the specific health care needs of persons affected by diabetes and in assessing whether or not the services which are provided by the provincially funded health care system are appropriate and adequate. If necessary, CDA will advocate to appropriate bodies to improve existing facilities.

Policies have been established to assist Divisions and Branches in defining and managing the volunteer and staff functions to assist and serve people with diabetes. The policies ensure that the CDA representatives do not overstep the boundaries between their roles and those of health profession.

A major component of health care services to individuals with diabetes is the Diabetes Education Centres. The term, Diabetes Education Centre, is used to refer to the network of both publicly funded and privately funded Diabetes Education programs and services which provide diabetes education and counselling to individuals and their families. CDA, guidelines and criteria which can be used by appropriate bodies.

A nationwide outreach program for native peoples is a need perceived by CDA as an important one. Diabetes has a high prevalence among the native population and death and disability rates are high. This group develops serious complications at an earlier age compared to that of the general population. A working relationship has been established among CDA, the Assembly of First Nations, the Medical Services Branch of the Department of Health and Welfare for Native Diabetes Education and Service Programs.

ADVOCACY

The advocacy goal of CDA is "... to increase awareness, and to influence and affect positive changes in attitudes, policies and practices of government, business and the general public on behalf of people affected by diabetes."

This goal emphasises the importance of increasing awareness of diabetes in the general public and focuses on changing attitudes, policies and practices within business and government. It recognises attitudes are difficult to change and that policies must be changed before practices. Thus, there is an increasing emphasis on the role of advocacy, social action, lobbying for change and influencing public policy.

The National Advocacy Council was launched in 1989 with a Public Affairs Office located in Ottawa. The mandate of the Council is to advise the National Board and to coordinate the advocacy function of the Association. It is composed of representatives from the Division as well as from the National Public Information Committee, The National Publications Committee, the National Board, and as individual members with expertise in this area.

The guiding philosophy of the Advocacy Council is that most people with diabetes can live full and productive lives. They should be judged on their individual merits, not as a stereotyped class of citizens. Through the advocacy role, that CDA strives to guarantee that no one shall be subject to any form of discrimination because they have diabetes.

The advocacy program is being implemented on five fronts:

1. It supports precedent-setting legal action in the various courts to ensure individual rights are consistent with the Charter of Rights.

2. It promotes policy guidelines relating to diabetes for the public and private sectors through continuing consultations both in government and industry.
3. It is establishing a national advocacy resource centre which will be available to members, professionals, employers and the general public.
4. The association encourages and promotes provincially and locally-based advocacy programs.
5. The Ottawa Advocacy Office continues to provide consultation with divisions and branches in support of their advocacy initiatives.

At all levels, the CDA allocates an increasing amount of human and fiscal resources towards advocating for change in public policy. This influence on public policy is illustrated by the achievements in the following areas:

- i) **Employment:** Working with government and employers to ensure that people with diabetes are not discriminated against in the job market. The association provides consultation services to individuals and employers seeking help and guidance. A recent example is CDA's consultation with the Toronto Fire Department to develop employment guidelines for people with diabetes, thus laying the groundwork for influencing policies of other organizations employing people in safety-sensitive jobs.
- ii) **Motor Vehicle Licences:** Developing non-discriminatory guidelines for granting motor vehicle licenses. A recent triumph was a successful restoration of an insulin-dependent truck driver's license on the grounds that the ability to function safely should be individually assessed.
- iii) **Insurance and Mortgages:** Working with the insurance industry and financial institutions to ensure that people with diabetes are not subject to discriminatory practices.

To date, individuals with diabetes are either subject to higher life insurance premiums or denied life insurance benefits solely on the basis of having diabetes. A feasibility study is underway, in conjunction with the insurance industry to establish guidelines for granting insurance on the basis of individual merit in conjunction with actuarial tables.

iv) Health Services: Most people with diabetes must pay several thousands of dollars annually for insulin and other self-administered supplies not covered by the provincial health care programs. The association is committed to reducing this health care inequity.

In the important nutrition area, the Association has recommended that the Federal Government test the suitability of a new sweetener, Sucralose, for people with diabetes. The CDA continues to be involved in evaluating the revision of Canada's Guide to Healthy Eating.

EDUCATING THE HEALTH PROFESSIONAL

The goal for educating the health professional is "... to develop, promote and strengthen educational programs for health professionals."

The CDA promotes and supports a number of programs which to ensure that all health professionals have access to current information and educational opportunities in the management of diabetes. These special educational programs are directed to nurses, dietitians, pharmacists, social workers and physicians. The Association's efforts have been focused on the following areas:

i) Academic/technical training: CDA works with academic institutions to foster excellence in diabetes-related training. To assist in this, CDA has conducted a survey to assess the extent of diabetes related training across the country as a basis for planning or adjusting programs. The Diabetes Educators' Section, in collaboration with the

University of British Columbia and the University of Calgary, sponsors continuing education courses for diabetes educators.

ii) Quality Control: Standards and guidelines for Diabetes Education Programs have been established. These guidelines offer standardized criteria for the establishment and accreditation of Diabetes Education Programs. As well, a national program for certification of diabetes educators has been implemented to insure quality and standardization of education and care among the health professionals working in the field of diabetes.

iii) Professional Publications: The Association reaches 14,000 family physicians through publication and distribution of the journal Canadian Diabetes which is distributed to all Canadian Family Practice physicians. As well, the association publishes a journal of diabetes education, Beta Release, for health professionals. It also acts as an advisor to a video series which links health care professionals in hospitals through a private satellite network.

iv) Position statements and guidelines: The CDA prepares position statements and guidelines for diabetes care for publication in professional journals as well as distribution to the association's professional membership. Position statements cover such diverse subjects as Guidelines for the Nutritional Management of Pregnancy", "The Role of Dietary Sugars in Diabetes Mellitus", "Commercial Weight Loss Programs for Persons with Diabetes".

v) Clinical traineeships and bursaries: The Association reviews and funds bursary applications for post-graduate work in diabetes-related training.

The CDA views its role as that of encouraging professional health care facilities to provide appropriate health care education in diabetes to health professionals. It is

committed to working with institutions to foster excellence in education related to diabetes. This is being accomplished by encouraging the implementation of continuing education programs and supplementing these by scientific and educational meetings/conferences coordinated by C&SS and DES.

National has the prime responsibility for providing leadership in the area of health care professional education. Divisions and Branches, however, play a vital role in the sponsorship, promotion and implementation of many local continuing education sessions for health professionals.

PUBLIC EDUCATION AND AWARENESS

The public's overall understanding of diabetes and of the Association's leadership role in addressing the many issues and challenges that diabetes presents is a vital measurement of the success of CDA in achieving their objectives.

In 1991, the CDA launched a major multi-media campaign designed to increase the public's awareness and knowledge and to motivate appropriate action.

The Association's first priority was to reach those 500,000 plus Canadians who have the disease but are unaware that they have it. Early diagnosis and treatment is vital to the health outcomes of those afflicted with diabetes. Awareness and information programs also target those at risk of developing diabetes due to lifestyle or other factors. For example, a portable public information display entitled "Are You at Risk" defines and emphasises the major risk factors for Type 2 diabetes of excessive Body Mass Index, android body fat distribution, and personal and family history.

A CDA publication targeted at the members of CDA and their families, *Diabetes Dialogue*, is published four times a year, and reaches 50,000 people. Other publications

targeted at increasing public awareness and understanding of diabetes include "Diabetes: What every Canadian Needs to Know" and "Improving the Quality of Life of Canadians Afflicted by Diabetes through Research, Service, Education and Advocacy."

FUNDRAISING

The fundraising goal of the association is an essential prerequisite to achieving other goals and is focused towards raising sufficient funds to sustain its present and to enhance its future activities and programs.

Campaigns and fund raising efforts in 1990-91 resulted in over \$6,500,000. The following were the major ventures contributing to the national income of the CDA:

- i) Contributions from Division and Branches exceeded \$5,000,000 in 1991 compared to \$3,904,488 in fiscal 1990. This increase was largely as a result of contributions from the Residential Campaign, also referred to as the Annual Appeal. The Annual Appeal, conducted in November, Diabetes Month, involves over 50,000 volunteers throughout the country in a residential door-to-door canvass.
- ii) Direct mail contributions amounted to \$461,000.
- iii) Bequests contributed \$973,520 in 1991, a decline from \$1,497,527 in the previous year.
- iv) Special initiatives in sponsoring special events. A notable campaign was the kindling of "The Flame of Hope" in London, Ontario, which raised \$1,000,000 to support research.

Other revenue was generated by the following sources, with total and proportionate amounts of the total revenue indicated:

"Diabetes Dialogue" Advertising:	\$94,573 (1%)
Literature Sales:	\$370,239 (4.8%)
Interest Income:	\$502,102 (6.5%)
Government Grants:	\$61,470 (less than 1%)
Other:	\$230,462 (3%)

Expenses incurred by the National Association fell into the following categories:

(i) **Research Expenditures:** For the fiscal year 1991, Research Grants and Personnel Awards decreased to \$3,231,119 from the previous year of \$3,733,896. This decrease was largely due to a decrease in total expenditures by the Association to avoid incurring a deficit and represented an actual decrease of expenditure in research from 45% to 41.5% of the Association's total expenditures. Over the previous six years, the CDA had increased its annual research funding by 72%, from 1.81 million in 1985 to \$3.231 million in 1991. However, the Association's capacity to support worthwhile Canadian research was constrained. In 1985, the CDA was able to fund 75% of all research applications received. In 1991, only 57% of applicants received support.

(ii) **Membership Activities and Services:** Membership activities and services accounted for \$1,690,227 or 21.7% of National's total expenditures. The schedule of members' services included costs incurred from Annual, executive and council meetings, the

publication and distribution of Diabetes Dialogue, educational literature and conferences, National Nutrition and other committee meeting expense, public information, and reimbursement to members or travel and accommodation expenses incurred as a result of their volunteer duties.

(iii) Fundraising Expenses: The costs of fundraising were \$99,808 or 1.3% of the total expenditures at the National level. This however, only represents the cost to National and does not represent the total costs of fundraising, since the costs of fundraising are incurred at the Division and Branch levels.

(iv) Division and Branch Development: Totalled \$979,189 or 12.5% of expenditures, an increase from the previous year from \$471,495. This increase is attributable to "...commitment on the part of CDA to establish a presence in the province of Quebec with its population of nearly 7 million" (CDA 1991a).

(v) Salaries and General Administration: The amount disbursed in 1991 totalled \$1,795,539 or 23%. This category includes salaries and benefits, insurance, purchase or lease of equipment and maintenance, professional fees, rent, utilities, and taxes, stationery and supplies and telephone.

CHAPTER IV

THE CANADIAN DIABETES ASSOCIATION AT THE PROVINCIAL LEVEL:

THE MANITOBA DIVISION

In this chapter, the structure and functions of the Manitoba Division of the CDA and the Brandon Branch are described.

The Division receives its mandate from the National CDA: "... to advance the objective of the Association and for the benefit of the membership, the National Board may establish divisions of the Association in Canada. Members of the Association resident in any locality may, with the approval of their local division and National Board, form a Branch of the Association" (CDA 1986).

By 1992, the CDA had a Division in each province.

Each Division may develop its own governing regulations but these regulations must be approved by the National Board of Directors. The links between the Division and the National organization are through the Division President who is a member of the National Board of Directors and through the Executive Director of the Division who, while responsible to the Division Board, also has a reporting function to the National Executive Director.

The committees at the Division level replicate those at National Level but the Division may establish committees reflecting specific programs. For example, in the Manitoba Division, committees have been struck to look after the Summer Camp and the Seniors' program.

While the legal status of Divisions and Branches is derived from the National Association, their activities are conducted with considerable autonomy. The Division office serves as a resource for the branches, primarily in matters concerning education and service. It relays communiques and directives from the National Board to the branches and its members. It is at the branch level that most individual members of the Canadian Diabetes Association receive the benefits and services of the Association. The activities of the branches include fund raising, locally sponsored workshops for the public and professionals, and facilitating support groups for seniors, youth groups and parents of children with diabetes.

Internal communication within CDA is fostered by Division and Branch newsletters. These provide information and news to the membership as well as obtain feedback from the membership. Questionnaire and program evaluation forms have been included in newsletters and, after completion by the member, are returned to the Branch or Division. In this way programs may be modified or new programs developed in response to the needs expressed by membership. For example, the goals developed in 1986 were based on feedback in the form of a survey of the membership.

General meetings of the branch membership allow for concerns to be expressed and information and ideas to be exchanged among the membership. They provide an opportunity for the membership to receive an update on current projects and activities and provide a valuable feedback service to the branch and its members.

PHILOSOPHY AND OBJECTIVES AT THE DIVISION LEVEL

The mission statement of the Divisions is identical to the CDA National. Restated, this is to "... to improve the quality of life of Canadians affected by diabetes by being the leading force in research, service advocacy and education."

The organisational goals are:

- to support research into the causes, prevention, cure, management and understanding of diabetes and its effects on those affected by diabetes.
- to promote, provide and strengthen services to people affected by diabetes.
- by advocacy, to increase awareness and to influence and affect positive changes in attitude, policies, and practices of government, business, and the general public on behalf of people affected by diabetes.
- to develop, promote and strengthen educational programs for health professionals.

ORGANIZATIONAL STRUCTURE AND MEMBERSHIP

The Board of Directors of the Manitoba Division is elected annually at the Division's Annual meeting. The composition of the board is seven elected executive members and seven board members who are Branch representatives, usually the Branch President. The 1992/1993 Division Board consists of the following officers:

Executive Officers:	President
	Past President
	First Vice President
	Second Vice President
	Third Vice President
	Treasurer
	Secretary

Board of Directors:	Brandon Branch President
	Dauphin Branch President
	Norway House representative
	Steinbach Branch President
	Swan River representative
	Thompson representative
	Winnipeg Branch President

FUNCTIONS AND ROLES OF THE MANITOBA DIVISION

While the philosophies and objectives of the Manitoba Division may be analogous to those of the National level of the organization, their implementation at the Division level takes on a different character as a result of the relative emphasis placed the goals. When the activities of the Division Board and its committees are examined, it is seen that the goals of member services, fundraising, and public and professional education have become the focus of Divisional activities. Research and advocacy receive less emphasis. For example, the role of Division in research is limited to raising funds to be sent to National. The Division does not support research directly itself. Its role in advocacy is limited to the support of the policies and programs established at the National level. The activities are described in detail in the following sections.

FUNDRAISING

The fund raising endeavours and projects carried out by Division are primarily for the purpose of raising funds to support the National Association's goal of research (and,

to a degree, advocacy and education), as well as its own member services, education programs and administrative and operational commitments.

The major sources of revenue in 1991 were as follows:

1. The second annual Lions Club cavalcade received donations totalling \$20,000 (compared to \$14,000 in 1990) for diabetes research, camps for children with diabetes, and the Lions International Fund.
2. The annual Residential Canvass, held in November, raised \$295,000 (\$300,000 in 1990). The funds raised in this canvass are forwarded to the National Office and designated for research.
3. The Direct Mail Program raised a total \$93,000 (1990 - \$46,000).
4. Special programs and established fund development activities included:

Employee giving programs:	\$52,000
Memberships, In-Memoria, & Donations:	\$205,000
Bequests:	\$7,500
Other fund raising projects:	\$40,000

5. A major source of revenue for the Division is the CDA's Community Collection Crew (CCC) which has the exclusive contract to provide merchandise for the two Winnipeg's Value Village Stores. The CCC solicits and collects re-usable merchandise which is sold to Value Village, Manitoba Division. This enterprise has realized a profit of \$375,000. This represents over 32%, the largest single contribution to the total revenue generated for 1991/1992 year for the Division.

MEMBER SERVICES

The services provided at the Division level were highlighted in the 1991/1992 Annual Report as follows:

1. Camp Birchbark is a Division sponsored twelve day residential camp program for children and adolescents with diabetes held annually at the YM-YWCA Camp Stevens in Kenora, Ontario. In 1990, 64 campers from Manitoba, Saskatchewan and Ontario, attended the camp. Twenty eight of these children were provided "campership funds" for any children who were not able to afford the fees. Manitoba Division is responsible for the solicitation, coordination and accounting of all funds supporting this camp. External support is received from the Children's Hospital Telethon and the Winnipeg Jet's Goals for Kids Foundation as well as service clubs and individual donors.

In 1990, a \$10,400 grant was received from Manitoba Health, to fund physician coverage and for the Diabetes Nurse Educator and the Nutrition Educator from the Children's and Adolescence Diabetes Education Resource in Winnipeg to attend the camp.

2. The Diabetes Product Centre provides diabetes care products, services and information to its members has been in business since 1989. Its aim is to offer a full range of meters, lances, cookbooks, syringes and other diabetes care products at a competitive price.

3. Two support groups are in place. These are the "Wonder Years" for people 18-60 and the "Seniors Program." Both program enable individuals with diabetes to enjoy speakers, videos, coffee and share ideas and experiences. These support groups are all in the city of Winnipeg and do not benefit rural members of Manitoba.

4. The Lending Library, situated in the Association's Winnipeg Office, makes available numerous books, periodicals and audio-visual materials for loan to both members and non-members.
5. The Meter Lending Program makes it possible for individuals with diabetes to borrow meters for a period of up to three months. Again, this service is limited primarily to residents of Winnipeg.
6. In collaboration with the Winnipeg Branch, R Koda, a day camp program for the 4-7 year age group has been sponsored since 1989 at Camp Manitou.
7. In cooperation with the Diabetes Resource Centre for Children and Adolescents (Health Sciences Centre), a Children's Christmas Party was held for approximately 60 children and their parents.
8. The provision of diabetes-related literature and other information at no charge to the public is an ongoing service of the Division.

EDUCATION FOR HEALTH PROFESSIONALS AND THE PUBLIC

Education activities of the Division include:

- sponsorship of an annual symposium on diabetes related issues targeted to health professionals.
- in March of 1991, a symposium in Dauphin, Manitoba was sponsored for people with diabetes, health professionals and the general public.
- a co-hosted with the Manitoba Kidney Foundation an educational event for all members as well as the general public.
- sponsorship of a Diabetes Educator-CDA Networking Workshop, the first endeavour of its kind.

- initiation of a pharmacy/supplier network and established a diabetes resource display at a Winnipeg pharmacy and in a seniors' section of a Winnipeg department store.

In 1992-1993, plans were underway for participation in a Manitoba Health Organization's workshop; sponsorship of a Symposium for Health Professionals; two jointly sponsored co-ventures, one with the Manitoba Kidney Foundation and one with the Canadian Institute for the Blind; presentation of four rural workshops; a rerun of the Educator-CDA workshop; and the continuation of the development of the supplier/pharmacy network.

The Manitoba Health Services Development Fund has provided an eighteen month grant of \$168,000 to assist the Manitoba Division in initiating a Province wide Diabetes Awareness and Prevention Program. As part of this program, research will be conducted on the knowledge level of the general population as it relates to diabetes, with an emphasis on identifying the particular needs of the Aboriginal population in the province.

ADVOCACY

The Division's first Advocacy Committee was established in 1990. One of the first tasks of the committee was to develop a brief to be presented to the provincial government's Health Promotion Task Force, the objective of which was to identify the "unmet needs" of individuals with diabetes in Manitoba. Some of the concerns identified by this brief involved the absence of Pharmacare coverage for blood monitoring meters, the need for programs addressing the emotional and psychological needs of individuals

with diabetes, and the special needs of the Aboriginal population as they relate to diabetes.

The Division provides representation on the Citizens For Eyecare Education Committee, a committee which addresses the problem of the shortage of ophthalmologists and operating rooms, critical issues for individuals with diabetes.

RESEARCH

The research activities of the Division are confined to fund raising to meet the targets of National. In 1992, the Division contributed \$300,000 to research.

FINANCES

The Manitoba Division has an annual operating budget of over \$1 million.

As described in detail earlier, fund raising endeavours contributed \$640,000 of the total revenues for 1992 with an additional source of revenue from the Value Village outlets of amounting to \$375,000.

Expenditures allocated to each of the Association's major goals are as follows:

Member Services	\$26,000
Research	\$300,000
Awareness Program	\$38,000
Fundraising	\$210,000
Administration	\$171,000

The goals of Health Professional Education and Advocacy are not allocated a specific portion of the budgeted expenditures. The funds to support these objectives are contained within the categories of member services and administrative expenditures

ORGANIZATIONAL CHANGE

As described earlier, the Manitoba Board is composed of seven executive members and seven branch representatives. A proposed restructuring of the board will involve regional representation in order to encourage the growth of branches in the smaller centres and to obtain a wide representation from the branches at the Divisional level. In 1992, two regions, CENTRAL and WESTMAN, had been defined on the basis of their fund raising activity in surrounding towns and the initiation of a request for office and staff.

As a result of the move toward regional development, it was proposed that the interim Board composition for the 1993-1994 term be composed of:

- Central Region - 4 representatives
- Westman region - 2 representatives
- Branches (Dauphin, Thompson, Swan River, Steinbach, Norway House)
- 1 representative each
- Members-at-Large: selected on the basis of expertise to bring the Board membership to 18.

The President will be elected to represent the Division and not seen as a branch or a regional representative.

At the 1991 Annual General Meeting of Manitoba Division, the membership accepted in principle the proposed change in the organizational structure. The official initiation of the new organizational structure will take place at the 1993 Annual General Meeting in March 1993.

THE BRANDON AND DISTRICT BRANCH

The first Brandon Branch meeting was held in 1963.

The goals and objectives of the Brandon and District Branch correspond to those of the Division and the National Office and can be enumerated as follows:

Service

1. To promote the development of support groups and/or educational events to suit the needs of the communities in the Branch area.
2. To promote the importance of a camping experience for youth and increase donations for Camp Birchbark.
3. To continue to provide literature and other pertinent information to those affected by diabetes.

Education

1. To work with Division in continuing to provide education to health professionals.
2. To work with Division to generate greater public awareness through a variety of ways.

Research

1. To assist Division in meeting the 1992-93 research goal.
2. To inform the public of the research being carried out in Manitoba

Advocacy

1. To work with Division to identify issues and develop a strategy to address them.
2. To continue to encourage persons who feel they are being discriminated against to come forward and make their concerns known.

ORGANIZATIONAL STRUCTURE AND MEMBERSHIP

The organizational structure of the Branch Board parallels that of Manitoba Division. A Board of Directors is elected annually and members formally take their position of office at the Annual General Meeting, usually held in the Spring of each year.

FUNCTIONS AND ROLES

The character, role and function of the Brandon and District Branch can be described in terms of a delineation of its activities throughout the year. The information was obtained from three sources: (1) The minutes of the Branch Board of Directors meetings for 1990/1991 and 1991/1992; (2) The reports presented to the Annual General Meeting of the Brandon and District Branch in 1991 and 1992; (3) The Branch Activity Reports for the four fiscal years including 1988-1992.

The activities can be described within the context of the five goals or objectives of the organization:

(i) Fundraising

- Annual Appeal and the coordination of advertising campaigns, volunteers for door-to-door canvassers
- Business campaign involving coordination of mail-outs requesting donations to the organization
- Celebrity Auction
- Promotion and sale of "Gise" products at the Brandon Winter Fair
- Charity Bazaar held semi-annually in the spring and fall
- Raffle for a Honda automobile
- Sales from a Pork Barbecue at the Brandon Summer Fair

- Participation in the Lions Cavalcade
- Fashion Show and Lunch
- Sale of Christmas trees
- Golf tournament
- Monster Bingo
- Spring Tea and Bake Sale
- Manitoba Division Appeal
- Division Tag Day
- Valentines Lunch
- Charity Bazaar held semi-annually in the spring and fall
- Airplane Toss
- Dance
- Rummage sale
- Sale of colouring books and wild rice

(ii) **Public and Health Professional Education**

The objective of education and increasing awareness for the general public as well as physicians and other health professionals was received secondary priority at the Board of Directors Meetings. It was concerning this objective that the two appointed consultants, the Nutrition consultant and the Nurse consultant played an active role. Both of these individuals are also staff of the Diabetes Education Service. Some examples of the educational events sponsored over the two year period were: an educational seminar for health professionals in Virden; entering a float in the Brandon Traveller's Day Parade;

a Diabetes Workshop for Health Professionals; a motivational presentation by Gord Paynter, a comedian who has become blind due to diabetes.

(iii) Research

The objective of research is dealt with from the perspective of raising funds to fulfil its budgeted commitment to the Charles H. Best Fund at the National level. It is noted from the 1991/1992 Annual report that \$1,250 was disbursed to National for Research with a proposed 1992/1993 target of \$2000.

(iv) Service

The function of "service" is carried out at the Branch level in two ways. First, the Branch promotes the camping experience for young people with diabetes by their donations to the Camp Birchbark Funds. In 1991/92, the Branch donated \$744 to the camp fund. Secondly, the Branch coordinates educational events for individuals with diabetes as well as increasing public awareness. As well, a considerable amount of CDA educational literature is distributed at these events. The events include: a public display at shopping mall Health Fair; evening speakers for Branch members as well as the public on nutrition topics; volunteer recognition evenings; public awareness displays at a Healthstyles Conference, a Health Day at a shopping mall, Brandon fair, Virden Fair, Reston Health Fair; and public speaking to Rivers Lions club and to the Streamliners Club.

The Branch Office is staffed by a full time office coordinator as well as volunteers and provides distribution of CDA literature, as well as a variety of services and information to those who access this office.

(v) **Advocacy**

The advocacy objective has not been documented as part of the Branch functions or activities.

FINANCES

The annual budget for Brandon Branch for 1990-1991 was approximately \$100,000. The major source of revenue was the Annual Appeal, accounting for 40%, with "specified donation" accounting for approximately 21%. Other sources include revenue from membership fees, "In Memoriam", literature sales, newsletter advertising, camp and Lions club donations.

Disbursements include salaries and other administrative costs related to the administration and operation of the Branch office as well as services to members such as CDA literature. Expenses related to fund raising account for approximately 20% of the total disbursements. Funds committed to National office and Division office comprise 46% of the disbursements.

CHAPTER V

A PROFILE OF ORGANIZATIONAL INVOLVEMENT AND ATTITUDES TOWARDS PARTICIPATION AMONG VOLUNTEERS IN THE WESTMAN REGION

INTRODUCTION

This chapter summarizes the results of descriptive interviews with a non-random sample of volunteers of the Canadian Diabetes Association working in the Westman Region. It provides a qualitative and demographic profile of selected volunteers involved in leadership positions in the Westman Region and summarizes informants' descriptions of the attitudes and motivations influencing their participation in this volunteer organization.

THE SAMPLE

The 1994 membership statistics indicate that the membership of the Canadian Diabetes Association in the Westman Region in Manitoba was more than 400, composed of men and women involved in varying degrees of voluntary participation in the activities of the Association. Of the twelve individuals chosen for interview, ten were current members of the Westman Board and two were long time active members of the association. These twelve individuals were identified as key informants because of their participation in leadership positions. It is acknowledged that they do not represent a random sample and may not fully reflect the perspectives of the general membership. Because the general membership list of the Canadian Diabetes Association is not available to the public, it was not possible to select a random or representative sample of key

informants. However, the information of individuals with current or past leadership experience provides significant information on participation among individuals with defined organizational involvement. These twelve individuals were interviewed using semi-structured interviews that elicited information about their participation patterns and motivation. The interview schedule (appendix) included questions focusing on the nature and extent of their volunteer activity with the Canadian Diabetes Association over the past year, their role as volunteers within the organization, their contributions at the local level, their motivations for participating as volunteers, and their perceptions of the barriers to voluntary action within the organization.

MULTI-METHOD APPROACH: COMPARING KEY INFORMANT EXPERIENCE WITH POPULATION SURVEY DATA ON VOLUNTARY PARTICIPATION

Quantitative summaries of the types and intensity of participation of the informants in volunteer activities are described in the tables. Qualitative data from the informant narratives will be used to describe individual accounts of how people became involved with the association, narratives describing their personal motivations for volunteering will also be used to document factors contributing to the informant's satisfaction with their volunteer participation.

To provide a population-based standard for interpreting the key informants' experience, their patterns of participation will be compared with voluntary participation patterns described in the National Survey focusing on Volunteer Activity, conducted by Statistics Canada on behalf of the Department of the Secretary of State in 1987. This survey was the first attempt to examine the multiple dimensions of volunteer activity in Canada. The survey documented the experiences of approximately 70,000 Canadians who

were fifteen years of age and over. In the Statistics Canada Survey, the initial screening questionnaire determined whether the individuals had been involved in formal and/or informal volunteer activity during the twelve month period from November 1986 to October 1987. A follow-up questionnaire was then sent to individuals who initially reported volunteer participation. This follow-up instrument collected detailed information on formal volunteer participation, which the survey defined as volunteering involving work with a recognized organization. A statistical overview of these survey results, "Giving Freely: Volunteers in Canada", has been published by Statistics Canada (Duschesne 1989).

Summaries of patterns of voluntary participation among the national population were published by Ross and Shillington, (1989) and Kent, (1989). It should be noted that the profile by Ross and Shillington documented experiences of each respondent with up to three voluntary organizations. In order to focus on participation in health-related volunteer participation, comparisons were made with profiles of volunteers working in health-related organizations as documented by Kent in Profile #9 (Kent 1989).

The focus of this national survey was on formal volunteer activity. Ross and Shillington differentiate between formal and informal voluntary work. They defined formal voluntary work as "activity conducted through a recognized organization frequently assisted by paid staff. Formal volunteer work is often performed on a regular or planned basis and involves a degree of commitment to the host organization" (Ross and Shillington 1989). Informal volunteer work, on the other hand, encompasses that broad spectrum of activities that are performed on a more individual basis. Typically, informal volunteer work consists of more spontaneous involvement and without coordination from an outside organization.

A PROFILE OF THE CDA VOLUNTEER

A: WHO ARE THE VOLUNTEERS FOR CDA?

The national survey acknowledged that volunteers represent a broad cross-section of the Canadian population. Individuals volunteering for the Canadian Diabetes Association are also drawn from a wide range of socio-demographic backgrounds.

In Table 1 the demographic characteristics of the key informants interviewed (including Westman volunteers) are compared and contrasted to the findings from the Manitoba sub-sample and the Canadian sample as reported in "A Profile of the Canadian Volunteer" (Ross and Shillington 1989). Where possible, the comparisons include data from Kent's examination of the participation of volunteers in health related organizations (Kent 1989). This comparison is not intended to provide a formal evaluation of the representiveness of the key informant sample or demonstrate the generalizability of the data.

AGE

The national survey indicated that volunteer participation rate increases with age, declining after midlife. Half of all volunteers were in the 25-44 age group and one-quarter in the 45-64 group. However, this participation rate declined to 11% for persons aged 65 and over (Ross & Shillington, 1989). Among the key informants interviewed, the ages of the CDA volunteers ranged from 25-75 years. Of this group, five or 42% of the individuals were in the 25-44 group, five (42%) of the informants were the 45-64 age group and two (17%) were age 65 years or more.

The age structure of the sample of key informants is similar to the age structure of the sample responding to the national survey on volunteer participation.

GENDER

The gender composition of the national volunteer sample indicates that women are more likely to volunteer than men. Six out of every ten volunteers were female (Duschesne 1989). The gender distribution of the CDA volunteers interviewed included a similar gender distribution. Seven out of 12 key informants were women. In Kent's analysis of the characteristics of volunteers working in health-related organizations in the national survey sample, 77% of the respondents were women.

The gender distribution among volunteers serving on the governing bodies of voluntary organizations such as CDA is also a consideration in interpreting the perspectives of elite key informants. The membership of the Westman CDA board includes six males (60%) and four females (40%). This inverse gender balance among the board members compared with the general membership is similar to disproportionate representation of men on the boards of other voluntary organizations. The national survey documented a higher proportion of females among the volunteer pool of the health related voluntary organizations (Duschesne 1989). However, Ross and Shillington observed a trend for males to be disproportionately represented on Boards and Executive Committees. Kent concluded that the boards of directors of health organizations were composed of two-thirds male and one-third female members. Thus, although women comprise over three quarters of the volunteer force (77%), men are more likely involved at the policy and decision making level of voluntary organizations.

MARITAL STATUS

Among the national sample, married respondents have a higher rate of volunteering. Ross and Shillington reported that 71.5% of their respondents were

married. Kent did not examine marital status in her report. Eleven of the twelve key respondents (92%) interviewed for this study were married.

LABOUR FORCE STATUS

The labour force status describes the individual's employment status. The key informants, were classified as employed, unemployed, or not currently working in the labour force. The use of this classification facilitated comparisons of key informants' work force participation with the occupational status of respondents to national surveys of volunteers.

Nine of the 12 key informants were employed full time. The other (3) informants indicated that they were not currently working. None of the key informants classified themselves as unemployed. The informants were currently employed or had completed careers as engineers, nurses, dietitians, educators, and secretarial or self-employed workers. Respondents who reported that they were not currently in the work force were retired or reported their role as homemakers.

Most of the key informants interviewed stated that they also worked as volunteers for other voluntary organizations as well as CDA.

The pattern of employment among the key informants is consistent with that documented in the national survey which found that two-thirds of national sample of volunteers were employed and that approximately 31% were not currently in the labour force. Only 4% of respondents to the national survey were unemployed and "looking for work" (Duschesne 1989). However, Kent's survey of volunteers working in health related organizations described somewhat different employment patterns among these volunteers. She reported that among health volunteers, 43% were not in the labour

force, 38% were employed full time, 14% were employed on part time, and 5% were unemployed (Kent 1989). Kent interprets these differences in gender and labour force status between the general volunteer sample and subsample involved in health organizations, as reflecting the fact that a higher proportion of women who are not in the formal work force may volunteer to work with health related voluntary organizations.

TABLE 1: DEMOGRAPHIC CHARACTERISTICS

Demographic characteristics	Key informants interviewed		All Manitoban volunteers (Ross & Shillington)	All Canadian volunteers	Canadian health volunteers (Kent)
	No.	%	%	%	%
AGE:					
15-24 years	0	0	14	13	5
25-44	5	42	50	49	54
45-64	5	42	25	27	11
65 and over	2	17	11	11	31
GENDER:					
Female	7	58	56	57	77
Male	5	42	44	44	23
MARITAL STATUS:					
Single	1	8	20	19	n.a.
Married	11	92	72	72	n.a.
Widowed	0	0	9	9	n.a.
Separated, Divorced					
LABOUR FORCE STATUS:					
employed	9	75	67	64	53
unemployed	0	0	4	5	5
not in labour force	3	25	29	31	43

* Totals may not add up to 100% due to rounding.

n.a. - comparable distribution not available in published data.

B: WHAT IS THE NATURE AND EXTENT OF VOLUNTARY ACTIVITY?

Volunteer activity may benefit an organization directly through volunteer participation in boards or it may involve direct assistance of individuals and families through activities such as counselling and peer education. The volunteer activities reported in the narratives of the key informants described a variety of functions which were perceived by the volunteers as being of benefit to both the organization and its individual members.

In the interview, the key informants were asked to describe the kinds of volunteer activities they performed for the CDA during the previous year. The key informants were also asked to estimate the approximate amount of time which they spent doing volunteer activities. In this type of inquiry, the possibility of bias and inaccuracy in respondents' recall of time specific information was recognized as a methodological problem. The tendency of the informant to overestimate time-related information in volunteer activity was recognized.

These twelve key informants committed a total of 1046 hours or 139.46 days of volunteer activities for the association over a one year period. This total time commitment equals to a 0.7 Equivalent Full Time salaried position. The mean value for participation among the twelve key informants was 87 hours per person per year. This level of time commitment to CDA activities compares closely with the yearly time commitment of 92 hours reported by volunteers in Kent's survey of participants in Health Organizations (Kent 1989). This level of time commitment also is comparable to Steven's estimates of volunteer participation in Manitoba. Stevens found that Manitoba volunteers donated a mean of 89 hours per person per year to voluntary organizations (Stevens 1989).

ACTIVITIES

The predominate work reported by the key informants involved fundraising or canvassing. The informants reported spending a mean of 40.5 hours per person per year on these activities. Fundraising accounted for 47% of total time commitment. This commitment of half of volunteer time to fundraising contrasts with activity patterns of volunteers documented by Kent. Kent reported that among the National Sample of volunteers in health related organizations, fundraising activities comprised only one-third of respondent's time commitment.

Fundraising is an essential activity enabling health-related voluntary organizations to offer programs, deliver services and support research. Fundraising activities sponsored by the CDA included: (1) canvassing door to door as part of the association's Annual Appeal; (2) representing the association at various community functions; (3) selling tickets, "Buffalo Burgers", and christmas trees; (4) donating baked goods and bazaar items; and (5) working at fundraising functions such as Bingos, the Celebrity Auction, and a "Hole-in-one day" golf contest.

Key informants spent a mean of 13 hours per person per year organizing, supervising and co-ordinating the various events sponsored by the association. This accounted for 15% of their total volunteer time.

The other major form of participation reported by volunteers involved serving on CDA committees. Because the majority of the key informants interviewed were members of the Branch Board of Directors, it was recognized that their participation levels may exceed those of the other volunteers. Among the key informants, board participation accounted for 29% of their total volunteer time. The twelve informants committed a mean of 25.3 hours per person per year participating in the activities of CDA committees,

including the Brandon Branch Board of Directors, the Branch Fundraising Committee, the Education Committee and the Westman Diabetes Educators Section Executive. This level of committee participation again clearly reflects the selection of key informants who were board members and therefore more likely to be involved in leadership activities and committee work.

Providing information to the public was another significant and visible form of volunteer participation. Key informants reported a mean of contribution of 5.75 hours per person per year or 6% of their total yearly time commitment to these activities. Involvement in providing public information included activities such as staffing information booths at health fairs or community events and speaking to other community groups about diabetes and its prevention. Volunteer involvement in information diffusion was targeted at increasing public understanding and awareness of diabetes, stressing the impact of diabetes as both an acute medical problem and long term chronic disease associated with other co-morbidity. Public information programs delivered by key volunteers also stressed the need to identify members of the general population who were at a high risk of developing diabetes.

Only one volunteer participated in recruitment of other volunteers or members. This individual, at the time of the interview, was President of the Branch, and defined recruitment of other members as one of his roles as chairperson. Other informants, however, acknowledged that they informally recruited other volunteers and members for the association.

None of the key informants interviewed identified counselling or advising other individuals with diabetes as part of their volunteer activities. Peer counselling or an advisory function was identified as an additional activity that key informants would be

interested in becoming involved if there was a need. A feature distinguishing CDA volunteer activities from the activities of participants in other self-help groups was the lack of involvement in counselling, care provision and volunteer participation in peer support.

In comparing the patterns of activity participation among the key informants with those documented among respondents to the national survey for health care volunteers, several common features are evident. Kent reported that the highest single activity participated by volunteers from health-related organizations was fundraising or canvassing for funds. These activities accounted for 55% of the reported types of participation and consumed 34% of the respondent's total time commitment. Other activities performed by volunteers in health organizations included: (1) providing public information (29% of all activities); (2) counselling, providing advice and friendly support (23% of all activities); (3) providing care (18% of all activities); (4) organizing events and supervising or co-ordinating activities (16% of all activities).

TABLE 2: ANNUAL HOURLY TIME CONTRIBUTION OF KEY INFORMANTS TO VOLUNTEER ACTIVITIES OF CDA

	Total time commit	Fundraising	Event organ	Board partici	Public info	Recruit
Mean hours per year	87	40.5	13.0	25.3	58	2.3
Percent of total annual time contribution	100%	47%	15%	29%	6%	3%

* Totals may not add up to 100 due to rounding.

FINANCIAL COMMITMENTS

In addition to voluntary time commitments, key informants were asked about additional contributions, such as out of pocket expenses, and donation of baked goods or other resources to the CDA. Three informants estimated that they donated \$50-\$100, three estimated that they donated less than \$50 and the remaining six (50%) replied that they either did not keep track or that they did not donate any resources beyond their time and service commitment. Data from the national survey indicated that the majority of the volunteers (70%) contributed less than \$100, 24% contributed between \$500 and \$499, and 6% contributed more than \$500. It was estimated that out of pocket expenses accounted for a total contribution of \$842 million to voluntary organizations in Canada

in 1986/87 (Ross and Shillington 1989). In Kent's report of health organization volunteers, 52% of volunteers indicated they had no expenses, 15% less than \$20 in expenses, and 12% spent over \$100 in connection with their volunteer activities.

LEVEL OF SATISFACTION

Key informants were asked about their satisfaction with types of volunteer activities they performed. More than half of the key informants replied that they were not satisfied with their time commitment to or the nature of their involvement in fundraising activities. Several stated that some of the fundraising activities were "a waste of time". Informants emphasized that the total amount of funds raised for the organization, in some instances, did not warrant the time and energy commitments on the part of the volunteer. Other informants described other areas of personal expertise which they felt they could better utilize in allowing them to contribute effectively to the organization. These informants perceived that their expertise as volunteers was not being utilized through their involvement in existing fundraising functions. The alternative functions or activities that informants identified as being preferable to involvement in fundraising included:

- i) giving advice or involvement in educational activities,
- ii) helping to raise public awareness of diabetes,
- iii) providing assistance to a support group for individuals with diabetes and their families,
- iv) assisting in the regional CDA office.

This gap between involvement and the volunteers' perception of ways of assuming a more meaningful role is an important issue for the Association to address in recruiting,

managing and retaining volunteers. Although the informants clearly indicated that they did not like participation in fundraising activity, they spent an average of 47% of their total volunteer time involved in this function. In contrast, they identified information giving as a more desirable form of volunteer activity, though this form of involvement accounted for only 7% of their total volunteer time.

C: HOW DID INFORMANTS BECOME INVOLVED IN VOLUNTEER ACTIVITIES?

This section summarizes the responses of the key informants to questions probing the reasons they became involved as volunteers with the activities of the CDA. Table 3 summarizes the themes describing motivation and satisfaction among the key informants. The table also provides an indication of the distribution of motivation factors reported by respondents in the national volunteer survey sample (Kent 1989).

TABLE 3: VOLUNTEER INVOLVEMENT

	Informants		Canadian Health Volunteers (Kent)
	N	%	%
Have diabetes themselves	6	50	n.a.
Family member with diabetes	4	33	n.a.
Health professionals	2	17	n.a.
<hr/>			
Approached by someone within the organization	5	42	50
Approached the organization themselves	4	33	19
Expectations of the job	3	25	3
<hr/>			
Satisfied with time commitment to volunteering:			
Yes	9	75	87
No	3	25	13
<hr/>			
Give more time (on an emergency basis)	3	25	43
Give more time	4	33	24
Would not give more time	5	42	23

n.a. - comparable distribution not available in published data.

CDA AS A PATIENT-MEMBER ORGANIZATION

In examining the characteristics of the volunteers interviewed, it is apparent that the characteristics of the CDA fit the profile of a patient-member organization. A patient member organization has been defined by Govan as one developed by patients themselves, or parents, family members and friends of the patient (Govan 1966). All key informants

interviewed, with the exception of two of the three individuals who were also health professionals, either had diabetes or were members of families which included a person with diabetes.

DURATION OF PARTICIPATION

A key issue in the literature on voluntarism focuses on factors which sustain participation. The length of time that the key informants had participated as volunteers in CDA appeared to be associated with the length of time since they or a family member were diagnosed with diabetes. Seven informants reported that they made the decision to volunteer immediately after they or their family members were diagnosed. Five individuals made the decision to volunteer several months or years after the initial diagnosis of the disease. Family linkages were also important in the timing of individual informant's decisions to become involved as volunteers. One individual reported that they had become involved as a CDA volunteer after marrying her spouse who had Type 1 diabetes since childhood. The informants who were also health professionals reported that they had become involved in CDA activities after they were hired to work at the Diabetes Education Centre.

RECRUITMENT

Key informants were also asked how they initially became involved in volunteering for the organization. Five informants (42%) reported that they had joined CDA after being approached by a member of the organization. This pattern is similar to that described by Kent (1989) who wrote that fifty percent of volunteers in health related organizations reported joining the organization after being approached by another

member of the organization. Four of these five key informants reported that they were encouraged to join by the Diabetes Education Centre staff or by other health workers in the hospital. Only one of the informants joined after being asked by a member who was not a health professional. This pattern of recruitment highlights the significant role of the health professional, including the physicians, diabetes educators, and other health workers in direct recruitment or referral of potential volunteers.

Self-recruitment or referral was the other route through which other key informants established links with CDA. Four informants indicated that they joined the organization on their own, around the time of diagnosis of diabetes. Kent's analysis of the national survey data indicated that 19% of the sample reported self-recruitment or self-referral.

Linkages between the CDA and participating health professionals involved in the treatment system were also an important mechanism for volunteer research. Three health professionals indicated they joined the CDA because volunteer participation was an expectation of their jobs. This pattern of job-related participation among three informants may be somewhat atypical. Among the national sample of volunteers, Kent found that only 3% of respondents participated because they were asked to join by a superior or employer. The overlap between professional and volunteer involvement among the key informants may reflect the impact of membership requirements of the Westman CDA Board which reserves two mandatory positions for health professionals. These positions are reserved to insure that qualified professionals perform professional liaison and health education functions.

CHANGING PATTERNS OF PARTICIPATION

In examining the issue of recruitment and retention of volunteers, an attempt was made to use informant narratives to describe changing patterns of voluntary participation. The informants were asked to describe how their voluntary participation had changed from the time of their initial involvement with the association. In applying this approach the methodological problems of retrospective reporting were recognized. In interviews in which respondents are asked to retrospectively describe activities and interpret life events, qualitative methodologists have recognized that a process of narrative reconstruction may occur (Williams 1986). In the narrative reconstruction, the focus of the individual's interpretations is not so much the 'act', in this case on the act of volunteer participation, but rather on reinterpreting the significance in terms of its impact on the informant's overall life adaptation. Theoretical work suggests that in this process of narrative reconstruction, that people will retell their life histories or stories, is framed in terms of their life-course events. These marker events may include the onset of a chronic disease, or a significant change in family adaptations. Through reconstructed narratives or accounts of their work, informants may attempt to order and "make sense" of their descriptions of their participation. Williams describes this process of narrative reconstruction as an "attempt to find some kind of meaning or sense of coherence in the midst of disruption that the illness has caused" (Williams 1986:1437). Individuals may be searching for a "unifying interpretation" of their life's events rather than objectively describing life events and volunteer work. Informal observation and responses to the less structured questions suggested that many key informants went through a process of narrative reconstruction in describing their careers as volunteers. Informants' descriptions of decisions involving their history of involvement were contained within the context of

their personal or family experience with diabetes. Key events were defined in terms of the individual's illness, and the physical and social disadvantages and disruptions caused by this illness. The sequence of their involvement as volunteers was then related to this series of life disruptions.

The key informants were asked how their participation had changed since recruitment. Content analysis indicated that seven informants had increased their participation. Three stated their participation had remained the same and two stated participation had decreased.

The primary reason for the increased participation identified by key informants involved in leadership of the Westman Region may be related to their roles as board members. However, several informants described the impact of other influences on their pattern of increased involvement.

One informant stated:

(My participation) Has its ups and downs, we were very active when our daughter was first diagnosed, going to all the meetings and conferences, getting the most information we could get, our activity decreases when we moved to Brandon, now it has picked up again and I would say we are at our peak.

Another stated:

(My participation) increased. In fact, we made the decision to devote more time to CDA now that we are retired.

Other narratives highlighted the impact of participation in the activities of her committees.

As one informant stated:

(participation has been) increasing since becoming involved with the fundraising committee.

Two of the narratives emphasize that the informant's professional involvement as Diabetes Educators was a primary reason for their increased participation.

The informant stated:

Increased, with becoming DES Regional Rep.

Yes, (my participation) has increased since taking this job. Prior to my job, I was not doing much. I have been involved in campaigning in the past, but only if asked and that was not every year.

A decrease in participation was reported by two of the informants. One stated that the change in their role had been influenced by the onset of health problems:

(My participation) Decreased, mainly due to my health.

The other informant attributed their pattern of decreased participation to "burn out":

(My participation) Decreased a lot. I just got burnt out. When I started I was doing just about everything, now I am doing mostly diabetes education stuff.

The most common reason documented by the national survey for why people stopped volunteering, was that "they were unable to continue". This generic category used in the "closed item format" in the national survey elicited a wide range of explanations for discontinuing volunteer involvement. Reasons included assuming other responsibilities, "health problems", moving away, and other explanations. The least prevalent reasons for discontinuing participation identified by respondents to the national survey were costs of participation, transportation problems and burnout (Duschesne 1989).

The twelve key informants were asked if they were satisfied with the amount of volunteer time they were contributing to the organization. Nine replied that they were satisfied, and the remaining three replied that they were not. The second part of this question dealt with volunteer willingness to commit more hours. One third of the informants expressed their willingness to commit more time to the activities of the organization, one quarter responded that they would volunteer more work time if their services were requested. Five respondents replied that they were not willing or were

unable to commit more time. The major barrier identified by the informants to making larger time commitments were prior obligations to families and other organizations. One informant expressed a desire to commit more time, but stated that her health status would not allow her to participate more fully. Another informant explained their decreased level of participation in terms of "burnout". In their responses to the national survey as described by Kent, 43% of the sample reported they were willing to give more time on an emergency or temporary basis, 24% indicated that they would commit more time as volunteer participants for the organization, and 23% indicated that they would not give more time. The major barrier identified by the respondents in the national survey were volunteer's commitment to family and other organizations.

D: WHY DO PEOPLE VOLUNTEER?

The aim of this section is to use the informants' narratives to document their motivation to volunteer and their perception of the benefits of volunteer participation. Rogers describes the basis for the phenomenon of voluntary action as a delicate balance of "egoism" and "altruism", for the sense of one's self-reliance and independence and responsibility for one's self and the sense of responsibility for their fellow human being (Rogers 1986). The impetus within an individual to freely give of their time and energy is the focus of the next group of questions which were used to document the incentives or motivations identified by key informants as influencing their participation.

1: NEED FOR A NETWORK FACILITATING INFORMATION SHARING, MUTUAL AID AND SUPPORT

When asked why they initially became involved in volunteering for CDA, one of the most common responses elicited from the informants related to becoming part of a

network which enabled the informant to access information and provide mutual aid and support. The functions of providing information, mutual aid and support complemented the networking activities of individual informants. The focus of contemporary diabetes treatment on self-care and self-management is reflected in informants' narratives. The essential need to know and understand the self-management skills required to effectively manage their diabetes was a central theme associated with volunteers' participation in the organization. Other informants indicated that access to peer support was also a significant motivation.

Several of the informant narratives describe themes of mutual aid, peer support and information. One informant reported:

We joined CDA for the support and mutual aid of being able to talk to other people in the same boat, also to get information on diabetes.

Another informant stated:

It (the CDA) satisfied some of my needs for support and information, that is to share and talk to others who had diabetes.

Another individual related their belief that both information and support functions were a benefit of voluntary participation:

Initially got involved for the information sharing; didn't really think I needed a support group. But once I became involved with CDA, I found the support from belonging, going to the information sessions and workshops.

Other respondents stressed their perception that their voluntary participation in the organization fulfilled their need to be part of a network which provides information or health education.

As one informant stated:

As well, we got involved for the informational aspect of belonging to the association. We were able to help organize and attend some educational sessions that benefitted us as well.

Another informant responded:

It is my personal belief in the concept that people with diabetes need to be educated for better outcomes of health and their diabetes control.

A third informant stated:

I think it is important for people to know and understand what diabetes is all about, that it is a serious disease, to know that it is there and how many people it affects. I can hope to increase the awareness of people about diabetes.

Another theme in the informants' narrative related to the connection with an information network directly linked with the Diabetes Education Program:

One informant answered:

Yes, information and support about our daughter's diabetes. When she was first diagnosed, we got all the education from Irene and Andrea at DES; they spent a lot of time with us going over all the things like giving insulin, testing your blood sugar, eating and all those things. We would phone her up in the evenings and on weekends to for help on adjusting her insulin dose. Now my wife goes back to Irene regularly for more education. It was very helpful to know that Irene was there when we needed her.

It was not only the individuals with diabetes who were the recipients of this mutual aid and support. The responses from the two health professionals also indicated that they also benefited from participating in this network providing information and support. Two of the informants working as health professions stated:

I enjoy the feedback from people. It gives you an idea on what they are thinking, what is going on with them.

I enjoy the networking, finding out how people are doing with their diabetes. Now I enjoy the stories of how different people are handling their diabetes. Everyone has a different perspective on how to manage their diabetes. Some have a real hard time to loose weight and follow

their diet and I like to encourage them. I will talk to them about their diabetes and their difficulties in managing and living with it.

These narratives sustain the assertion in the literature that voluntary participation is reinforced by the benefits of networking and participating in peer groups, rather than rewards associated with participating in the formal organizational structure.

White asserts that:

Voluntary organizations have a high degree of loyalty to the group, and an ability to network that cannot be achieved by governments or private enterprise because of the bureaucratic requirements of official agencies or profit and loss statements (White 1986).

This role of the voluntary organization in providing support and networking for its volunteers is validated by the narratives of key informants who volunteered for the Westman CDA.

2: VOLUNTARISM AND RECIPROCITY: THE NEED TO GIVE BACK TO THE COMMUNITY

Another dominant theme in the informants' description of their initial motivation to participate as a volunteer was that of "giving back to society or the community". Being able to give something back by reciprocating for some perceived benefit or service received from the organization was a dominant motivation among both these key informants and the respondents to national survey. This theme among participants in volunteer organizations asserts that "volunteering is a two-way street" in that the volunteers themselves also gain significant benefits from their volunteer activity. As Ross and Shillington emphasize, "The primary motivation for volunteers is reaching out and helping their community, but in doing this they also fulfil many of their own unmet needs" (Ross and Shillington 1989). The response patterns to this national survey indicated that

volunteers consider their activities to be an important element in their lives. In addition to receiving benefits; such as acquiring new skills, many respondents indicated they had gained from the interaction with other volunteers through self-help groups; which in turn enabled them to resolve some of their own problems. This "win-win" situation, as experienced by both the participant and recipient of volunteer activity, is described by

Allen:

The contributions of voluntary action are most often recognized and framed in terms of the good to the client or the community. Discussions of the returns to the volunteers themselves appear much less frequently within the literature of volunteering. People who work with volunteers or who volunteer themselves will confirm however, that the benefits to the volunteer are at least as great as the benefits to others (Allen 1979).

There were many examples in the key informants' narrative describing these benefits of "giving back to the community". Informants described these benefits of participation:

Personal growth, personal satisfaction that I am giving something back.

Another informant stated:

A sense that you have been a help, to the association through your time devoted to the organization in terms of service. A good feeling, a sense of accomplishment.

Another individual responded:

Information, socialization, a good feeling from doing something good.

Other informants describe their belief that it was their responsibility to give back the

Association. Informants stated:

I believe in volunteering. I have the belief that I must give something back to the community, to CDA, to society, to make a contribution. I have volunteered for various causes, eg. Y.M.C.A. and the United Church as well as CDA. Decided when I retired I wanted to devote more of my volunteer energies to CDA.

To do something to help the community, to give something back.

Well, I think that everyone should have some form of community project or community involvement. To be part of your community.

The feeling of reciprocity and voluntarism was described by one informant:

Because of the help and response that we have got from CDA. We wanted to give something back. We were involved with the Heart and Stroke and Cancer previously, for much the same reason. I have family that have been affected by both these diseases. And we received help and support from these organizations, and then you just want to give something back to them.

Rogers has examined this fundamental belief in mutual support and reciprocity in the Canadian culture. He states that:

There is a delicate balance of 'egoism' and 'altruism' which is the impetus for voluntary action. When individuals ally themselves with each other and bind together to work towards a common cause, in doing so they reduce their own individual dependence, and through their interdependence are then able to work towards autonomy and an environment of mutual support for their community or group (Rogers 1986).

There are countless examples in the literature and in the informants' narratives which suggest that the act of volunteering is motivated by the desire to seek help or comfort by getting together with other volunteers in similar situations. It is through the process of sharing their experiences, hope and strength that volunteers are enabled to reduce their dependency on others, achieve self-reliance and develop the capacity to care for and help each other.

3: A SENSE OF BELONGING

Another reward accruing from volunteer participation is associated with establishing and maintaining social connections. Volunteers perceive that volunteering can offer the participant 'a sense of community'. This 'sense of community'

incorporates a perception of belonging to a group, working toward a common cause, and being accepted as a peer. The broader literature and data from key informants suggests that this sense of belonging is a key benefit. White states that some of the attributes of voluntary organizations derive from the fact that they "represent a degree of visible support for a particular cause and an organized response to perceived needs" (White 1986).

This feeling of belonging and contributing is evident in the responses of the informants. One volunteer stated:

Diabetes is our cause, to raise money for research to find a cure for diabetes, and also to enable those with diabetes to better control their disease and avoid complications.

Another commented:

Its a good cause, volunteering has become a family affair, all of us get involved. To help others, those with complications and with the costs.

Other key informants emphasised their perception that through the contribution to research by organizations such as CDA, a cure for the disease that has so profoundly affected their lives would be found. One key informant stated:

It's my cause; to find a cure for diabetes and to help those who already have diabetes. There's gotta be a better way to improve the lives of people who have diabetes.

4: SELF-ESTEEM: A GOOD FEELING

The literature suggests that voluntary participation gives the individual a sense of belonging and purpose. Because participation is voluntary, the individual feels good about themselves and their contribution to society. White proposes that, due to the spontaneous nature of voluntary participation, it holds significant potential for the promotion of health and development (White 1986). A number of the informant

narratives emphasized the motivation associated with "feeling good" with roles in volunteer participation. For some volunteers, pure altruism may be the primary source of internal motivation and validation. However, for many volunteers the motivation "to help others" may be based consciously or unconsciously on the desire to receive external validation of self-perceptions involving "being a good person". This validation is derived from helping others (Graff 1991). This internal and external validation of helping roles may explain the motivation of volunteers who are reported in the literature as experiencing a "helpers' high". Certainly, anticipation of the positive reinforcement associated with the "helpers' high" may be a significant and valid form of motivation. Stated in its most basic form this interpretation emphasizes:

If helping another helps the helper, then so much the better.

Several of the responses of the informants emphasize the theme of "feeling good" as a primary reward associated with participation. They reported:

A good feeling about doing something for someone else.

A good feeling from volunteering.

A good feeling about doing something for CDA and for other people.

It is apparent from the key informant narratives that helping another person, also helps the helper.

5: PERSONAL EMPOWERMENT

Another theme which emerges from the literature centres on the impact of voluntary participation in the process of personal empowerment. Gaining a sense of personal control over aspects of one's life can be vitally important, particularly for those who may have lost control because of illness or disability (Graff 1989). Only a minimal

body of research has attempted to identify the factors that facilitate personal empowerment and to explain the process whereby people move from varying degrees of dependency and powerlessness to achieve a sense of control and participatory competence. Lord and Farlow, in their study of personal empowerment found that the process of participating itself, was both empowering and self-reinforcing. As people gained in self-confidence, they would seek more avenues for participation; their involvement in community activity would, in turn, enhance their self-confidence and sense of personal control (Lord and Farlow 1990). Lord and Farlow found that volunteering, as one of the forms of participation, appeared to contribute to individual empowerment because it increased social contacts, reduced isolation, and enabled people to take part in meaningful activity (Lord and Farlow 1990).

Two informants articulated themes centered on providing opportunities for empowerment. One stated:

I wanted to make a difference. It is an important thing, the only way to get information out there to others who might have it so that they can be helped. That is what we are put on this earth for, to help one another.

Another commented:

We (my husband and I) felt we had a lot to offer. When we did most of our earlier volunteer work, the Branch was just getting going, there was not yet an office. We felt we could offer the local association something of our organizational skills. As well, we got involved for the informational aspect of belonging to the association. We were able to help organize and attend some educational sessions that benefitted us as well.

These narratives support the interpretation that voluntary participation enables the individual to exert some personal control and regain a sense of personal empowerment which a chronic disease has begun to erode.

6: REWARDS OF SOCIAL PARTICIPATION

The literature describes the process of voluntary participation as a united effort among the members of a group of people working toward a common objective and, through participation, satisfying basic human needs for affiliation and integration. Simply meeting new people, making new social contacts may be a significant motivation and reward for volunteerism.

Key informants of CDA described the motivations in becoming involved in friendship networks. One stated:

There is a satisfaction I got from volunteering. A reward from making new friends, I enjoy people, and meeting new people.

Another stated:

Volunteering is a family affair. When its time to do something for CDA we all do it together and its a family outing.

Another theme in the informants' description of motivating factors focused on social and interpersonal benefits of their volunteer experiences.

One stated:

I benefit from meeting new people and learning from them, talking to them.

Another informant commented:

Interpersonal skills form involvement with all different kinds of people.

A third responded:

Well, I have made a lot of social contacts through CDA.

7: FORMAL PROGRAM BENEFITS

A: Information

Personal rewards of volunteer participation may be differentiated from the benefits associated with formal membership. Informants were therefore asked whether they had received anything back from the organization itself? This question was asked to document informants' perception of the ways in which the CDA as a formal organization impacted on their personal lives. When asked the question: "In the past year, have you benefited from being a member of CDA?", eight of the twelve respondents answered that the information obtained from the educational workshops sponsored by the CDA was a valued formal benefit.

It is evident from the responses of the key informants that the programs and workshops sponsored by CDA were perceived to be a primary benefit of membership by individuals in leadership positions. One informant stated:

Mainly from workshops and informational sessions. I don't feel that we need a support group, but I do like the information sharing.

A second individual stated:

Attending workshops for information and education, get some support there from talking to other people. I receive and read all CDA materials I get such as Banner and the newsletter.

Yes, I read all the pamphlets and journals that they produce, get updated on new developments in research and education, new product development Beta Release, Diabetes Dialogue, attend all the diabetes workshops. I feel the information aspect of CDA is a real benefit.

The educational literature distributed by the association was also perceived to be an important benefit by many of the informants.

Another individual stated:

Participated in informational and educational workshops and received the information material from the organization.

Another individual contrasted the benefits associated with education and training materials in contrast to board participation.

Well, from belonging, yes. I get a lot out of the workshops that they sponsor, education wise I have benefited a lot. And they have excellent reading material which has helped me in the past. But from being on the board, no.

Some descriptions of formal benefits of membership related to informants' description of the complementary roles of their professional and volunteer activities. One informant emphasized that the volunteer experience enhanced her effectiveness as a Diabetes Educator:

Volunteering enables me to mingle with people who have diabetes on a different level, helps to deal with different issues at a volunteer level than you would in the Diabetes Educator-client level. Also, gives a broader perspective on what their education needs are from talking to them and listening; for example, Type II or "borderline" diabetes required special education needs.

Another health professional supported this view:

Yes, (the volunteer role) helps me at work, to do a better job with the clients.

B: Skill Development

The development of skills, knowledge, and expertise through the volunteer experience is a common theme in the literature on volunteer participation (Graff 1991). However, skill development was not perceived to be the primary reward associated with involvement among the key informants. Only three felt that they had developed additional communication, organization or management skills as the result of their volunteer participation. These individuals felt that skill development had occurred primarily from their experience as members of the regional executive committee. The

majority of the other informants felt they had already acquired the required skills prior to volunteering. Among those informants that felt that they had acquired new skills, organizational and management techniques were identified as specific areas by two individuals.

Organizational and management skills from sitting on the executive.

I have learned some organization and management skills from some of the volunteer work.

A third informant identified communication skills:

Probably learning about communication, through being secretary and on the Board.

However, the majority of the respondents indicated that they had not acquired new skills through volunteering for CDA. Most indicated that they already have the needed expertise at the time they joined the organization. One informant responded:

No, I feel I have developed my skills through my job more than CDA. I think it would be the other way around, that is I would be using the skills I have in the volunteer work I do for CDA.

Another informant emphasized prior skills enabling him to participate as a board member:

No, not really. I have attended the Treasurers workshop which were interesting. I do know accounting. And handle a million dollar budget with my work, so I don't feel that I have really learned anything new.

The results of the national survey indicated that the majority of volunteers in the sample acquired additional skills and only 20% reported no skill acquisition (Duschesne 1989). The abilities most commonly acquired by volunteers were interpersonal skills, communication skills, and organizational or managerial skills.

8: EXPECTATIONS OF THE JOB

As with other voluntary organizations, volunteers who are health professionals, including nurses, dietitians and physicians, find themselves often wearing "two hats". They may be one of the health professionals employed at the Diabetes Education Centre as well as participating as a volunteer in the Association's activities. The implications of dual roles as professionals and volunteers was explained by the fact that the professional's job description included the expectation that the professional would also participate as a volunteer. Positions such as Diabetes Educator carried along with them the expectations that the individual would participate fully in the CDA.

One informant stated:

It was an expectation of the job. This would be a different motivation than why I became involved with other organizations, eg. the Alzheimer's Association. When I volunteer for this organization, I feel I am helping at a personal level, that we can share with others some of the things that we went through, and try to help them with their problems. Also, I am more interested in raising research dollars for these other organizations because I have family members who are affected by the disease, where with diabetes I do not have.

Another reiterated the linkage between job expectations and volunteer participation.

As long as I have this job, I will be expected to volunteer, at least in an advisory capacity.

Even though these informants' initial motivation to volunteer may have been less altruistic, one informant also emphasized the need to give "something back" to the organization.

Initially, (I volunteered) because I was asked. Now, (I volunteer) because it was part of my job. But also a reason is that I that I can relate what I m doing to who I am, that is I am someone who has diabetes and this organization is working for me, so maybe I should do something for it. Before I said no.

The complete combination of motivation described by the key informants confirms that the decision to volunteer is a private one and which may combine elements of "egoism" and

"altruism". As Graft has observed, "by far the most critical motivating factors for volunteering is the nature of the work itself and the rewards to the volunteer of that work" (Graff 1991).

E: THE ROLE OF CDA IN THEIR LIVES

To delineate the role of the Canadian Diabetes Association in the Westman area, the respondents were asked to articulate their perceptions of the appropriate role and functions of the organization. It was expected that the respondents would identify common themes because they were current or past board members or long-serving active members and would be familiar with the Association's mission statement and published objectives. Hence, the key informants' definition of the appropriate role of the CDA may have been influenced by their roles as board members and framed within the Association's definition of appropriate roles for volunteers in research, service, education and awareness, and advocacy.

The responses strongly suggested that the key informant's perception of the major role of the association was that of providing education and increasing public awareness. Ten out of twelve informants identified this role as their first response. Nine of the twelve respondents identified support of research as an important role, although it was more often identified as secondary role. The role of providing service was mentioned by five of the respondents, and advocacy was mentioned by four individuals.

1: Providing Education and Increasing Public Awareness

In identifying the role of providing education and increasing public awareness as a fundamental function of the Association, the informants clearly defined the target

audience as being not only the individuals with diabetes, but also health professionals involved with their health care, as well as individuals who had identifiable risk factors.

As one key informant stated:

(The) educational component is paramount. They have built up an excellent organization which distributes a wealth of information to its members and families with diabetes, to health professionals, to doctors. They have set standards of diabetes education and care.

A common element in the informants' narratives was the emphasis on giving a clear message about the seriousness of the disease and its impact upon the lives of those who have diabetes.

As one informant expressed:

Awareness and education regarding diabetes, both for the person with diabetes and the general public to make them more aware of how serious a disease diabetes is and what living with it is like for the person who has it.

Another informant stated:

I think education and public awareness are the major roles. I feel that education of the public and increasing public awareness of the seriousness of diabetes is a very important role. I don't think the public has any idea about what it is like having diabetes. Some of the public awareness things that CDA sponsors are good for that, like the Celebrities having diabetes for a day. That is helpful for promoting public awareness.

A third respondent reiterated this theme:

I think making the public aware of diabetes and that it is a serious disease and that it must be taken care of. You know, to test your blood sugar, and to eat properly and get your exercise.

Another respondent emphasized:

Information to the public about diabetes, increasing the awareness of diabetes as a serious disease.

And, it was at least the opinion of one informant that the Association was attempting to provide this function:

(The association is) willing to provide education to the lay public and health professionals as well as those with diabetes. This is a very important function, and one which no one else does to the extent that CDA does. At a local level, CDA is willing to sponsor educational workshops, however, the response is both hot and cold, with some sessions very poorly attended.

A related theme expressed in the informants' narratives was belief that the Association should place more emphasis on prevention in its public awareness campaign rather than cure or control of disease:

To promote diabetes awareness of the disease and its complications, that anyone can get it. There should be more on prevention. They (CDA) say that they have a role in prevention, they should prove it. They say that type II can be prevented, they should be looking at the family members of those with diabetes who are "at risk" and focus on preventing diabetes from happening to them.

Another informant stated:

There should be more on prevention of type II. So much of the stuff is aimed at Type I's, and we know that they make up only about 10% of the diabetic population. They certainly do not make up the majority of the volunteers for CDA, do you think?

This more formal role of the association in providing education and heightening public awareness is an aspect of the function referred to in the literature on voluntary participation as social innovation. One role of voluntary organizations is to encourage new social ideas and experiments from which governments, business and private institutions can select and institutionalize program elements fitting their own agendas (Smith 1973). Ross and Shillington suggest that it has often been the role of voluntary action to discover and articulate the unmet needs of the community and then organize the services to meet these needs. Often, after a period of time, and following diffusion of the innovation to a broader range of consumers, the government then appropriately steps in to take responsibility for delivering the service (Ross and Shillington 1989). This

broader context of social innovation may involve organizations in mobilizing educational campaigns to increase awareness among both the general public and professionals. Mobilization messages emphasize the seriousness of the disease and describe primary preventive strategies for controlling Type II diabetes. At the present time (1995), broad new health promotion initiatives directed at prevention of Type II diabetes have not been adopted and implemented by Manitoba Health.

2: The Informants' Perception of the Role of the Organization in Supporting Research

The work of the CDA in supporting research was one of the other important roles identified by the twelve key informants. Like other voluntary organizations focusing on chronic conditions, such as the Heart and Stroke Foundation, scientific review and coordination of research is centered at the national level in the Canadian Diabetes Association. It is evident from the informants' narratives that they perceived the legitimate role of the Association at the local level to be to raise funds to support the national research initiative.

One informant stated:

Also, research to find a cure, or rather fundraising to support the research to find a cure is an ongoing role.

As one informant described the role of local volunteers in supporting research:

Fundraising, primarily for research, not only for a cure, but also to help those people with diabetes to cope, and to avoid complications.

Another informant articulated the value of research sponsorship:

Research, to find a cure for those who don't have diabetes yet, and to improve life for those who do have diabetes, ie. preventing complications, the psychosocial aspects of living with diabetes.

Even though some of the individuals interviewed acknowledged that they knew very little about the details of the research being funded, they maintained their support of this role of the organization.

Research is important, it (a cure for diabetes) will not be in my lifetime. They have not come up with anything yet and they have been working a long time at it.

3: Provision of Service to the Membership

Historically, voluntary associations have had a significant influence on the provision of various services such as health care, preventative health activities and rehabilitation. The Canadian Diabetes Association has held as one of its primary organizational mandates the provision of services to its membership and to the wider community. The CDA delivers services in four primary areas: education, social support, economic support and support for supplemental health services. However, it must be recognized that the association is not a direct provider of health services and provides only indirect support for health services delivered by other providers. A CDA policy has been established to assist volunteers in defining the boundaries regulating their involvement in direct provision of health services. The indirect service role of the organization has involved sponsoring summer camps for children with diabetes and establishing public shopping outlets which provide diabetes care materials. The service that was most frequently identified in the narratives of the key informants, is that of providing diabetes self-care and self-management information to individuals with diabetes, their families and to the health professionals who treat them.

Self-management information is most commonly disseminated in the form of written publications which are provided without charge to anyone who is diagnosed with

diabetes. As well, various workshops, conferences and seminars are sponsored by the CDA. These forums provide current information both to individuals with diabetes and to health professionals. In describing the services perceived by the informants as important, one of the informants reported:

Providing the informational materials is important, regular mailouts of newsletters, "Diabetes Dialogue" and so on.

Another informant responds:

Another positive is that CDA does have good literature available to people with diabetes. And it is good literature in that it is accurate and helpful in giving information about diabetes.

The informants' narratives illustrate their perception that the provision of informational materials as one of the strengths of the association. As one informant put it:

(CDA) is a caring organization which is concerned about the people in it, it cares about those with the condition of diabetes, their families and those at risk and makes an effort to give a service to the people.

Another informant stated:

(The association's) strengths are the information available from CDA, ie. the pamphlets and information booklets, the educational workshops, I don't know much about the research that is going on.

4: Advocacy

The role of the CDA in advocacy was identified by only four of the twelve key informants. This function of advocacy is a relatively new one for CDA, formalized with the establishment of the National Advocacy Council in 1989. In performing advocacy functions the CDA has had to address a number of key issues such as employment discrimination, barriers in motor vehicle licensing, the development of guidelines for granting life and mortgage insurance, and establishing an equitable system of reimbursement by provincial health care programs for the costs of insulin and other self-

administered supplies. Interestingly, none of these areas of CDA involvement were perceived by the key informants as reflecting the involvement of organization in advocacy. The two key informants who identified advocacy as a major role for the CDA, described the function as lobbying the government to ensure that any potential cuts of health services which would not effect the individual with diabetes.

One of the informants stated:

Advocacy to support some of the health reform issues is another important role that CDA will have to look at. The threat to some of the health programs such as diabetes education must be a concern of the association. They have done much work to put in place the mechanism for the production and distribution of many diabetes education pamphlets, journals, expert committees, position papers, educational workshops and so on to support the government funded diabetes education facilities. I will become necessary for the organization to become proactive in presenting the reality of the necessity of the maintenance of the diabetes education centres and to advocate for their survival during the "restructuring" or "realigning of health care dollars".

Another informant asserted:

Also advocacy. Now with the Health reform going on, advocacy will take on increasing importance.

The minimal emphasis placed on advocacy functions of the CDA may reflect the perception that, although an advocacy role was identified by the National organization, local leaders and workers were not sure how this role would be implemented at a local or regional level.

One informant articulated this perspective:

Advocacy, but not at a local level other than to refer to Provincial Committees.

Another response was critical of the association's role in advocacy:

I don't believe that CDA is totally effective and active in advocacy.

Another informant offered a personal opinion:

Advocacy, I have no thoughts for myself. I have never felt that I needed anyone to advocate for me or my rights. I suppose that some people would, those in the workforce who are being discriminated against. But I feel there are more important things for people.

5: Social Integration

Other themes emerged from the interviews referred to other less formal roles, not officially mandated by the association. However, these roles were perceived to be meaningful by the informants. For example, the voluntary sector, and voluntary work itself often provides members with opportunities for social integration, helping volunteers to fulfil the needs for affiliation, integration with a caring community. The act of volunteering itself involves people acting together in pursuing a common objective within their group or community.

The narrative of some of the key informants refers to this feeling of community and caring:

Its strengths are the people in it. I think the people volunteering for CDA are very caring and committed.

On the negative side, there has not been a clear message to people that you don't have to have diabetes to be part of the organization or to become a volunteer. There seems to be that stigma attached to belonging to CDA and I feel that the organization may be losing some of its potential members because they don't want to be seen as a "diabetic".

6: The Role of the Organization as a Countervailing Force to Centralized Control of Services by Government

Voluntary organizations function uniquely as the defender of those programs and services which are in place for the benefit of the targeted population, in this case, individuals with diabetes and their families. In the current era of "health reform" involving policy initiatives directed at "realigning health care dollars", programs such the Diabetes Education Services and the Diabetes Education Resource are perceived by both

the staff and volunteers to be threatened by budget cuts. The key informants' statements about roles in advocacy imply that the Association's role should be to identify the areas such as threatened cuts in public funding of the Diabetes Education Services and to develop a plan of action to defend these programs.

7: Limitations of Volunteerism

The actual experience of volunteers did involve a negative dimension. Informants expressed perception that some volunteers were being inappropriately utilized.

As one informant explained:

On the weakness side though; there is a lack of volunteers within the organization. There are the same people doing most of the volunteer work or there are some volunteers doing inappropriate volunteer activity, like getting a health professional to sit at a booth selling tickets or something. This limited pool of volunteers makes it difficult for other volunteers. I feel I would rather be used as a resource person than for some of the fundraising activities.

An interesting remark by one informant focused the limitations of a patient-member organization in fundraising activities.

Volunteer dollars are needed locally. CDA depends on its membership for fundraising, and this membership came about because they or their families had diabetes, rather than their interests and abilities for fundraising. If you look at the other organizations who are very successful at fund raising, such as the Lions Club, their members are local business people, whose interests and abilities are more suited to fundraising.

Another informant saw the need for the association to give something back to its volunteers for their fundraising efforts.

CDA needs to become more professional. CDA has got to give something back to the people in its fundraising events. For example, the MS Walkathon was a great success. It was very well organized, had great participation and the participants got lots of stuff from being involved. That way you feel like doing it again.

Yet another critique involved the perception that the CDA did not use volunteers effectively in fundraising activities.

Fundraising is not always a success, when compared to other organizations who are very successful at fundraising locally, for example MS. and Heart and Stroke. These have very successful functions. CDA needs to assess their fundraising approach.

These perceptions of the negative dimensions of fundraising as a volunteer activity suggests that a significant barrier is the diminished personal satisfaction associated with voluntary participation among the volunteers within this association.

CONCLUSION

This thesis has attempted to present an overview of voluntary activity among Canadian Diabetes Association volunteers in the Westman Region through examining key informants' description of motivations, barriers and changing roles in their experience. It is clear that the contributions of volunteers are significant in terms of both the volume and scope of volunteer activity. These twelve key informants alone contributed an average of 87 hours per year or the equivalent of a 0.7 full time staff position to the activities of the Westman association. These activities encompassed functions of fundraising, participation in boards and committees, supervising and coordination of events and providing information about diabetes. However, an important theme highlighted by the key informants was the perception that the majority of the volunteers were not satisfied with the experience in fundraising. Most identified alternative activities include counselling or advising, involvement with support groups and giving information to heighten public awareness as areas of involvement in which they would like to be more heavily involved.

The Canadian Diabetes Association is an organization with the majority of its membership sharing the experience of having diabetes or having a family member with diabetes. The responses of the key informants suggest that motivations for volunteering to work in CDA activity vary from individual to individual and are influenced by a variety of personal and organizational facts. The motivations which were cited most frequently by the key informants were a need for a information network, mutual aid and support, a need to give back to the community, a sense of belonging, and a good feeling. Less dominant incentives were described in informants' references to a feeling of empowerment and receiving the rewards of socializing, information and skill development.

Finally, the essential roles of the organization, as perceived by the twelve informants, were those of education, increasing public awareness of diabetes, and providing support for research. Additional roles identified by key informants include the provision of indirect health services to individuals with diabetes, advocacy to maintain the existing direct health services and the provision of a countervailing force to changing government policies that might place individuals with diabetes at a disadvantage.

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