

Nova Scotia

PWA Coalition

HOLDING OUR OWN

**An Assessment of the Needs of Persons
Living with HIV in Nova Scotia**

A project funded by

**Health and Welfare Canada
Health Promotion Directorate
AIDS Community Action Program**

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Summary

The following is a report of a Needs Assessment Study of persons living with HIV infection (PLWHIV) in Nova Scotia. The findings suggest that the individual support needs of PLWHIV are at a minimum being met and that more emphasis needs to be placed on community education and advocacy as it relates to improvement of the lives of those who are HIV infected.

The study was undertaken by the Nova Scotia Persons With AIDS Coalition. The results and the discussion thereof is relevant to the needs of a group of forty-one such persons, the majority of whom live in the Halifax-Dartmouth Metropolitan area. While this group is not necessarily statistically representative of the 198 persons who are known to be currently living with HIV infection in Nova Scotia¹ the report provides some insights into the situation of this population.²

The study involved the distribution of comprehensive questionnaires as well as personal interviews. Although PLWHIV were the main source of data, also included in the study is information on the needs of persons living with HIV infection from the perspective of a number of professional care givers who are known to have clients who are HIV+ .

The dilemma for organizations which are attempting to meet the needs of persons living with HIV infection (PLWHIV) like the Coalition is that the scope of the disease is too large in magnitude to be dealt with without an wholistic approach to support. HIV

(ii)

¹ The Nova Scotia Department of Health and Fitness reports that as of May 30, 1990, 230 persons have been tested HIV+ in Nova Scotia or have reported such test results in the Province to a medical doctor. Of these, 62 persons have been determined to have AIDS. Thirty two of the 230 persons had died as of this date.

² See Part 1, Section C "Interpreting the Findings" for a discussion of the group relative to the entire population of persons living with HIV infection.

infection creates a broad spectrum of needs to investigate: physical, emotional, social and political.

The majority of persons living with HIV infection responding view AIDS as a "manageable" illness. By and large these individuals have a positive sense of well being, strong personal support networks in which partners, family members, close friends, and counselling and health care professionals play a prominent role.

While most respondents attend to their health through good eating habits, exercise and vitamin supplements, few have experimented with complimentary approaches involving special diets or therapies such as accupuncture. Interest in knowing more about these others approaches is high and this interest increases with the occurrence of AIDS symptomatic infections.

HIV diagnosis has not led many members of this group to feel sexually inadequate or unattractive, nor has it led to a large number of them to be sexually "inactive". Sexual activity is however most often experienced in the context of relationships which always adhere to safer sex practices.

The majority of respondents consider themselves "spiritual" rather than "religious" and few in either category have had their beliefs shaken by their HIV diagnosis.

The majority of persons surveyed have not experienced HIV related-discrimination although almost all of them, as well as the professional caregivers, believe that such discrimination is a major problem. The study suggests that AIDS remains a topic that PLWHIV feel is not safe to talk about in most situations and this is reflected in a strong preference for relatively anomonus forms of assistance.

In terms of their information needs, respondents indicated that they were most interested in medical treatments, nutritional alternatives, complimentary therapies and legal issues and resources.

More PLWHIV than caregivers ranked public advocacy as the most important work of the Coalition. This was followed in importance by emotional and practical support. Advocacy for most includes public education directed towards improving the lives of PLWHIV (as compared to stopping the spread of AIDS).

The study confirms the importance of providing many reasons for people to come together. Personal support cannot and should not be seen as separate "programs" of the Coalition. Efforts to empower PLWHIV must be rooted in real and immediate needs. The Coalition must continue to accommodate a wide spectrum of involvements and maintain a structure that is sensitive and flexible.

There is a need for greater recognition of the fact that the needs of those who are HIV infected cannot be separated from the needs that result from life experience and situation. The fact that most PLWHIV are gay, for example, must be more explicitly reflected in the Coalition's efforts to provide support and advocacy. While making these links carries with it certain risks, such factors are often the more significant ones in terms of peoples' ability to live happy and meaningful lives.

The study makes several specific recommendations. These include a more concerted effort to make the Coalition's presence felt outside the Halifax-Dartmouth Metropolitan area.

This report does not represent an end to the process of investigating and reflecting on the experience and needs of PLWHIV. It will, it is hoped, spark discussion and action that will assist the Coalition develop a greater understanding of the struggle which so engages us.

Preface

A Needs Assessment study was undertaken to determine the education, support and advocacy needs of persons living with HIV infection (PLWHIV) in the province of Nova Scotia. The study was funded by the Nova Scotia Persons With AIDS Coalition which is supported by the AIDS Community Action Program of the Health Promotion Directorate of Health and Welfare Canada. It was conducted in collaboration with the Community Development and Outreach Unit of Dalhousie University's Henson College of Public Affairs and Continuing Education.

The design and organization of the research, the analysis of the results and the preparation of the report, was undertaken by Robert Allan, Michelle LeBlanc, and Michael McDonald, in collaboration with Grant MacDonald of Henson College. Michael O'Sullivan of Henson College also provided valuable assistance with respect to questionnaire design and analysis. Julie Martin carried out the data entry and J.J. Lyon provided office support. **The study is dedicated to the memory of Raymond, Lawrence and Hazen who made a vital contribution to the project but were not able to see it through to the end.** Thanks is expressed to the PLWHIV, their caregivers and the institutions and organizations who participated in the study.

A Note on Terminology

This report uses the term **"persons living with HIV"** and its abbreviation, **PLWHIV**, to represent all persons who know that they are HIV infected, including persons with AIDS. This term, which is one increasingly being used, was chosen because of its emphasis on "living" and because HIV infection spans a broad spectrum of situations from those who are HIV+ but a-symptomatic to those who are experiencing opportunistic infections. It is hoped that no one will be offended by the use of this term in its abbreviated form, PLWHIV. The term **PWA** is also used here to designate those HIV+ persons who have developed AIDS.

Halifax, December 1990

Part 1: Introduction

A. Rationale and Purpose of the Study

AIDS represents a global challenge to individuals, groups, and communities.¹ Yet, having realized this challenge for some time, researchers have reported little on the spectrum of needs of persons who are HIV+.² Instead, the literature on AIDS has dwelt on issues involving biomedical research, epidemiology, preventive education and testing procedures.³ This information is extremely valuable to help understand the disease and its transmission, prevent its spread, and find a cure.

In the absence of an effective remedy, however, it is also important to address the needs of those persons living with HIV infection. Community-based organizations have emerged to fill this void in an attempt to improve the quality of life for persons who live daily with HIV infection including its physical, emotional, social and political dimensions⁴. They have tried to do so without the benefit of systematically collected and detailed information about the needs of their constituency.

In Nova Scotia at present there are three community-based organizations (Church Members Assembled to Respond to AIDS, the Metro Area Committee on AIDS, and the Nova Scotia PWA Coalition) which exist to assist PLWHIV. Although a wide array of services are currently being offered by these groups and by other agencies, no formal effort has been undertaken to determine the actual needs and

¹ Berlinguet, M. "AIDS: A Challenge For Social Workers" The Social Worker, 57 (1), 1989.

² Mail, P.D. and Matheny S.C., "Social Services for People with AIDS: Needs and Approaches" Current Science Ltd, 3, 1989, S273-S277.

³ Benjamin, A. E. "Perspectives on a Continuum of Care For Persons with HIV+ Illness, Atlantic Information Services, 1-13, 1990.

⁴ McGuire, J.F. "AIDS: A Community-based Response" Current Science Ltd, 3 (1), 1989, S279-S282.

wants of this constituency. It was in this context that the N.S. Persons With AIDS Coalition decided to conduct a province-wide assessment of the needs of persons living with HIV infection.

It was hoped that the investigation would enable the Coalition to:

1. Find out if services needed by PLWHIV are being provided.
2. Better set priorities in planning programs
3. Better address the concerns of care givers with respect to the needs of PLWHIV.
4. Provide background and support for presentations to funding and policy-making bodies.

Given these goals and the time and resources available it was decided that the needs assessment would employ elements of both an **action research** model and a **participatory research** model⁵. Action research implies an investigation, **the result** of which is knowledge that can benefit the people "being researched", while participatory research implies an investigation where **the process** fully involves and is directed by those "being researched" in a way that increases their capacity to inquire into and change their situation.

The following pages constitute a report on a needs assessment research project. It includes, in this section, an overview of the research process, the methodologies chosen, the conduct of the research and the methods of analysis and interpretation of the findings. A discussion of some of the major issues confronted in the process, such as confidentiality, is included here.

⁵ For the theoretical distinctions between action and participatory research see, for example, L.David Brown and Rajesh Tandon "Ideology and Political Economy in Inquiry: Action Research and Participatory Research" in Journal of Applied Behavioural Science, Vol.19, No.3, 1983, pps 277-294.

The second section of the report is a summary of the findings of the needs assessment. It is divided into six sections which outline the demographic and HIV-related features of those who responded, the personal resources of this group (financial, housing, legal, etc), their interest in complimentary therapies, their state of well-being (self-esteem, sexuality, spirituality, social acceptance, etc), their information needs and their interest in AIDS activism and advocacy.

The third and last section of the report considers the implications of the research in terms of the role of the Coalition and the shape of its programs. This section also includes some thoughts on the research results and the need for further investigation.

B. Methodology

The project was initiated with the idea that what was required was a systematic process which would find out the needs of PLWHIV in Nova Scotia, how many people are experiencing these needs, why some of these needs exist and what some possible ways to address these needs might be. At the outset an effort was made to establish some goals and objectives for such an undertaking, to determine how information would be used and who would use it, to select the areas of need to be studied, to decide how this information would be collected and confidentiality would be maintained⁶.

⁶ Resource materials on needs assessment research were examined early in the process. Most helpful in the course of the project were Doing It Right: A Needs Assessment Workbook, published by the Edmonton Social Planning Council and the United Way, 1988 ; D. S. Abbey and D Abbey-Livingstone Enjoying Research: A How-to Manual on Needs Assessment, (Toronto: Government of Ontario, 1982) and C. Woodward and L Chambers Guide to Questionnaire Construction and Question Writing, Hamilton: Canadian Public Health Association, n.d.)

1. Whose Needs?

It was agreed that first and foremost it was the needs of PLWHIV that should be assessed. This was to include all persons, who, by virtue of being diagnosed HIV+, are the primary constituency of the Coalition. There was also discussion regarding the desire to determine the needs of those who provide care for these persons including lovers, family members, friends and health care professionals.

For both practical and conceptual reasons it was decided to limit the investigation to the needs of PLWHIV from their own perspective as well as to seek information on their needs as perceived by professional care givers.

2. What Information?

It was decided that the kinds of information that should be collected should include:

1. Demographic information on the population, including some baseline data regarding HIV diagnosis or status.
2. Support needs information including practical, emotional, psycho/social, spiritual, health (alternative therapies) and financial needs
3. Advocacy needs information including views regarding the role of government and community-based organizations
4. Education and information dissemination needs including views on most effective formats

3. Where can this information be found?

Although government information puts the number of HIV infected persons presently living in Nova Scotia at about 200 there was no easy way of reaching them. While the Nova Scotia Department of Health and Fitness maintains a list of such persons by Health Unit and MSI number this information is, by law, not available. This means that there is no accessible statistics on the age, geographical distribution or other characteristics of this population. Most are not known to the community-based organizations concerned with assisting PLWHIV. It was also recognized that the majority of these persons do not wish to be known and that any approach to research would have to pose no threat to their anonymity.

Because there was no means of selecting randomly from the HIV/PWA population, **there was no way of assessing the needs of a representative sample.** Furthermore it was thought unlikely that all PLWHIV in Nova Scotia might be reached as a complete "census" would demand. For this reason, it was decided that the Needs Assessment should attempt to reach as many PLWHIV as possible in the hope that information would be gathered on a group that would be larger than the number of PLWHIV who are already "out" and/or involved in one or more of the community based support organizations. In terms of numbers, the goal was to reach and get results back from 75 PLWHIV as such information would substantially add to the Coalition's knowledge of it's constituency even though little could be assumed about the representativeness⁷ of this information.

4. How Can It Be Collected?

It was decided, given the importance of anonymity within the PLWHIV population, to employ questionnaires as the principal

⁷ Representativeness is taken to mean the extent to which the information collected can be said reflect, or to hold true for, the entire PLWHIV population in Nova Scotia.

research method and that the information gained through questionnaires would be supplemented by interviews with ten to fifteen PLWHIV whose makeup as a group reflected a cross section of some of the important characteristics we might look for in the PLWHIV population. These characteristics would include HIV status (HIV+/PWA), recently diagnosed HIV+ persons, as well as those with advanced AIDS, and those of different ages, genders, socio-economic status, and community involvement.

It was determined that one way of making contact with PLWHIV would be through their professional care givers, most particularly medical personnel, social workers and community workers who specialize in the treatment or care of PLWHIV or whose case load is known to include a number of PLWHIV. It was decided that these persons would be consulted about serving as intermediaries, that is, they would be asked to distribute questionnaires to their clients.

The construction of the written questionnaire and the interview guide was preceded by a literature search. The literature search involved selected journals, books and articles which were read to determine what past studies have found with respect to the needs of PLWHIV. Some of the literature on the needs of persons living with cancer was also examined in the hope that this might provide some basis of comparison⁸. This search failed to provide a picture of the full spectrum of needs that HIV infection in its various stages may present. For example the article "AIDS: The Community-based Response" by Nils Clausson, gives details of what services are provided by community-based groups which is not necessarily a reflection of needs.⁹

A paper by Leetha Fraulino and Joyce Simpson entitled "The AIDS Epidemic: Developing an Institutional Response", focuses mostly on institutional and professional needs.¹⁰ A more useful example is

⁸ Some of the more relevant sources are listed in the bibliography.

⁹ Canadian Journal of Public Health Supplement 1, Vol. 80, May/June 1989, pp 518-520.

Nancy Lovejoy and Theresa Moran's piece "Selected AIDS Beliefs, Behaviours and Informational Needs of Homosexual/Bisexual Men with AIDS or ARC"¹¹ However, it is limited to an examination of what respondents know about AIDS, not what they would like to know.

While some of the research acknowledges the educational, emotional, social and practical needs of PLWHIV, few provide much detail and even fewer consider a wide spectrum of needs.

The concern for maintaining anonymity was a vital one and expressed itself in both the distribution and return of the questionnaire as well as in its design. The questionnaires were, by and large, distributed to PLWHIV through health care professionals. All questionnaires were returned by mail in stamped, self addressed envelopes. Researchers also took care not to include that questions which solicited answers that might be identified with particular individuals and instructions included with the questionnaires stressed that respondents need not answer all questions.

(a) Questionnaire Design and Distribution

Beginning in January 1990, the questionnaire took shape through a series of eight meetings which produced 6 increasingly developed drafts. Some PLWHIV outside of the project team were consulted with respect to certain sections. The resulting final draft questionnaire consisted of 95 questions containing 292 possible responses or "variables". Only a handful of questions asked directly about "needs". Most addressed themselves to the situation, behaviours and beliefs of individuals. The questionnaire was divided into seven sections relating generally to the following subject areas:

- a. AIDS/HIV+ diagnosis: stage of disease, where diagnosed, mode of transmission, who knows of diagnosis.

¹⁰ Seminars in Perinatology, Vol.13, No.1, February 1989, pp 44-48.

¹¹ Source unknown, 1988-89.

b. Demographic information: age, sex, place of residence, education, income, sexual orientation, who knows of sexual orientation, etc.

c. Living with HIV: support system, reliance on others, living arrangements, legal services, interest in complimentary therapies, financial needs.

d. Well-being: self description, counselling interests, sexual life, social reaction to HIV diagnosis, sources of community support.

e. Spiritual and religious needs.

f. Attitudes with respect to AIDS as a societal or public policy issue.

g. Information interests and role of community-based organizations.

In mid-March the draft version of the questionnaire was tested with 14 PLWHIV (9 HIV+ and 5 PWA). A few changes were made on the basis of their experience with the questions. Rather than asking them to complete the final questionnaire, their responses were incorporated into the main body of responses with only minor alterations in coding.

Following some consultation with co-operating professionals regarding the number of questionnaires each might need, 168 questionnaires were distributed the week of March 26, 1990. The goal was to have 75 returned to the Coalition by the due date, May 31st. This date was extended to June 15th because of the difficulty some professionals had in reaching a large number of PLWHIV in this restricted period.

An additional questionnaire, based on, but shorter than the principle questionnaire, was constructed for a "caregivers" group

consisting of 14 persons, made up predominantly of professionals involved in AIDS work as well as several "non professional" but "significantly involved" persons. This was distributed directly to these persons and at the same time as the main questionnaire.

Of the 168 main questionnaires given to those serving as intermediaries, 106 were returned undistributed. This meant that sixty two reached PLWHIV. Of these, twenty-seven were completed and returned by mail to the Coalition. This represents a response rate of 44%. These, when added to the completed pilot questionnaires, resulted in responses from 41 PLWHIV. Eight of the fourteen "caregiver" questionnaires were also returned completed.

The use of professionals as intermediaries in the distribution of the questionnaires had a number of drawbacks, some foreseen, some not. It was expected, for example, that in the two month period in which the questionnaires were in distribution, not all PLWHIV would find themselves needing professional assistance. It was also recognized that not every situation where a questionnaire could be given out would be conducive to doing so. Staff at the Infectious Disease Clinic at the Victoria General Hospital, a potential major vehicle for the distribution of questionnaires, was only able to distribute 5 of the sixty questionnaires they were given.

One of the factors not foreseen was the arrival on the scene of a competing needs assessment questionnaire from the Federal Centre for AIDS to be similarly distributed. That questionnaire was in the hands of Clinic staff two weeks before the NSPWAC questionnaire and almost certainly made its distribution somewhat more problematic.

(b) Interviews

Too often the expression of rich information is inhibited in questionnaires which have a majority of close-ended type questions. To address this concern a decision was made to conduct a number of structured interviews as an adjunct to the questionnaire.

Not as much attention was paid to the design of the interview questions and interviewing process as there should have been and as a result there was a lot of overlap and duplication of questions from the questionnaires. Furthermore the interviews provided more of an opportunity for respondents to indicate what they thought about the needs of PLWHIV in general than a chance to talk freely about their own situation.

Twenty-five interviews were conducted by 3 interviewers. The interviewers followed a set interview format to limit the amount that respondents were influenced by the interviewer's prompting. Fourteen PLWHIV and 11 professionals and care givers participated in this part of the study.¹² The purpose of interviewing the professionals was to obtain information that could be used to compare the needs of PLWHIV as perceived by others and the actual needs as stated by PLWHIV. All the care givers interviewed dealt with PLWHIV in some significant capacity.

The interviews with professional caregivers solicited some information relevant to medical, public health and education issues which is not reported here¹³.

C. Interpreting the Findings

The data from the questionnaires and interviews was analysed using the following approaches:

1. The main PLWHIV questionnaires were coded and the data from the 292 variables was entered into a raw data file set up on an office PC. The raw data file was then transferred to a VAX mainframe computer at Dalhousie University and using SPSSX software was summarized on a question by question basis.

¹² These persons were the same as those who completed the main questionnaire in its test form. Eight of the fourteen PLWHIV interviewed were Coalition Board members.

¹³ This information is available, in summary form, from the Coalition.

2. Notes taken in interviews with PLWHIV were transferred, in summary form, to a single document.

3. Notes taken in interviews with "caregivers" were similarly summarized.

4. The "caregiver" questionnaire results were summarized in textual form rather than being coded for numerical analysis.

5. The numerical results from the main PLWHIV questionnaire were examined on a question by question basis and discussed.

6. Using a list of about ten key variables a number of simple cross-tabulations of the main questionnaire data were made. These key variables included: HIV status, education, income, sexual orientation, length of diagnosis and age. In some cases the number of variables were collapsed to reduce the categories so that the numbers would be somewhat larger in each.

7. Based on question-by-question responses and cross tabulations, a summary, explanation and analysis of the main questionnaire results was written. Information from both sets of interviews and the caregivers questionnaire was referred to with respect to each area of need or issue where it supported or contradicted other evidence.

The final report went through four complete drafts each of which was discussed and edited collectively. Much of the study team members' own analysis and thoughts concerning the information are not reflected in the final report as it's purpose is to promote further discussion of the issues raised not to preempt or constrain it.

Part 2: Needs Assessment Findings

A. The HIV/PWA Population

Since 1981 when doctors first identified a disease that was affecting the immune systems of many gay men, the terminology and jargon used has under gone many changes. Terms such as GRID (gay related immunodeficiency, 1981), HTLV (human T-cell lymphotropic virus, 1984), and ARC (AIDS related complex, 1982) have been used in the past.¹⁴ At present, the term AIDS (acquired immunodeficiency virus) is used and recognized as a spectrum illness¹⁵ More often, however, doctors are refering to HIV infection as the disease rather than AIDS which is at the end of the spectrum and the extreme of HIV infection.

In Canada there are approximately 1, 639 persons who are living with AIDS and approximately 50,000 are thought to have the HIV virus¹⁶. In Nova Scotia, there are 62 reported cases of AIDS amongst the 230 reported cases of HIV infection¹⁷. These figures, however, are believed to be much lower than the actual population of HIV infected persons. There have been widely-quoted estimates of 75,000 to 100,000 HIV infected Canadians and 3,000 to 5,000 Nova Scotians. At best these estimates are speculative¹⁸. There is no reliable information on the number of persons infected.

¹⁴ Crimp, D. (ed) AIDS: Cultural Analysis, Cultural Activism, Cambridge: The MIT Press, 1988

¹⁵ Province of Ontario, Minister of Education, Education About AIDS, 1987

¹⁶ Personal communication, The Federal Center for AIDS, May 1990

¹⁷ N. S. Department of Health and Fitness, AIDS in Nova Scotia, May 1990.

¹⁸ Godin, R. "CARAS Experiences Both Success, Sorrow", Mail Star, Halifax, April 1990

In Nova Scotia people are inhibited from being tested because of the informing procedures and the inefficient method of government documenting cases. The Nova Scotia Task Force on AIDS reports that 58% of Nova Scotians are not confident that breach of trust would not occur if he or she tested positive¹⁹. This implies that people are not likely to come forward to be tested. The statistics are further made inaccurate by the procedure of documenting cases only in the province in which you were diagnosed. This means that if someone had been diagnosed as either HIV+ or PWA in another province but is living in N.S. the statistic is calculated in the former province. Not knowing how many persons are infected and government's lack of action makes providing services to those in need exceedingly difficult.

1. HIV Status

Forty-one (41) persons responded to the written questionnaire survey of whom 14 were also interviewed. Of this total number 15 identified themselves as PWAs and 24 as HIV+. Two persons did not respond to the question of their HIV status. The mode of transmission of the HI virus was sexual transmission in 39 of the 41 cases.

The following charts show how the survey population compares to the total population of PLWHIV in Nova Scotia in terms of HIV status.

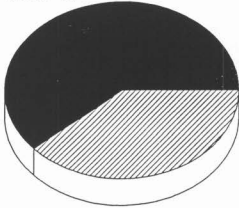
Of the twenty four HIV+ persons, 11 report that they are HIV "symptomatic". Of the fifteen PWAs, 16 have experienced thrush or candida, 12 - swollen lymph nodes, 11- night sweats, 9 - weight loss, 8 - diaharrea, and 7 PCP. Three reported Cytomegalovirus and one Kaposi's Sarcoma.

¹⁹ O'Connell, P. "Government Rejects Anonymous Testing", Mall Star, Halifax, October, 1988

HIV Status

HIV+ and PWA Populations
PWA Needs Assessment Survey

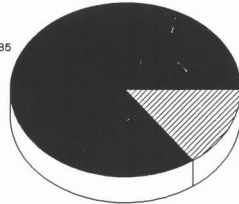
HIV+ Percent = 59



AIDS Percent = 37

HIV+ and PWA Populations
N.S. Department of Health and Fitness
(Presently Living with HIV, May 30 1990)

HIV+ Percent = 85



AIDS Percent = 15

Of the forty one persons, over 60% of those who responded were diagnosed HIV+ from 1987 to 1989. The earliest diagnosed case, of which there is only one, was in 1984. Thirty-two of those responding (78%) were first diagnosed in N.S. with the remainder being diagnosed elsewhere in Canada.

Of those responding, 44 % have shared the fact of their diagnosis with "all members of their immediate family", 39 % with "all close friends" and 17% with "co-workers" and 17% with their "employer". Where people are more restrictive about sharing the fact of their diagnosis, a few close friends are more likely to be confided in than family members.

2. Demographics

It was felt that it was important to find out some basic demographic information about the PLWHIV population. This would

provide some useful insights into the complex problems faced by them. Characteristics such as: age, sex, level of education, race, first spoken language, principle place of residence and income level all may have a bearing on the design of support programs.

The age levels of this group are relatively evenly distributed between 20 and 49 years. Two persons indicated that their age fell into the 50-59 year old category. No members of the group who responded were less than 20 years of age or more than 59 years of age.

Thirty-nine of those responding were men and two were women. Thirty-eight indicated their race as white, one indicated he/she was black and two did not respond.

Thirty-four of persons responding reside in the Halifax-Dartmouth Metropolitan area and only three persons indicated that they resided outside of Halifax County area. Significantly, none of the persons responding resided in the eastern part of the mainland or in Cape Breton.

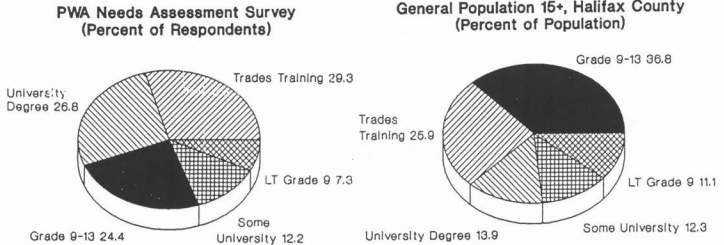
While the results may reflect the general geographic distribution of the PLWHIV population, the absence of cases outside of the Halifax-Dartmouth area make it difficult to draw any conclusions about the needs of that part of the population that is geographically isolated from the AIDS-related services based in the Metro area. The research therefore provides little evidence to support or deny the belief that there are a large number of people "outside the Metro area living with AIDS alone."²⁰

Thirty-two percent of those responding indicated a high school or grade school as their highest level of schooling. Forty percent indicated the completion of some level of post-secondary education and twenty-eight percent indicate a university degree. Twenty percent of the group have post-graduate degrees. While the results of a written questionnaire would normally be biased towards more

²⁰ Quotes like this characterized a number of the research interviews.

highly educated persons, the strength of the results suggest that the educational level of the forty-one persons is higher than the average level of education of the general population.

Highest Level of Education



Source: Statistics Canada

Forty-one percent of the group were employed at the time they filled out the questionnaire while 27 percent classified themselves as unemployed as a result of disability. Twenty two percent described their current job status as "engaged in unpaid work". Of the persons employed, all indicated that they worked full time. About a quarter of those employed classified themselves as "self-employed".

In terms of sexual orientation, 37 persons, or 90% indicated that they were gay or lesbian. Two persons responded that they were heterosexual and two responded that they were bisexual. Just over half of the people responded that they had made their sexual orientation known to all members of their immediate family and all close friends. Of those who are "out" in a more restricted way, close friends are more likely to know about their sexual orientation than immediate family members. Thirty seven percent indicated that they were out to "some co-workers".

B. Personal Resources

AIDS is a multifaceted disease requiring the co-operation of health care professionals, family, friends and people in the community. It is a disease in which acute ill health and remission can occur in rapid succession. This has significant implications for the person and the people providing support. It has been described by some as a "roller coaster ride" involving disruptions in daily living and the disruption and often the end of one's work life. These changes pose difficulties and may be unmanageable for some.

Of the respondents who have developed AIDS, 82% rely on others to provide some personal assistance. About 20% of these require assistance most or all of the time. This may include cooking, shopping, cleaning and dressing. This confirms that the onslaught of AIDS is physically disabling.

Thirty-two or 78% of those repoding to the questionnaire regard themselves as "self-supporting" individuals three of whom carry the additional responsibility of dependents. This is interpreted to mean that these individuals sustain themselves economically through employment or through one or more of the social programs to which they are entitled.

Individuals supporting themselves primarily through employment are predominantly those whose status is HIV+ while those reliant on social programs are predominantly those who have developed AIDS. The following table indicates the variety of sources of income reported by respondents.

Reported Sources of Income of Respondents

Source	No of Individuals ²¹
Employment	18
UIC	4
Municipal Social Assistance	7
Social Assistance	7
Prov. Social Assistance	7
Canada Pension Plan	15
Private Pension/Savings	11

Forty of 41 persons responded to the question on household income currently and before diagnosis. About half of those, or about the same number reporting reliance on UIC and social assistance, report incomes at or below the Canada Assistance Program poverty line for individuals. About 40%, or about the same number reporting full time employment, report annual incomes in excess of \$29,500.

Of the respondents, the average household income of those who have developed AIDS is significantly lower than that of those who are HIV+. Seventy-three percent of PWA's have household incomes below \$20,000 per year, while only 34% of those who are HIV+ fall into this category.

The data also supports the notion that a drop in income is associated with the development of HIV symptoms. Sixteen persons reported such a drop. Part of this drop is explained by the loss of work due to the onset of AIDS and the disability that may be associated with it. ²²

Forty-four percent of those responding indicate that "since their

²¹ Individuals were asked to report all their sources of income. Since some have more than one source the total number of individuals is greater than 41.

²² Half of those interviewed said that they believed that HIV + diagnosis affected their own or another person's employment.

diagnosis they have required financial assistance" to meet their basic needs. The basic needs most cited by this group are those of food, rent and utility bills. While it is impossible from the results to indicate the magnitude of these needs, given the areas of need and the numbers of people, these needs are probably being experienced most by those on social assistance. Financial assistance was cited by most of those interviewed as one of the two most important needs relevant to the improvement of the quality of life for PWAs.

Twenty-four percent of respondents cited money for "rent" as one of their greatest financial needs and most of the professionals and care givers interviewed cited "housing" as a significant concern for PLWHIV. When asked directly about their "accommodations", however, 88% indicated that they were "adequate, on the whole" in respect to cost, condition, and convenience²³. Fifteen persons responded that they were homeowners while the remainder (56% of the total) indicated that they rented, paid board or were a member of a housing co-operative. Thirty persons (73%) indicated that they presently lived on their own or with one other person and an equal number regarded such an arrangement as the preferred one for them.

C. Complimentary Therapies

After ten years of research and experimentation, much of it initiated by PLWHIV, much more is known about how to make AIDS a more manageable illness as well as how to help people to live longer with the disease. Most of the focus in terms of managing AIDS has been on the use of different forms of intervention directed at enhancing the

²³ This apparent contradiction may only reflect that people can be relatively content with their housing arrangements and feel that they are reasonably priced and yet still experience difficulty meeting the rent because it takes such a large bite out of their income. The comments from professionals and other caregivers that housing is indeed a concern could also indicate that the situation of the respondents is not representative of those they know.

immune system. Many naturopaths and other health practitioners have been advocating that PLWHIV maintain a positive attitude and supplement traditional medical treatments with the use of complimentary therapies.

In other words many people maintain that the disease is more defeatable by combining traditional approaches to healthcare, including drug treatment, with other therapies. Complementary approaches focus on such things as diet, vitamin and other nutritional supplements, acupuncture, exercise and stress reduction techniques.

Supporters of complimentary therapies believe that such approaches serve to enhance the immune system while traditional anti-viral drugs such as AZT, DDC, and DDI and prophylactic treatments such as Aerosolized Pentamidine, fight off the opportunistic infections. While there are varing opinions on this subject, there is widespread acceptance, certainly among PLWHIV, that complimentary therapies can lengthen their lives. Eight questions about complimentary therapies were included in the questionnaire to determine what treatments are most popular and which have implications for program development.

Seventy-six percent of those responding answered that they were "interested" in natural, complementary, alternative or wholistic therapies. However, other than routine attention to the need for physical activity, less than 20% of those responding appear to have used, or are presently using, complimentary therapies in a vigourous or regimented fashion.

Special dietary programs such as those which emphasize vegetarian, macrobiotic, reduced meat and low cholesterol intake are of much less interest than dietary additives such as vitamin and protein supplements.

Of the stress management-related complimentary therapies, meditation and professional massage are widely accepted although

not in frequent use. Over 60% of the professional/care giver group were positive in their assessment of the value of complimentary therapies to PLWHIV.

It is difficult to determine which complimentary therapies are of interest or in use as a direct consequence of HIV infection. Exercise, high fibre diets and vitamin supplements, for example, are not necessarily associated with HIV infection. Furthermore, few respondents indicate that they use more specialized products such as blue-green algae and Ensure or therapies such as acupuncture.

Responses indicate that most persons are aware of alternative diets and the availability of special products and therapies in the Halifax area. Most also indicate an openness to such approaches and an interest in talking with others who have experience with them.

Somewhat fewer HIV persons are interested in alternative therapies than PWA's (73% versus 80%) and there is more interest in complimentary therapies among those with higher formal education.

Of the 20 persons who indicated whether their dietary or complimentary therapy programs were professionally or personally directed, 15 indicated that they were personally directed. Only 1 of the 9 PWA's responding indicated a professionally directed program. Since this group is more likely to use complimentary approaches this indicates a high level of self education among PWA's concerning them.

D. Well Being

It is well documented that the mental health²⁴ issues surrounding

²⁴Mental health in this context is understood to mean the capacity of the individual, the group and the environment to interact with one another in ways that promote subjective well being, the optimal development and use of mental abilities (cognitive, affective and relational), and the achievement of individual and collective goals consistent with justice and the attainment and preservation of conditions of fundamental equality. Wellness is

AIDS are enormous²⁵. AIDS often elicits fear which is transformed into stigmatization, isolation, rejection, and avoidance of those who are HIV infected. Social rejection and isolation can themselves have an overwhelming impact on an individual's psychological health²⁶. The situation is further exacerbated by the acknowledgement that death could be imminent. Such factors may produce reactions such as anger, depression, hopelessness, fear and feelings of worthlessness. These are natural reactions and require resources and information to encourage self-help and community support.

1. Self Esteem

The majority of the persons surveyed seemed to be relatively optimistic about their situation. When given the choice of classifying their illness as either "a manageable chronic illness" or "an unmanageable chronic terminal illness", 76% of those surveyed chose the former. One could infer that this positive outlook may be due in part to the effective personal support systems that PWA/HIV+ persons say that they are receiving from lovers, close friends, family, professionals and community organizations. Professionals and care givers were evenly split on whether AIDS is a "manageable" or "unmanageable" disease.

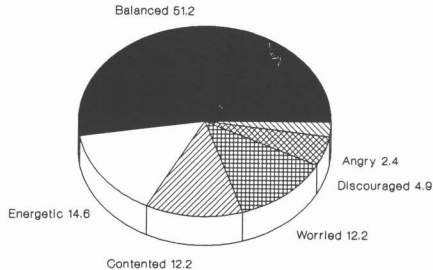
Furthermore, over half those polled (51%) described themselves as "relatively balanced persons". When one adds to this number the persons who described themselves as either "peaceful and contented" or "active and energetic" the total becomes 78%. Those who considered themselves as "discouraged" were only 5% although another 12% described themselves as "uneasy, worried".

another concept which applies here. It encompasses factors broader than those associated with physical well being as it refers to maximizing the potential of which the individual is capable. See: Minister of Health and Welfare, Canada, Mental Health for Canadians: Striking a Balance, (Ottawa, 1988).

²⁵ Mail and Matheny, op.cit

²⁶ Ibid.

Sense or Description of Self (Percent of Respondents)



A notable 83% claimed to have their own close circle of friends with whom to share and from whom to derive support. A positive sense of self is more prevalent among PWAs (93%) than among HIV+ (74%) and among those HIV+ a-symptomatic than those HIV+ symptomatic. This suggests that many PLWHIV are attending to their mental health and that the early signs of AIDS are more traumatic than the initial shock of a positive HIV diagnosis.

Nearly 54% of those responding consider a professional counsellor important to their positive outlook and nearly 70% of this group are presently receiving some level of counselling. The importance of counselling is similarly reflected in the rank assigned counsellors in peoples' support systems.

It is worth noting that medical doctors and psychiatrists are ranked above psychologists and social workers in terms of to whom people turn for counselling. While these two groups of professionals are an essential part of the AIDS support network, certainly some PLWHIV turn to them rather than to other counselling professionals

understanding is supported by the income profile of the group and the fact that 83% of those polled have never been diagnosed with mental illness.

Responses to several questions regarding the value of formal peer support groups indicate that they do not or would not be highly valued alternative in most individual's personal support structures. Only 20% of the respondents indicated that they thought they "would benefit from participation in a peer support group", while 42% thought that they would not benefit from such participation and 39% were not sure. This is not surprising perhaps since, as noted earlier, 88% of those responding say that they presently have "an effective personal support system". This finding also seems to challenge the belief expressed by most of those interviewed that "support meetings" would be of great value²⁷.

Most of the professionals and care givers interviewed believed that counselling would be beneficial to PLWHIV and almost all of them felt a peer support group program would be a preferred approach.

A very significant number of respondents (90%) indicated that work and their ability to work loomed large in their sense of self-esteem. As reported earlier, current job or work status had indicated that a total of 56% of respondents were disabled and unable to work, unemployed or doing unpaid work, while only 41% described themselves as either employed or self-employed.

When ranking the benefits associated with the ability to do paid work respondents rated financial independence and financial security highly as the most important factors. In terms of non financial benefits, "intellectual stimulation" received the most mention as important with 80% of respondents rating it highly. "Social contact"

²⁷ It was not absolutely clear whether those interviewed equated "support meetings" with organized "support groups" set up for the purpose of counselling, or whether they meant all meetings of community-based AIDS organizations.

was ranked in the top three non-monetary factors in 56% of all responses.

The lowest rated benefit and the single highest incidence of absolutely no ranking was the benefit described as "value to others and the community" This could indicate a low premium on altruism among PLWHIV, but is more likely an indication of a high standard associated with the meaning of the term and an awareness of the fact that few jobs fall into such a category. Given the relatively high self esteem among those who responded it is unlikely that this is an indication of a belittling of the social value of one's own work.

2. Sexuality

The questionnaire included a number of questions on sexuality none of which people seemed reluctant to answer. The purpose of these questions was not to determine the nature of sexual activity among PLWHIV but rather how they felt about this part of their lives.

What is of note with respect to this area of concern is the fact that HIV diagnosis has not led individuals to feel sexually inadequate, unattractive, nor has it in fact led large numbers of them to be sexually inactive. About half (54%) of those responding describe themselves as "sexually active", with the remainder (46%) describing themselves as "sexually inactive". These terms are of course relative ones with persons answering in terms of their own experience or in terms of assumptions or beliefs about the average level of sexual activity within their community or peer group .

Twenty-two percent described their present sex life as "on hold...but negotiable" while 17% describe it as "quiet". If the designation "quiet" is considered somewhat of a pejorative term in describing one's sex life, and this is not necessarily the case, along with those who describe their sex life as "a washout", only 19% of those polled expressed discontent with their present sex lives. If "quiet" can be taken as a neutral comment, then a surprisingly low

percentage of 2.4% expressed discontent with their sexual life²⁸.

In a comparison of questions concerning changes in respondents' evaluation of themselves sexually (attractive versus unattractive) upon a positive HIV diagnosis, only 12% indicated a change in their image of themselves as sexual persons since or as a result of their diagnosis²⁹.

Fifty-four percent of respondents consider themselves "sexually active." Approximately half of these respondents experience their sexual activity within the context of "a relationship" while 30% describe their sexual activity in "uncommitted or recreational ways" and 20% indicate that they experience sexual activity both within and outside of committed relationships.

Only 27% of the forty-one respondents have participated in safer sex workshops although almost all of those who are sexually active report that they always practice safer sex. Those who report that they do not practice safer sex appear to be involved in "relationships" with partners who are also HIV+. The availability of condoms is not a major factor in terms of inhibiting safer sex practice. Seventy-eight percent of respondents found condoms readily available and within budget.

Where ongoing sexual relationships exist, a significant number 37% felt that their partner was comfortable with the knowledge of HIV infection within the relationship. No one reported that their partner was unaware of their HIV diagnosis.

3. Social Acceptance

Respondents' perception of their acceptance in society is fairly

²⁸ Other descriptions of sexual life, of which there were six, are evenly distributed among three kinds: positive, negative and 'have not had time to think about it' kinds of responses.

²⁹ Over half of those persons experiencing weight loss have gained or maintained a positive view of their own sexual attractiveness after diagnosis.

evenly divided between those who perceive that people "react differently" towards them since their HIV diagnosis (44%) and those who perceive no change in reaction of others toward them (41%). The remainder of responses are those that report that "no one knows about their diagnosis". Of those who report that people "react differently" several indicated that this reaction was supportive rather than unsupportive.

All persons interviewed (professional caregivers and PLWHIV) believed that PLWHIV as a group, as well as individual PLWHIV, had been the object of discrimination. Indeed, while the extent of discrimination against PLWHIV should not be downplayed, the perception is that problem is more serious than is reflected by the actual personal experiences of the respondents.

This evidence however ignores the experience of those who did not respond to the questionnaire, perhaps because of the fear of exposure and discrimination, and the fact that the study asked about AIDS-related discrimination, not discrimination based on sexual orientation which is almost certainly more frequent.

Of those who perceive a "new reaction" towards them that is negative, the most common description of this change is only that "some people act in a sympathetic but unsupportive manner". Avoidance and "rude" treatment is also cited by 17% and 15% of all respondents respectively as ways they have experienced some of the reaction. Three persons (7%) report that "some people have acted violently towards me".

When prompted to analyse this change, responses indicate that most who have experienced it attribute it to "a fear or dislike of gay people (which includes the presumption that because one is HIV+ they are gay)". Others attribute the new reaction to a "fear of contacting AIDS" or "discomfort, fear or dislike of IV drug users" and the presumptions surrounding that kind of person.

Almost all of the professionals and care givers indicated that they

believe that PLWHIV experienced "stigmatization" and they most often attributed this reaction to a "lack of understanding" of AIDS.

4. Sources of Support

One question was asked regarding the source of "HIV+ related support". Most of the respondents interestingly enough indicated that they derive their most positive support from friends, other PLWHIV, family and medical personnel.

Members of the professional and care-giver group who were interviewed also believed friends were the most important source of support for PLWHIV. This group also indicated that their relationship with PLWHIV was mostly professional but that "professionals must address other needs." than those that might be regarded as strictly medical or psychological, to use two examples.

The question was not as well constructed as it might have been and therefore it is difficult to determine in what areas respondents experience the least HIV+ related support, although the employment (employer and fellow employees) situation appears to be one. Social service personnel were ranked equally positive and negative where they were ranked at all. A number of people (32%) considered them irrelevant. This is probably reflective of the fact that those respondents who are working have not encountered social services staff. It is only when PLWHIV find themselves unemployed or hospitalized and on social assistance that social service personnel are likely to begin entering their lives.

5. Spiritual and Religious Needs

Generally speaking the majority of people polled (80.5%) considered themselves "spiritual persons". Of these, those who classified themselves as participating members of a specific tradition (Christianity, Judaism, etc) or as spiritual persons who

draw on religious traditions but are not committed to any one, amount to 29% of all respondents. Those classifying themselves as agnostic or atheist were 12% of the total.

Spiritual Orientation Of Respondents

(term which best describes their belief system)

Spiritual	51%
Spiritual within one religious tradition	20%
Spiritual within several traditions	10%
Agnostic	5%
Atheist	7%
No Response	7%

There is little indication that being diagnosed HIV+ has had much of an impact on respondents' spiritual beliefs. This finding is supported in part by the fact that specific religious commitments and/or denominational affiliation is of little importance to most members of this group. It is not surprising then that few respondents indicated that they would consider a pastor to be a likely person to approach for counselling, although it would be a mistake to think that the relationship between religious beliefs and acceptance of pastoral counselling is predictable in every case. It is worth noting that the care givers interviewed indicated that they believed religion to be somewhat more important to PLWHIV than the evidence from this group would seem to suggest.

The fact that the shock of initial diagnosis didn't alter most respondent's (59%) spiritual or religious beliefs whatever they may have been could be seen in a positive light. However, the crisis that individuals may experience has also not resulted in mass "conversions" Only two persons indicated that this happened in their case. The "revival" of which some 20% spoke was indicated to be in terms of previously held spiritual/religious convictions.

Within the smaller grouping of persons indicating affiliation with a specific religious tradition, the majority have not, contrary to popular belief, experienced rejection at the level of the community, parish or congregation. Only two respondents reported such rejection. This may indicate that the harshness or presumed inhospitality of churches or other religious communities is expressed more on a theoretical rather than on a practical level and hence is associated with the image and persons of authority figures, pastors, teachers, etc. This is corroborated somewhat by the fact that 17% of respondents felt they have received adequate pastoral care within their religious tradition while 12% feel they have not.

Another interpretation of this data might be the irrelevance, actual or perceived, of religious practice to the combined issues of AIDS and homosexuality. The irrelevance interpretation is a possible one to the extent that respondents compartmentalize their religious beliefs thereby keeping other significant parts of their lives separate from their "religion".

This irrelevance interpretation could further be supported by the fact that spiritually minded or religiously involved persons who found their own tradition pastorally or informationally inadequate did not in large numbers seek the same either in other traditions or from institutional chaplaincies such as that provided by the Victoria General Hospital. However, the number of responses prevent this or any other interpretation from being drawn from the data regarding spiritual or religious support.

E. Advocacy

Given the prejudicial attitudes, ignorance and discrimination that exists in relation to PLWHIV, the need for activism and advocacy is an important issue. The terms advocacy and activism, while related, have different meanings. The understanding used here is that **advocacy** means "to add voice", to speak on behalf of, and in the interest of, others. It requires that the person or group that is

advocating is in a position of greater power or influence than the person or group that is being advocated for. **Activism** means to speak on one's own behalf and/or in the public interest. It implies an effort to seek change through the promise or actuality of political action. Activism requires that people be empowered to act individually and collectively.

The literature suggests that involvement in political and organizational change efforts with respect to one's own illness is part of the healing process³⁰. Such change is identified in the Coalition's goals and it seeks to accomplish this by advocating for, and the promotion of activism by, PLWHIV. For this reason some questions concerning people's attitudes and actions with respect to advocacy and activism were incorporated as part of the study.

Responses overall suggest that there is a definite interest in increasing individual and collective action to eliminate discrimination against PLWHIV. Among those responding, 87% felt it was important for people to speak up against such discrimination.

Most persons expressed a willingness to speak up themselves if a family member or a close friend spoke badly of someone with AIDS. Indeed, 85% agreed strongly or agreed that they would say something in this situation. Only 31% however, said that they would speak out publically. For example, few indicated a willingness go up and say something to a stranger in a restaurant if they over heard a discriminatory statement. While speaking to a stranger in a restaurant is different than speaking in front of a group either on one's own or as a member of a panel, few respondents want to draw attention to themselves publically. This is consistent with the view held by all who responded that the government bears much of society's collective responsibility to eliminate discrimination.

Those willing to speak up in a public setting are, for the most

³⁰ For example see Callen, Michael "Surviving and Thriving with AIDS" in Michael Callen (ed) Surviving and Thriving with AIDS, Volume 2, (New York: People With AIDS Coalition, 1988), 130-139.

part, persons who have acknowledged their situation to people other than their immediate family and close friends, through some contact with, if not involvement in, a community-based AIDS organization. This suggests that such involvement is either an indication of, or important in building, peoples' confidence about speaking out. The number willing to speak out who have had contact with the Coalition is somewhat greater than those who have had contact with other community-based AIDS organizations. This suggest either that the Coalition is somewhat successful in its efforts to empower PLWHIV or that persons who are already relatively empowered have been attracted to the Coalition because of its philosophy.

Most of those who responded believe there is a need for more work by municipal (85%), provincial (95%), and federal (68%) governments. Areas identified in the questionnaire for governments to work on included banning discrimination against PWA's, providing protection for sexual orientation, and creating a work environment that can effectively incorporate or care for persons diagnosed with AIDS.

As a group, respondents indicated that there was a link between advocacy and education. There was a need for further education of society at large, especially to overcome the misrepresentation of AIDS and PLWHIV. Eighty percent felt that PWA's should do more to educate the public. The interviews also indicated a desire to see more education around both AIDS and sexual orientation, particularly within the schools.

Those who responded appear to be a relatively empowered group. This is not surprising given the demographic characteristics and the inherent bias of the research methods used. However, few respondents appear to be unconcerned or immune to societal responses to themselves as people living with HIV.

F. Information and Education

Of the 41 PLWHIV responding most have had some contact with a community -based AIDS organization.

Contact With AIDS Organizations³¹

(Percent of persons receiving services from the following organizations)

Canadian AIDS Society	02.5%
CARAS	04.9%
Metro Area Committee on AIDS	44 %
N.S. Persons With AIDS Coalition	54 %
other organizations	02.5%

Eighty percent of those in the professional/care giver group were aware of all of the local organizations: MACAIDS, NSPWAC and CARAS.

There has been much information about HIV/AIDS disseminated over the years on a wide variety of topics and in various forms. Our interest was to sort out what information has been received, by whom, and what information people would like to receive, and in what language and format.

Most of those who answered the questionnaire indicated that they had received the most information on medical treatments and that this was the the subject of most interest in terms of wanting more information. The next two most important areas of interest are nutrition and alternative therapies. While 58% have already received some information on nutrition, 51% of all respondents said they need more information. The figures are slightly lower for alternative therapies: 36% have already received information and 43% said they need more. These priorities were also reflected in the PLWHIV

³¹ Totals more than 100% because some individuals have received services from more than one organization. Respondents were asked to indicate all who they had received services from. What constituted "received services" was left up to the decision of each respondent.

HIV/AIDS Information

Percent of respondents who have received information and would like to receive more.

	Infor Received	Infor Needed
Medical Treatments	83%	63%
Basic AIDS Information (AIDS 101)	71%	10%
Safer Sex	68%	7%
Nutrition	58%	51%
Community support services	46%	15%
Alternative Therapies	37%	44%
Legal Issues and resources	37%	32%
Financial Resources	27%	19%
Spiritual & psychological support	24%	15%

The major sources of HIV/AIDS information for most who responded have been medical professionals followed by the NSPWAC, MACAIDS, and friends. Eighty percent of those responding ranked government sources of information low in importance.

The majority of those responding requested further information in English (83%) while 10% wanted information in French, and 7% said they would like it in either language.

The formats most useful to respondents are print, video and personal consultation. Workshops and other kinds of group forums ranked relatively low, probably because they do not allow for anonymity like print materials and others forms of information.

Respondents were asked who has contributed most to the improvement of the lives of PLWHIV and who should be leading this work. While the Coalition received the highest ranking on both issues, the important point is that people felt that community-based organizations have contributed more than government but that the

latter should do much more, perhaps in partnership with community-based groups.

The last question in the questionnaire dealt with what people would like to see the NSPWAC doing on their behalf. The responses indicate that advocacy work is most important directly expressed need. Over half of the people ranked advocacy the first, second or third most important activity of the Coalition. Emotional support (eg.counselling), practical support (eg. transportation) and public education were thought to be the next most important activities respectively. Neither the provision of financial assistance or more information regarding HIV/AIDS treatments were ranked as high priorities for the Coalition.

There is a sense, from the answers to the question about what the Coalition should be doing, that people answered according to what the Coalition should be doing for PLWHIV in general rather than for them personally. This is the tendency when asking people about their needs directly and one which manifested itself even more strongly in the interviews.

Five members of the professional/care giver group interviewed indicated that there were consequences to be considered if the Coalition were to give greater priority to its advocacy role. Typically they suggested that "the Coalition is too public and politically oriented" and therefore PLWHIV may not want to be involved for "fear of being found out". People fear, it was suggested, "that if they go to the Coalition (for help) it will be assumed that they are gay."

PART 3: Implications of the Study

A. The Role of AIDS Organizations

The challenge for organizations that are attempting to meet the needs of PLWHIV is that the scope of the disease is too large in magnitude to be dealt with without concern for wholistic approaches to the support of individuals as well as action with respect to changing community attitudes and structures.

For community-based AIDS organizations such as the Coalition, responding to this wide spectrum of needs raises the issue faced by many other community organizations. To what extent should we concentrate on providing services to individuals and to what extent should we be engaged in advocacy and community development efforts which seek to change systems and empower people?

Service to individuals is not easily separated from advocacy and community development work. Providing various kinds of support to individuals keeps us firmly linked to the reality faced by our constituency - persons living with HIV infection. Providing services on a more or less ad hoc basis has helped the Coalition to build a small but supportive community whose meeting place formally and informally has become our office. This could not have happened by providing support in a planned programmatic fashion. Community development demands sensitive and flexible responses not characteristic of most highly "managed" organizations.

The fact that this needs assessment has not thrown up a clear cornucopia of needs only serves to reinforce the value of our present

approach, one based on the philosophy that empowerment happens in "doing". People come together for different reasons. For some it may be hospital visits or a discussion of a new film in town around a pot of coffee. For others it might be to draft a submission to government or to speak to a university class.

This study has also brought us face to face with the realization that HIV infection and its accompanying physical, emotional, spiritual and social impacts cannot be separated from the life experience of those the virus inflicts. Those with AIDS and those who have tested positive for HIV but who have not yet developed AIDS, need support of various kinds not just because they are all HIV+ but because they are, for the most part, HIV+ and Gay. Indeed, few of the needs indicated in this study are strictly HIV related. Likewise, support in its various forms, is certainly HIV related but it is often not only HIV related. It is our view that our investigation of the needs of PLWHIV suffered too much from a "this is only about HIV" perspective. The possible program implications of this perspective ought somehow to be addressed.

Despite this and other conceptual problems and the fact that the survey population was small and not necessarily representative, the needs assessment has been useful directly and indirectly (through the discussion and discovery process in which it was imbedded) in helping us to disentangle some of our understanding of the world of PLWHIV. It has provided a more realistic picture of the lives of a significant group of PLWHIV, one more complicated than simplified. It has also provided us with some specific pieces of information which have implications for the work of the Coalition.

B. Program Implications

The findings report that the individual support needs of those PLWHIV who responded are at a minimum being met and that more emphasis needs to be placed on education, both of PLWHIV and groups

in the community, and on political advocacy. While the daily emotional, practical, spiritual and psychol-social needs of those who are chronically affected by AIDS will continue to be a priority, in most other respects, the majority of persons who responded to the study are, with the support of individuals and organizations, successfully "holding their own".

This leads us to the conclusion that the Coalition should not make any wholesale changes in its overall program of support and information services, education, and advocacy. The flexibility, sensitivity and responsiveness of the Coalition to both individual and group needs remains it's major strength.

One of the underlying goals of the investigation - the need to know more about PLWHIV who have remained relatively anonymous - was not significantly realized. The desire for anonymity is only partly responsible for the fact that a large number of PLWHIV did not respond³². While the study does not shed any light on how the Coalition can better serve this group more directly it is with some certainty we can conclude the following about the 157 persons whose needs the study did not directly capture:

1. a higher percentage of them live outside the Halifax-Dartmouth metropolitan area than those who responded.
2. they fear discrimination or stigmatization as a result of being identified as a PLWHIV or a gay person more than those who responded.

This suggests that the Coalition should make a more concerted effort to make its presence felt outside the Halifax-Dartmouth Metropolitan area. PLWHIV in other areas of the Province are more likely to benefit from information, education and advocacy efforts at the community level that do not require forms of support that are

³² The principal reason is that the majority of PLWHIV did not receive a questionnaire.

social or that require contact with persons outside their usual or familiar support system.

The needs assessment data itself more directly suggests that the Coalition consider the following considerations in terms of future planning:

Individually oriented rather than group oriented kinds of support services will probably be preferred. For example, individual counselling appears to be of greater interest than group counselling and the provision of written information is preferred to workshop formats.

The spiritual needs of PLWHIV are much broader and more general than the practices associated with particular religious traditions. Although specific spiritual needs were not captured in the investigation, the results suggest that any efforts in this area be rooted in a much broader conception and practice of spirituality.

The results suggest few PLWHIV are highly concerned with enhancing their immune system through complimentary therapies. Information and education efforts in this area, although important, should not be a high priority. Alternative therapies are of interest, but, it would appear, not at the expense of radical changes to one's lifestyle. Interest in both medical treatments and complimentary therapies increases however with the onslaught of AIDS. It should be noted that the study was not particularly useful at uncovering respondent's levels of knowledge about the physical health implications of HIV infection (ie. the nature of one's immune system).

The study suggests that advocacy efforts may be warranted to raise the issue of accessibility to psychological and social counselling through MSI funding.

There is some evidence of the need for education

directed to PLWHIV about safer sex practices between HIV+ partners. There is growing evidence that one can transmit different strains of the HI virus as well as other viruses and bacteria.

This report does not represent an end to the process of investigating and reflecting on the experience and needs of PLWHIV. It will, it is hoped, spark discussion and action that will assist the Coalition develop a greater understanding of the struggle that so engages us.

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