Hearing the Stories, Charting the Changes

An Analysis of AIDS Vancouver's Project Sustain Case Management Database

Prepared by Deborah Graham, Warren O'Briain and Jeff van Steenes

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This project has been possible first and foremost because of the thousands of individuals living with HIV/AIDS who have been involved with AIDS Vancouver's Project Sustain: as clients, as volunteers, as staff, and as community supporters. This project honours nearly 3,000 stories and represents our efforts to learn from this collective wisdom.

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Ce document est aussi disponible en français sous le titre « Des histoires au présent pour l'avenir ».

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BACKGROUND

The Agency

AIDS Vancouver, founded in 1983, is Canada's oldest AIDS service organization. From the beginning of the epidemic, the agency has been dedicated to channelling community energy into direct support initiatives for persons living with HIV and AIDS.

AIDS Vancouver's offices are located in the Pacific AIDS Resource Centre, a facility shared with our PARC partners: BC Persons With AIDS Society, the Positive Women's Network, and the Wings Housing Society. From these offices and other settings in the Vancouver area, AIDS Vancouver offers a range of education, prevention and support services.

AIDS Vancouver's programming is funded by Health Canada, the British Columbia Ministry of Health, the Vancouver/Richmond Health Board, community organizations, and corporate and individual donors.

Confidentiality

Information provided by AIDS Vancouver clients is retained in a combination of paper and electronic records. Paper records are kept in secure storage; electronic records are also kept secure. Access to this information is strictly limited. Clients retain control over their information, and any records which contain identifying information cannot be released without a client's informed, written consent.

AIDS Vancouver's record management is guided by the British Columbia Freedom of Information and Protection of Privacy Act.

The Project Sustain Database

In the late 1980s and early 1990s, with the involvement of infected and affected communities, AIDS Vancouver sought to meet the needs of persons living with HIV/AIDS at various points along the continuum. Several sustaining programs and resources were developed to provide income assistance, nutritional supplementation, social interaction, psychological support and practical care. In 1993, these programs and resources were organized into Project Sustain.

Early on, staff and volunteers began collecting basic information at intake, first on paper and later on computer. Data tended to be organized by program, and soon we had several separate databases running independently, with nothing to link the information they contained. These organically developed systems were inadequate to handle the huge

influx of new clients that occurred in the mid-1990s. It was time for a new database that would consolidate all the existing data and eliminate duplication.

Highly skilled computer and research professionals were recruited as volunteers to assist us in developing an integrated database system. By 1995, all our client data had been consolidated into a single, easy to use, client-centered case management database. The mechanics of this database were showcased by our volunteers at the XI International Conference on AIDS in July 1996.

By early 1997, AIDS Vancouver's case management database contained extensive records of community care and support services provided to more than 2,400 individuals living with HIV/AIDS. Vancouver continued to have the highest per capita rate of AIDS in the country. Every day, new clients were requesting assistance from AIDS Vancouver. The time had arrived to take a step back and examine the stories so many clients had shared over the years, and to learn from those stories. With that in mind, and with a modest grant from Health Canada, we set out in June 1997 to examine the information we had collected and see what lessons we could learn from it as we prepared for the future.

PROJECT DESIGN

In some ways, the project was designed for us. To provide needed services, AIDS Vancouver had gathered certain information from its clients: basic information such as addresses, phone numbers and emergency contact persons; details, such as sexual orientation, income sources, health history, and personal support systems, needed to create individual service plans; and some simple questions about HIV transmission, designed more to aid discussion about safer sex, needle use and our secondary prevention goals than to assist with a particular epidemiological objective. Using the case management database as a program planning tool only became a possibility once we stopped looking at it in the light of its primary purpose: as a tool to help organize and deliver services to an enormous number of clients. Careful examination of the information led us to believe that within the database we might find answers to some of the core questions facing many AIDS service organizations in the late 1990s:

- Who exactly are we serving, both demographically and geographically?
- Who are we not serving?
- What factors lead people to our services?
- Are we accessible to individuals from a wide range of life experiences?
- Do our service users reflect current epidemiology and newly emerging risk groups?
- Are some programs limited in the demographic populations they serve?
- Is there a relationship between program availability and quality and length of life?
- Are there patterns in service access or usage which could inform future program planning?

We also suspected that questions and relationships which had never occurred to us might emerge once we were able to look closely at the data and solicit input from a broad range of individuals interested in the agency, its history and its future.

The 1996 version of the database was in excellent shape as an individual service planning tool. However, a year of use had highlighted some categories of information that had been overlooked or had not proved useful, and demonstrated that improvements to both software and hardware were called for to cope with the increasing volume and complexity of the data.

We employed a local database design consultant to revise the database, and enlisted our network administrator to upgrade our system and fine-tune the database so it could better meet both service and data needs.

Paper records at AIDS Vancouver had been carefully compiled and maintained. However, much relevant data that existed in written form, particularly prior to 1995, had never been entered into the computer database. In the autumn of 1997, after alterations to the database had been completed, volunteers were recruited to assist with a mountain of data entry. These data entry heroes, who entered into a confidentiality agreement, must be

acknowledged for the diligence with which they reviewed more than 2,500 very detailed files. The data they entered pertained primarily to demographics and program usage.

By March 1998, the enormous task of data entry had been completed, and the database now contained more than 2,950 records. We proceeded with our analysis of the data by running a number of queries on the database, generating graphs and charts, and examining the results. A draft report was prepared and circulated to a group of reviewers to ensure that the conclusions drawn were consistent with the data available, and to solicit additional suggestions for data analysis that might help us to meet our objectives.

Project Limitations

One of the limitations of the project is the lack of consistent data for clients who registered with AIDS Vancouver prior to 1992. If information was clearly recorded in the paper file, it was entered into the database; if there was any ambiguity at all, no information was entered. Also, the database does not include information about clients who died prior to 1993 and whose files were closed at that time. Prior to mid-1995, clients were not asked about HIV risk factors, and, as a result, this information is not recorded in the database for a large percentage of clients.

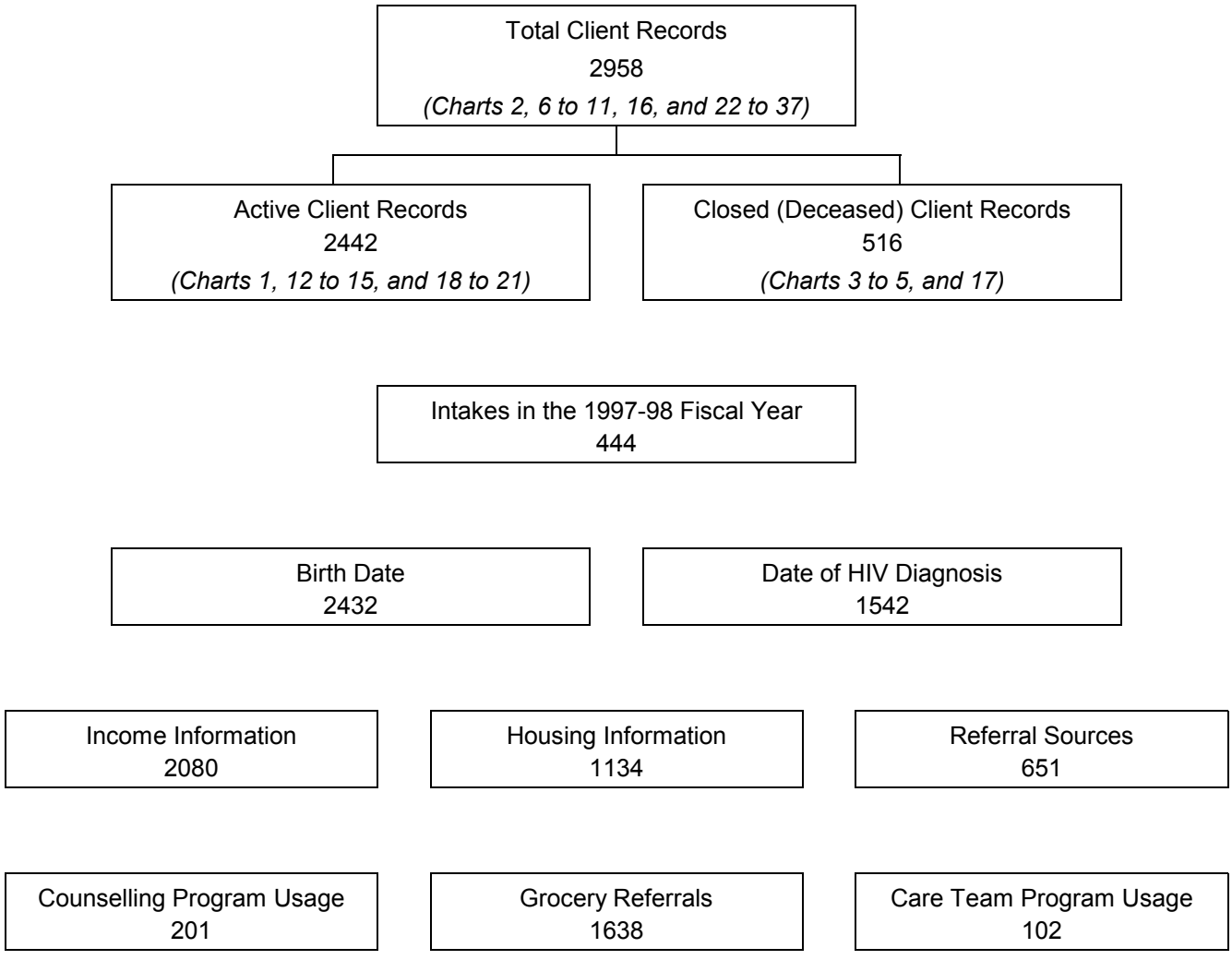
Information in the database is recorded as provided by the client, and this is an obvious limitation on the statistical results of this study. As an example, some transgendered clients report their gender as transgendered, while others identify their gender as male or female; some state their sexual orientation as transgendered, while others give their sexual orientation as gay/lesbian, bisexual, or heterosexual. Similarly, ethnic background and cultural heritage are recorded only if provided by the client. Clients are not consistently asked about aboriginal status; when they are asked, it is usually only in the context of determining eligibility for health service or medication coverage.

We also rely on our clients to keep the information in their records current. For example, some clients may use drop-in services regularly, but not notify us of a change of address, since such notification is not required to obtain services. Our analysis of client geographical information may, therefore, be based on slightly outdated information, but we are confident that overall numbers are large enough to allow us to identify geographical trends.

RESULTS AND ANALYSIS

Database Schematic

This diagram shows, as of March 31, 1998, the numbers of client records that provided the categories of information considered in the analysis that follows.



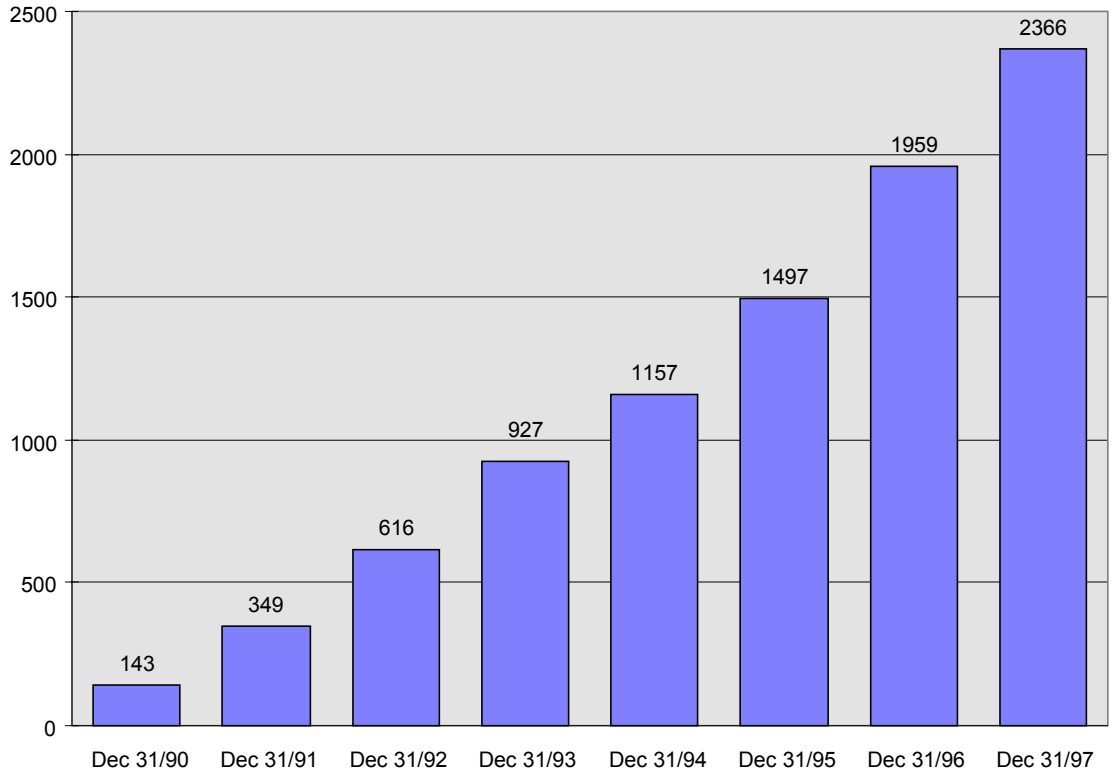
Tracking the Epidemic

Over the past three and a half years, Vancouver has seen a drastic expansion in the AIDS epidemic. The number of individuals turning to AIDS Vancouver for community support has also soared. The British Columbia Centre for Disease Control Society reports that the total cumulative number of persons who had tested positive for HIV in BC by the end of September, 1997 was 8,878.

The total number of clients who registered as clients with Project Sustain over the same period was 2,852.

In other words, about one of every three British Columbians who test positive for HIV registers for services with AIDS Vancouver's Project Sustain.

Chart 1: Total Number of Clients at Calendar Year End



Death Rates

Vancouver continues to have the highest per capita rate of AIDS in the country. However, according to the British Columbia Centre for Disease Control (BCCDC) Society, the total number of deaths related to AIDS in British Columbia has declined somewhat each year since 1993. AIDS Vancouver's records of client deaths closely parallel the provincial statistics.

Project Sustain's support programs are being presented with new challenges as early intervention, better support and improved prophylaxis mean persons living with AIDS are living longer. For example, in 1996 (the year with the greatest number of new clients), 124 Project Sustain clients died during the same period that 585 new clients registered for services, resulting in a net increase of 461 clients.

Chart 2: Client Deaths and Intakes by Calendar Year

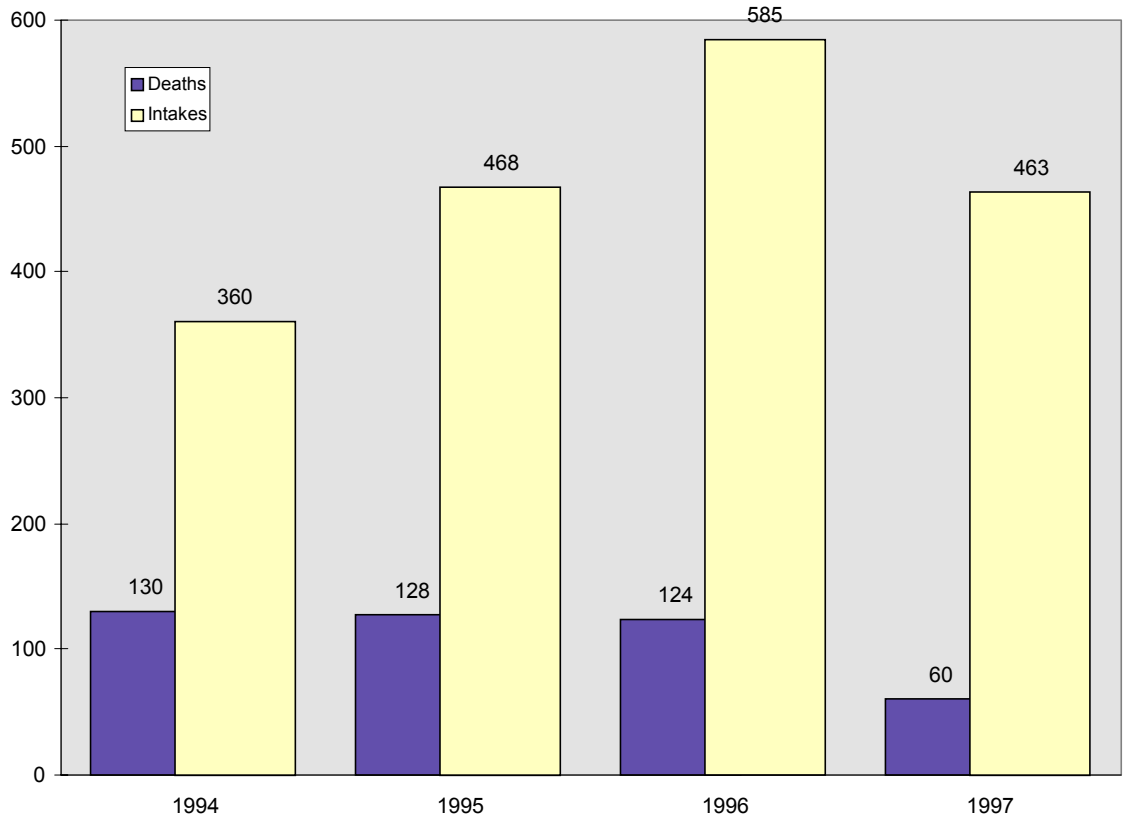


Chart 3: Deceased Clients by Gender (n=516)

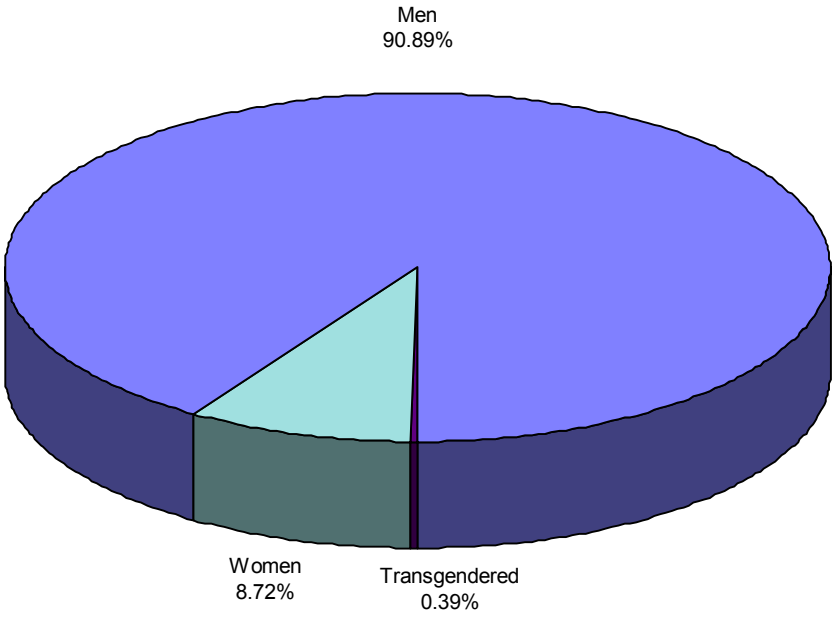


Chart 4: Deceased Clients by Sexual Orientation (n=516)

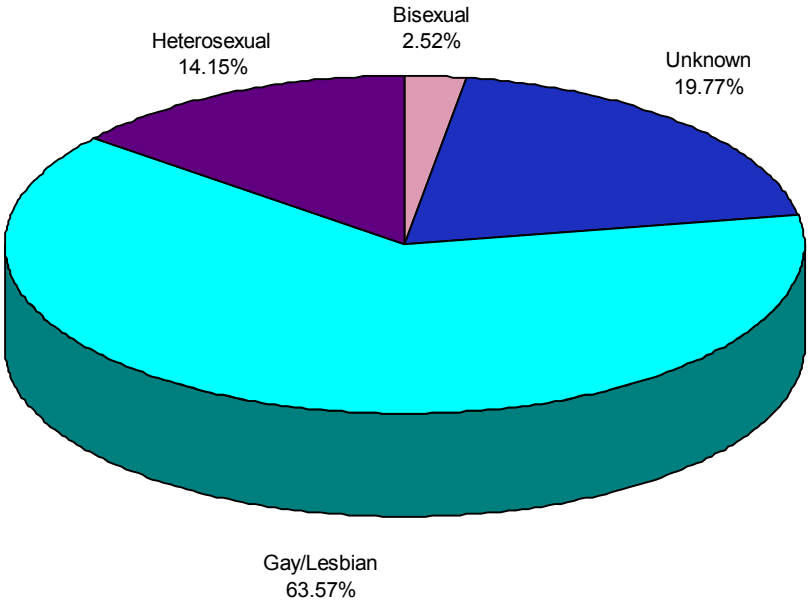
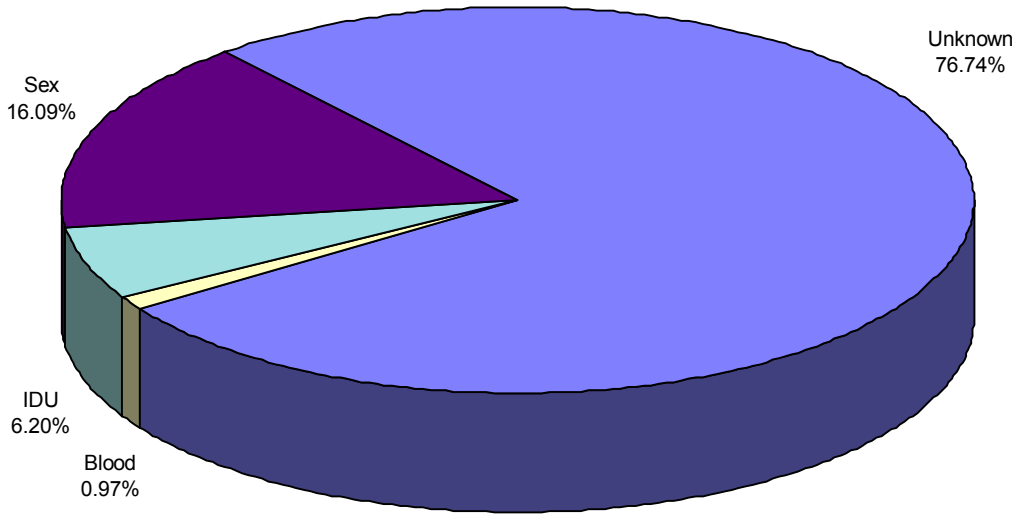


Chart 5: Deceased Clients by Risk Factor (n=516)



Vulnerable Communities

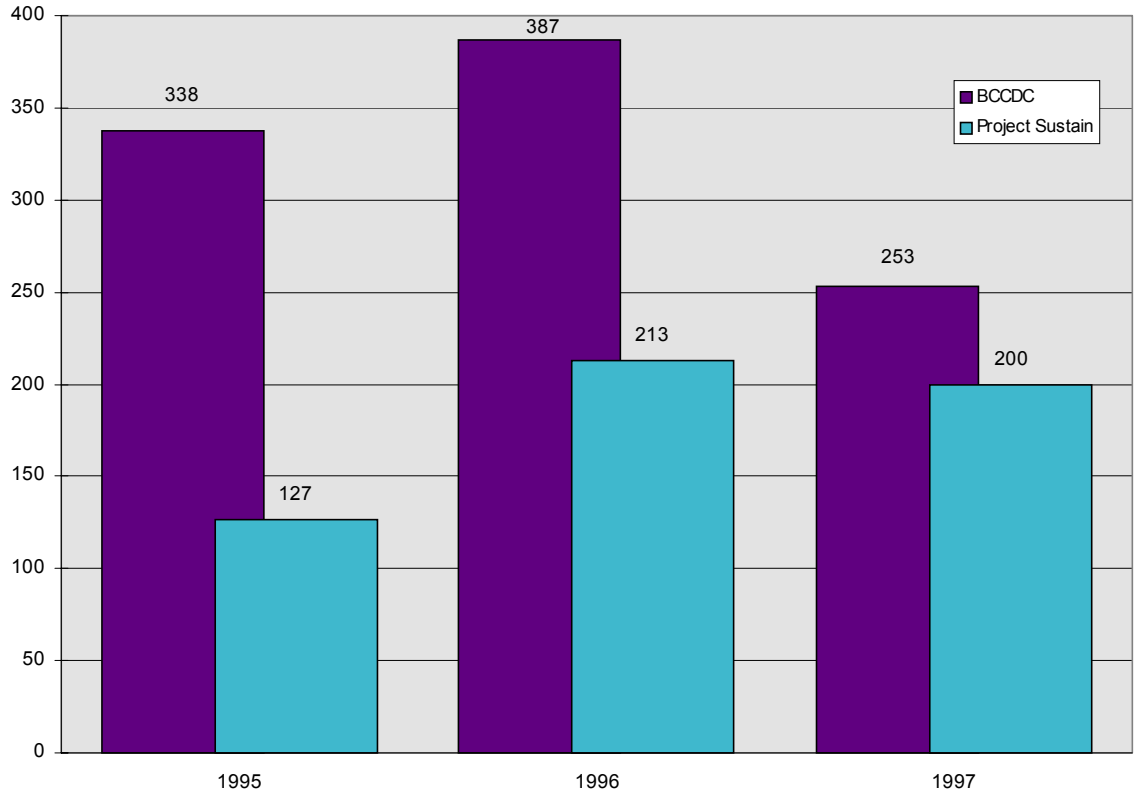
Although the epidemic has spread to various vulnerable communities, gay men remain profoundly affected by HIV. Young gay men are still among the groups most at risk for infection. This reality is reflected in Project Sustain's client base.

However, in 1997, for the first time, new male clients who identified as heterosexual outnumbered those who identified as gay. This shift seems to be directly related to the growing HIV epidemic among injection drug users. Recent studies of injection drug users in Vancouver have given us more accurate information about the spread of HIV into that community. By 1997, Vancouver had one of North America's worst infection rates among injection drug users, and officials were calling the situation a public health crisis.

We wanted to see if the data could tell us if Project Sustain was responding to this expansion in the demographics of HIV disease. To do this, we examined statistics made available by the British Columbia Centre for Disease Control Society, STD/AIDS Division, and compared them to see if there was a clear relationship or not.

The following graph compares Project Sustain's intake data with BCCDC statistics for injection drug users.

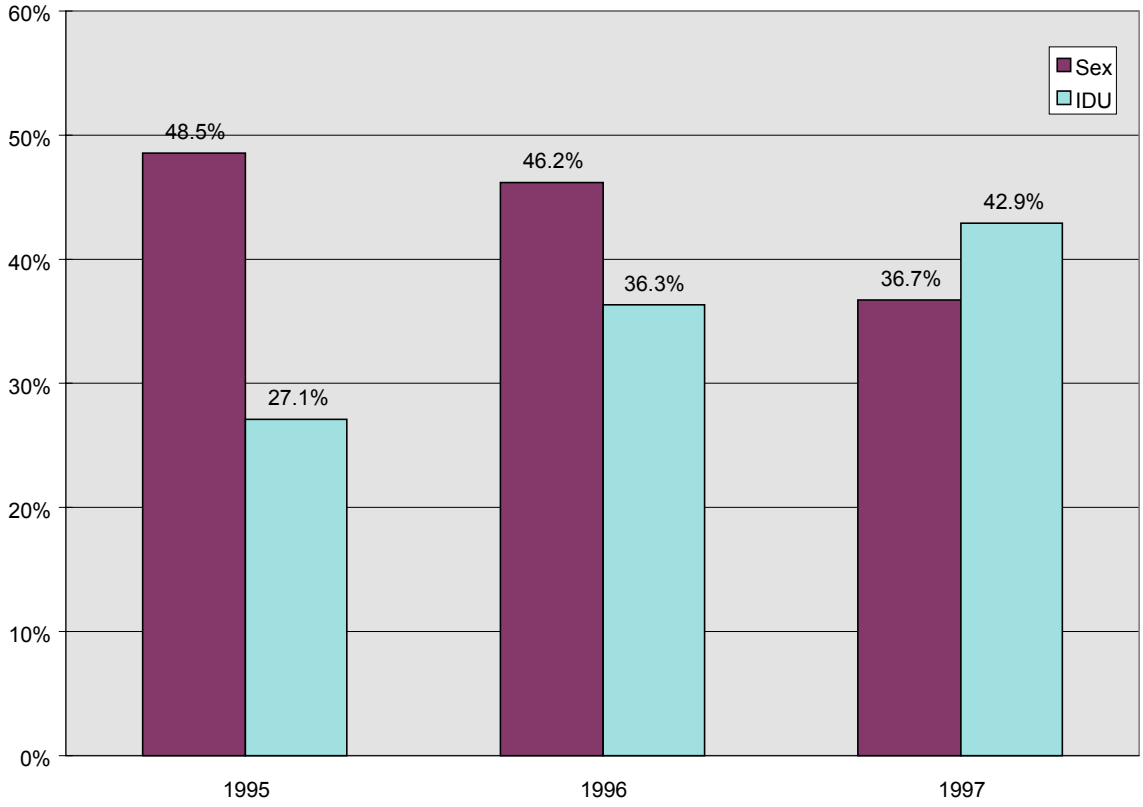
Chart 6: A Comparison of Project Sustain and BCCDC Data on Injection Drug Use as a Risk Factor, 1995 to 1997



The preceding chart suggests that current and former injection drug users will continue to form a growing percentage of Project Sustain's client base as recently diagnosed individuals register for services.

Project Sustain's programs were developed in the early 1990s, when the vast majority of clients were gay men who reported the route of HIV infection as sexual contact. We wanted to look at the numbers of clients who, at intake, identified either sexual contact or injection drug use as a risk factor.

Chart 7: Percentage of Clients Identifying Sex or Injection Drug Use as a Risk Factor, 1995 to 1997 (n=1207)



As the chart above suggests, 1997 was a watershed year for Project Sustain as, for the first time, injection drug use was the most frequently identified route of HIV infection among new clients.

The results of this comparison will influence:

- planning for new program development
- an examination of our ongoing relevance to the communities from which AIDS Vancouver developed
- planning around secondary prevention
- staffing decisions

Demographics

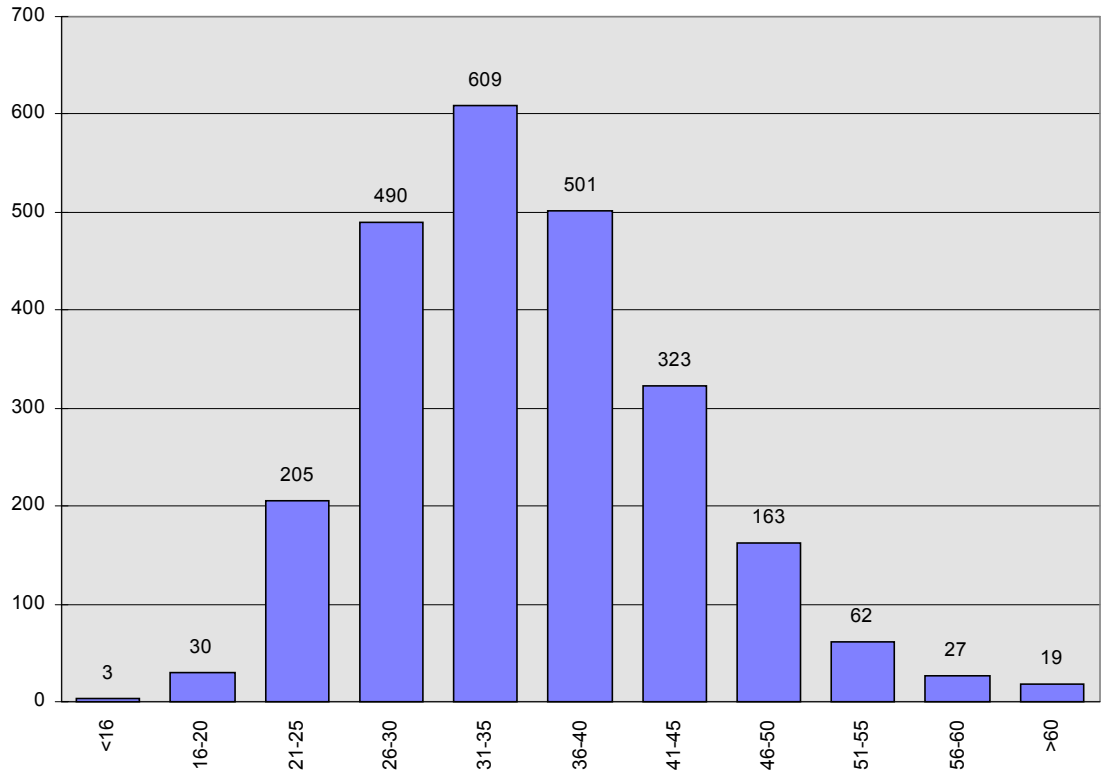
It is important to acknowledge that the route of HIV infection is only one among a wide range of demographic and social factors which must influence program analysis and planning.

In recent years we have worked hard to increase the accessibility of our services to emerging populations. AIDS Vancouver's contract with the BC Ministry of Health specifies that services be available to all British Columbians. In practical terms, Project Sustain's services are available to anyone living with HIV disease and requesting community support who resides in the Greater Vancouver Regional District (GVRD) or an adjacent municipality. We wanted to examine our current client profiles in the light of available epidemiological information to see if we were in fact serving a broad range of individuals.

Age

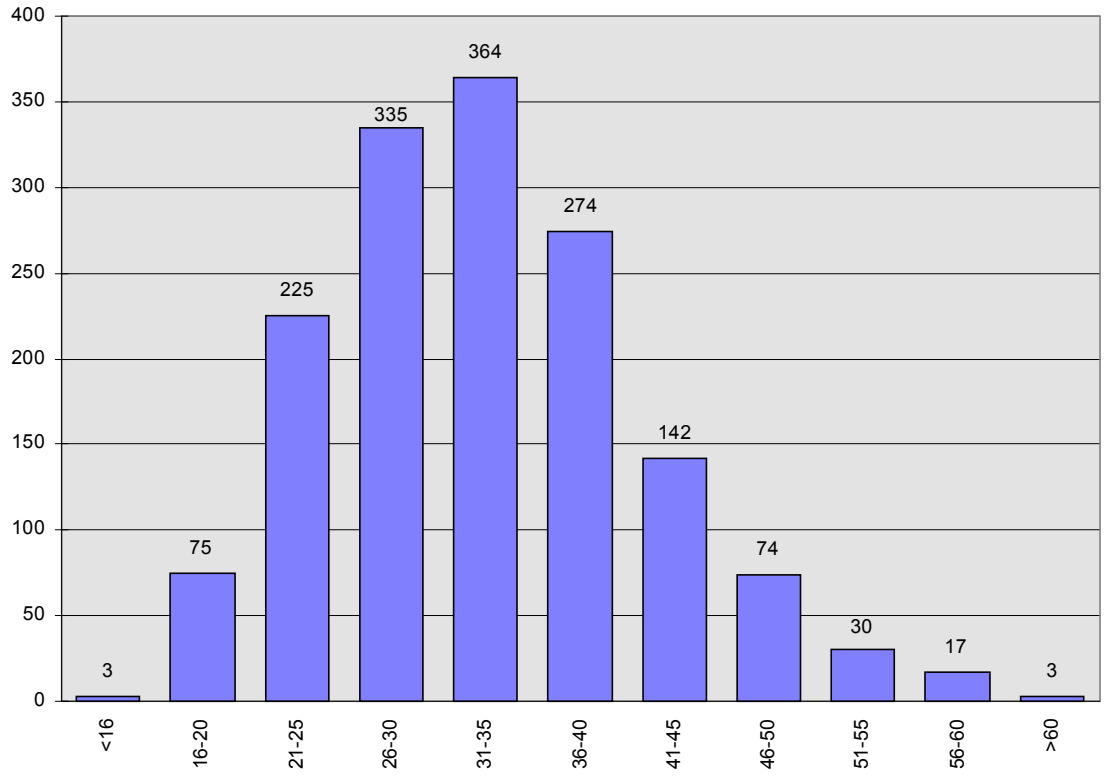
The Canadian Strategy on HIV/AIDS has identified five emerging vulnerable groups: those who use intravenous drugs, women living in poverty, many Aboriginal communities, prison inmates, and young gay men. We were curious to know if Project Sustain registration data reflected the epidemiological data with respect to young people in general, and young gay men in particular.

Chart 8: Client Age at Intake (n=2432)



Interestingly, we found that almost a third of new clients were 30 years old or younger at the time of initial intake. We compared this information with reported client age at the time of seroconversion or first positive test result.

Chart 9: Reported Age at Seroconversion or HIV Diagnosis (n=1542)



When we then looked at this information in greater detail, by selected gender and sexual orientation groups, we arrived at the following picture.

Chart 10: Client Age at Intake by Selected Gender/Orientation Groups (n=1994)

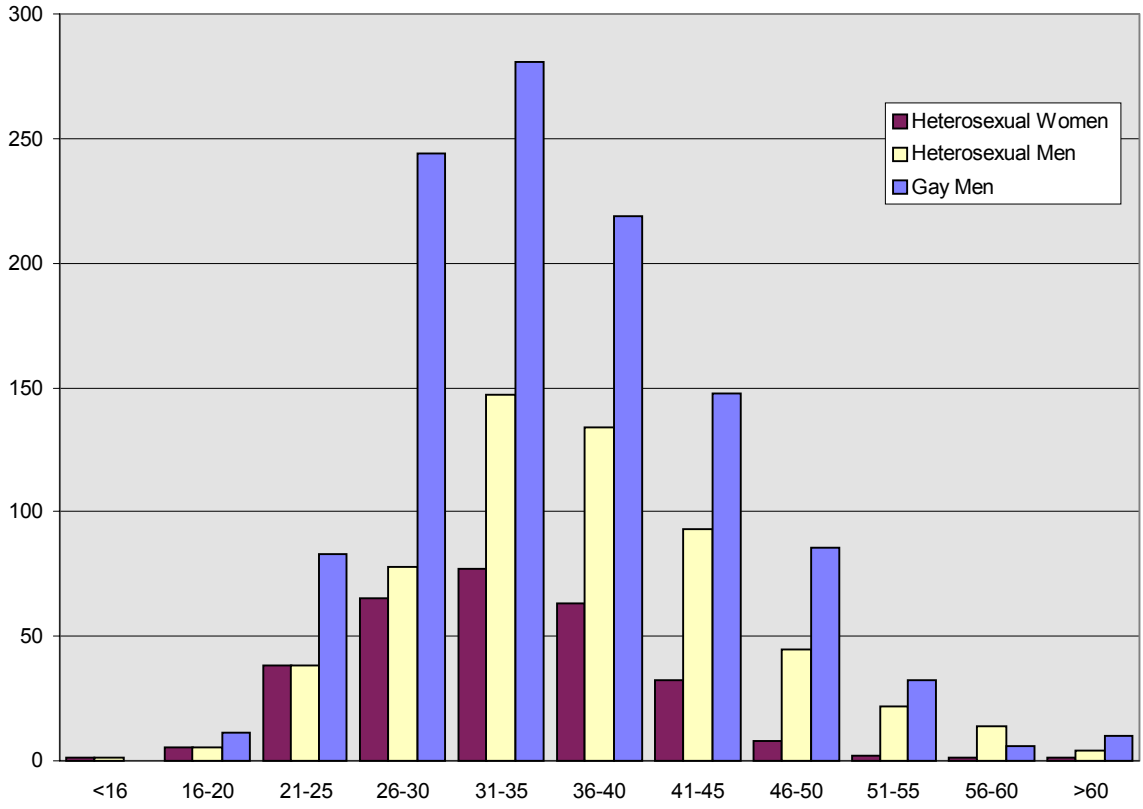
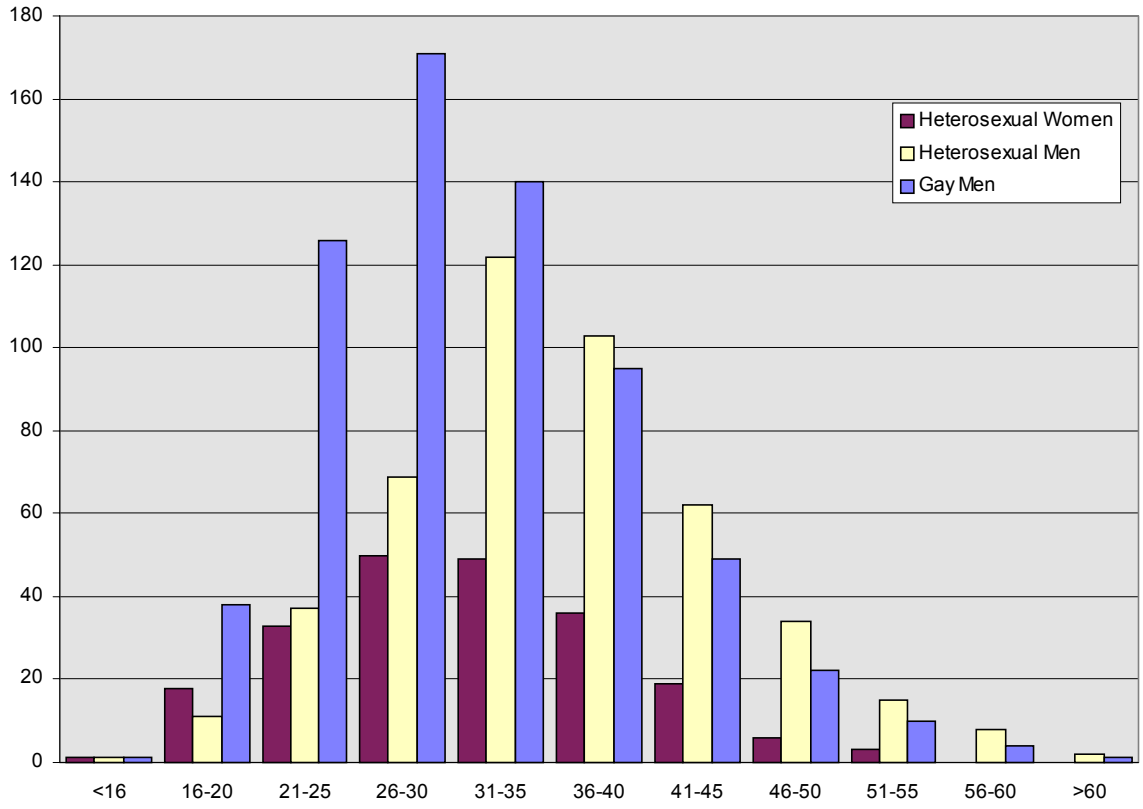


Chart 11: Reported Age at Seroconversion or HIV Diagnosis by Selected Gender/Orientation Groups (n=1336)



While these graphs do demonstrate that young gay men are registering for services, there appears to be a delay from the time of reported first positive test result to the age at intake for this population. We discuss this situation in greater detail under "Time between HIV diagnosis and initial intake," beginning on page 30.

Gender, orientation, and risk factors

The following charts represent an analysis of Project Sustain's case load by gender, sexual orientation, and reported risk factor. Bear in mind that the information presented is as provided by the client. Some clients reported their gender as transgendered, others reported their sexual orientation as transgendered, and some transgendered individuals identified themselves as either male or female.

The route of infection is identified for only 57 per cent of our client base. There are several reasons why this figure is so low. One is that we did not begin asking new clients about HIV risk factors until mid-1995. Another is that some clients did not wish to state the suspected route of infection. A third reason is that, in many cases, clients simply did not know how they came into contact with the virus. Chart 14 shows the 57 per cent of

the client base for which the route of infection is known, broken down into the known risk factors.

Chart 12: Clients by Gender (n=2442)

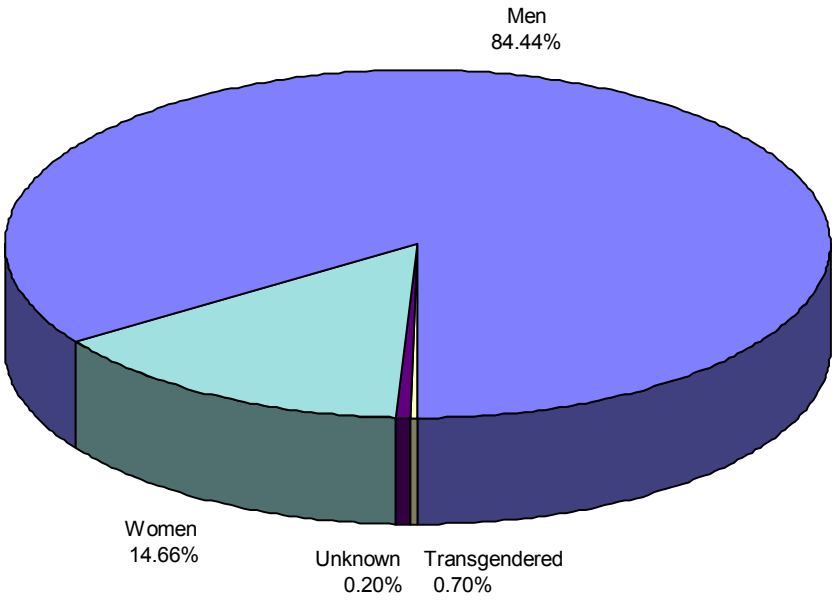


Chart 13: Clients by Sexual Orientation (n=2442)

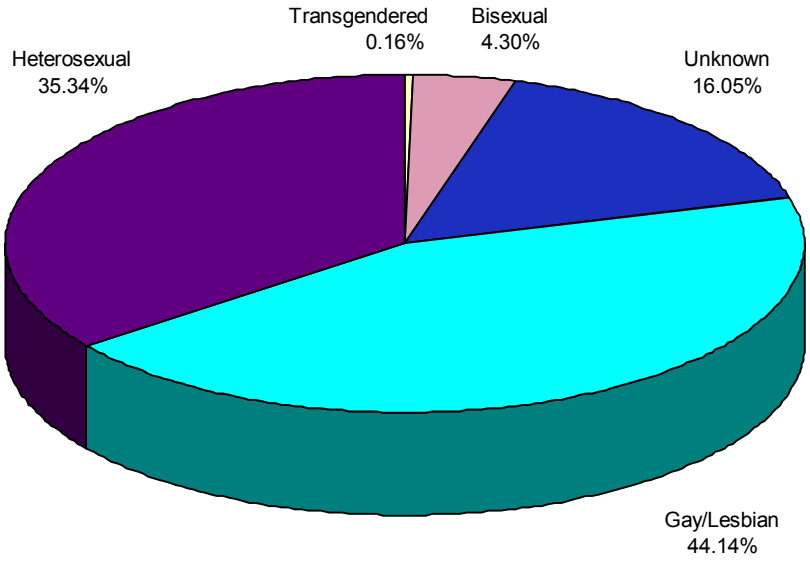
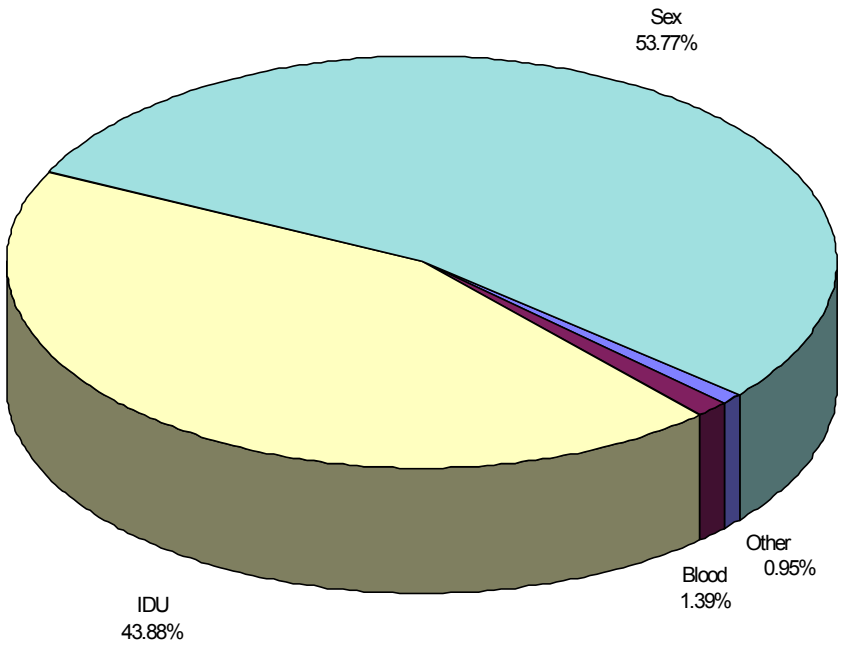


Chart 14: Clients by Known Risk Factor (n=1365)

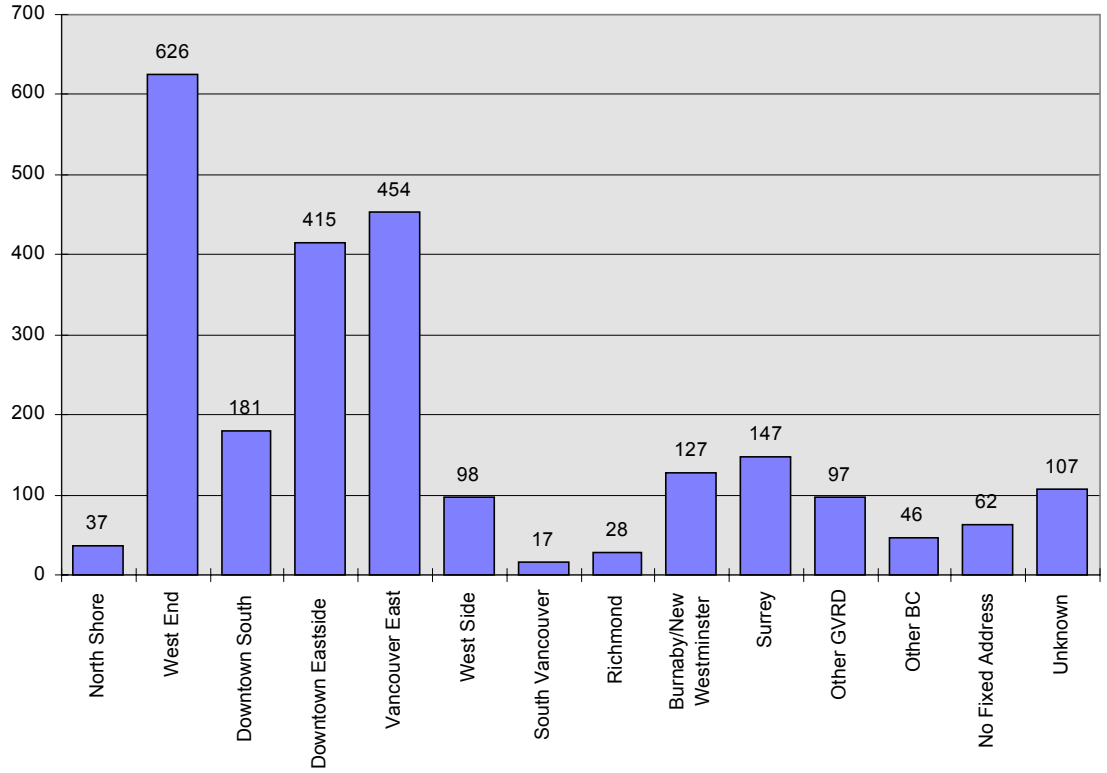


Geography

From its inception in 1983, AIDS Vancouver has been strongly associated with Vancouver's West End. The West End, with a large gay population, was the early epicentre for HIV in Vancouver. Numerous primary care physicians with HIV experience, and other support networks — AIDS Vancouver among them — located in and around St. Paul's Hospital. St. Paul's Hospital, located in the West End, developed expertise in HIV/AIDS care early in the epidemic and remains BC's leading HIV/AIDS care hospital.

By 1995 it had become clear that the epicentre for HIV had broadened to encompass Vancouver's entire downtown peninsula, including the Downtown Eastside. This neighbourhood, Canada's poorest, was starting to see an explosion of HIV infection among injection drug users and their sexual partners. An analysis of client addresses by area confirms that in fact our client base has been shifting geographically to the east.

Chart 15: Clients by Area (n=2442)



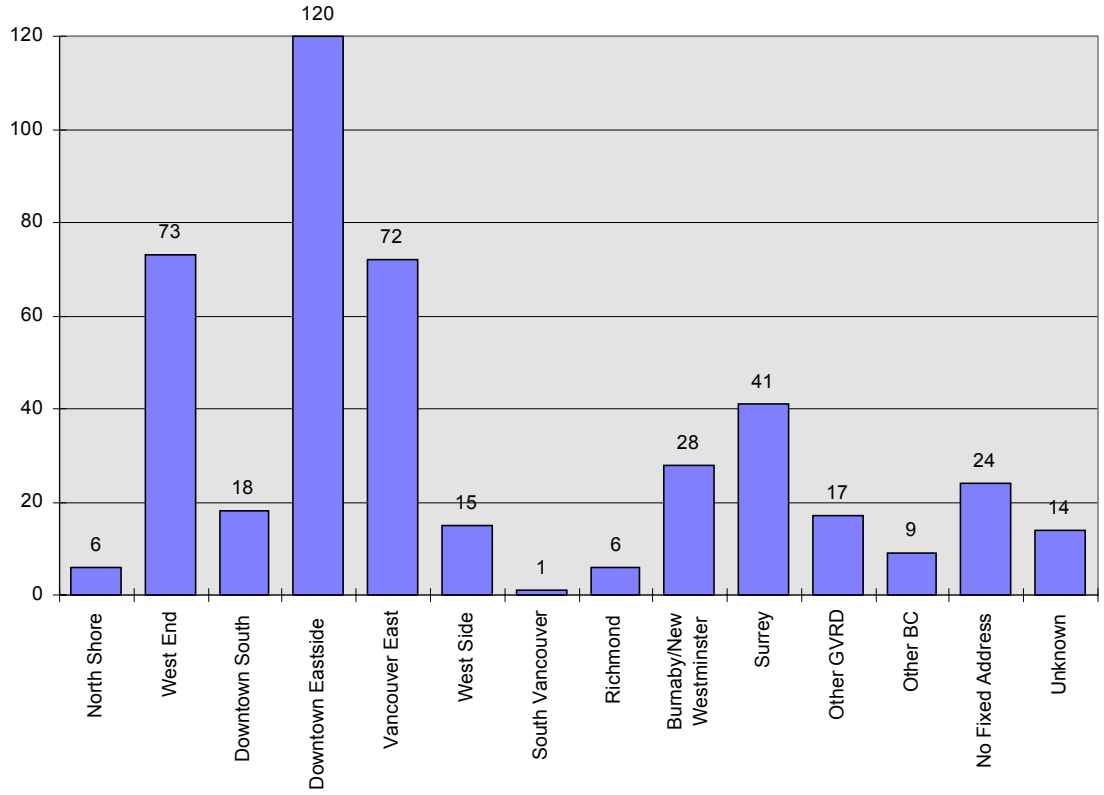
From a program planning perspective, it is most useful to note the surprising numbers of clients living in Vancouver East. Unlike the West End and the Downtown Eastside, where Project Sustain staff work in partnership with a number of agencies and clinics and are physically present at these sites, AIDS Vancouver has no formal presence in Vancouver East, other than through in-home volunteer programs such as the care team program.

Significant numbers of Project Sustain's clients live in the Burnaby/New Westminster and Surrey areas. These communities are a considerable distance from AIDS Vancouver's offices. Clients in these communities who are poor and in ill health must endure long, uncomfortable and inconvenient trips on public transit in order to obtain our services.

What are the implications for agency and program planning? Do we need to consider Project Sustain's presence in Vancouver East? Can we look at Project Sustain's presence in Burnaby/New Westminster and Surrey, perhaps with a view to establishing new partnerships and bringing services closer to home for those clients?

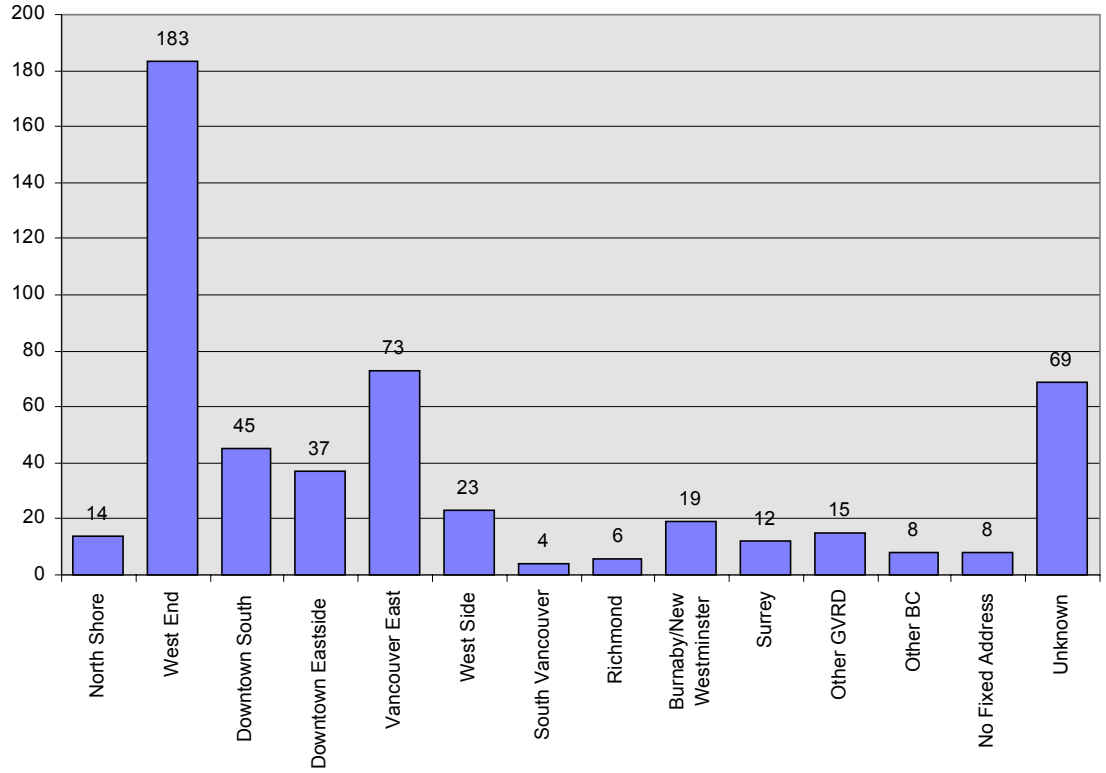
An examination of addresses for new clients who have registered with Project Sustain since March 1997 emphasizes the need to consider the above points in future planning.

Chart 16: New Intakes by Area for the Year Ending March 31, 1998 (n=444)



The records of deceased clients confirm that a significant number of those who have died were residents of the West End. Our records contain the most recent addresses provided by our clients. In some cases, as their health became progressively worse, clients from various communities moved closer to services clustered near St. Paul's Hospital, and so were recorded as West End residents. End stage community care demands can be extensive, and there continues to be a very large group of Project Sustain clients living in the West End who rely on the knowledge that AIDS Vancouver programming is available should it be needed.

Chart 17: Deceased Clients by Area (n=516)



Income Sources

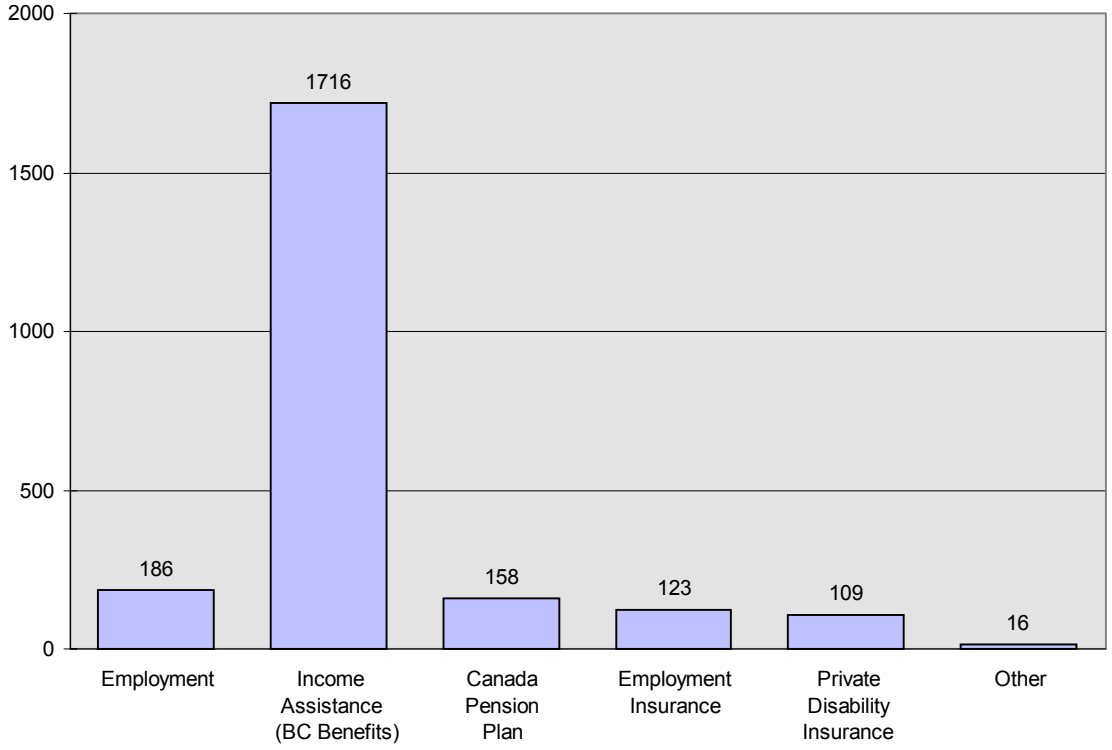
Perceptions about AIDS Vancouver's relevance to people living in poverty vary widely. Some clients and community groups have suggested that AIDS Vancouver is more relevant to those in reasonable financial circumstances, while others have complained that programming is targeted almost exclusively at those with pressing financial needs.

In fact, Project Sustain continues to target those living in isolated, poor, and unsupportive conditions. With increasing survival rates, it is not surprising that chronic poverty, lack of appropriate affordable housing, growing rates of HIV-related mental illness, and inadequate nutrition are becoming more and more common. The expanding numbers of immigrant families and women with children who register with AIDS Vancouver are turning case management and volunteer support programs into an ever more complex challenge as staff and volunteers assist clients in negotiating a multi-systemic maze of helping networks.

The following graphs show that the overwhelming majority of Project Sustain clients rely on government income support programs, and a great many of these clients receive the highest available level of provincial disability benefit. This level of dependence on income support programs reflects, in part, the fact that many of our clients are young and

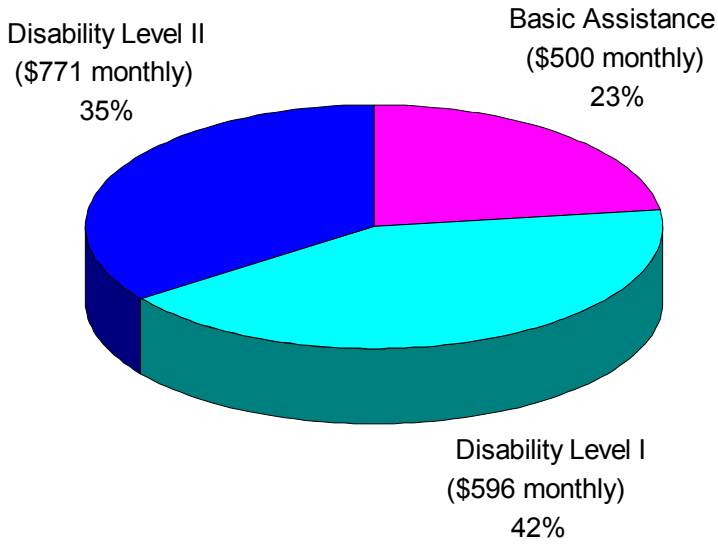
therefore do not have sufficient workforce involvement to qualify for private benefit plans. It is also indicative of the paucity of income options available to many of those who find themselves living in isolated, unsupportive circumstances.

Chart 18: Clients' Income Sources (n=2080)



Clients who receive income from more than one source are included under each applicable category in the preceding chart. For example, some individuals who receive Canada Pension Plan benefits are given an additional sum under the BC Benefits Act to a combined maximum of $771 per month.

Chart 19: Income Assistance Levels for Clients Receiving BC Benefits (n=1716)



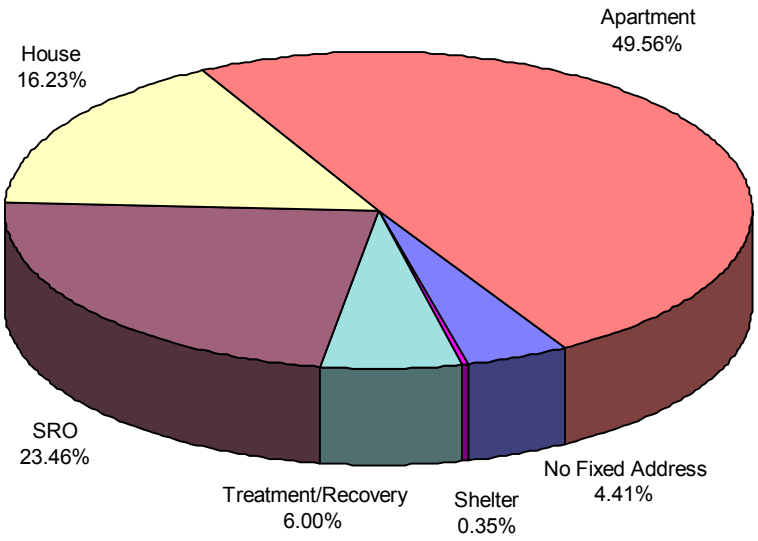
It is shocking that nearly a quarter of Project Sustain clients subsist on basic benefits of $500 per month. Some clients, particularly refugee claimants, do not qualify for higher benefit levels, irrespective of their health status. Clients in receipt of the maximum amount of benefits under the BC Benefits Act have a total annual income of $9,252 — considerably less than $17,409, which is the current figure Statistics Canada gives as the low income cut-off for a single person in a city with a population of over 500,000.

Housing

Next we wanted to examine housing, the most costly of basic needs. Anecdotal evidence suggests that higher rents and living costs have been driving individuals living with HIV from the downtown peninsula into more affordable living circumstances in Vancouver East and surrounding suburbs.

The results of our research were no surprise. While apartment dwellers continue to make up a large proportion of clients, reliance on income assistance has forced many clients into single room occupancy (SRO) hotels. Rooms in these hotels are often without plumbing or cooking facilities, and bathrooms are usually shared, sometimes by as many as thirty people. Such circumstances are obviously highly unsuitable for persons living with HIV/AIDS. Other clients, among our city's most marginalized residents, were already located in unstable housing circumstances at the time of their HIV diagnosis. At the time of intake with Project Sustain, their housing situation remained essentially unchanged. More than a third of our clients have no housing, or are living in temporary situations, or have long-term but substandard housing.

Chart 20: Housing Circumstances at Intake (n=1134)



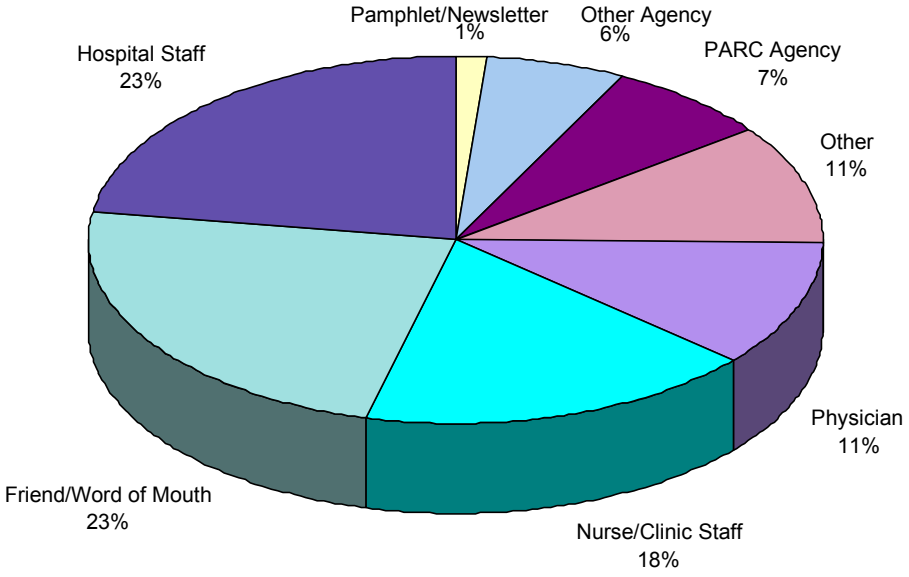
These findings emphasize the urgent need to provide adequate housing for people living with HIV/AIDS.

Patterns of Service Use

Referral sources

We did not begin tracking referral sources consistently until early 1996. There may be too few records here to give us reliable community profile data on which to base our planning. Project Sustain's history of close collaboration and service delivery partnerships with hospitals, clinics, and physicians has resulted in enhanced staff awareness at those settings; together, they generate more than half of the referrals recorded.

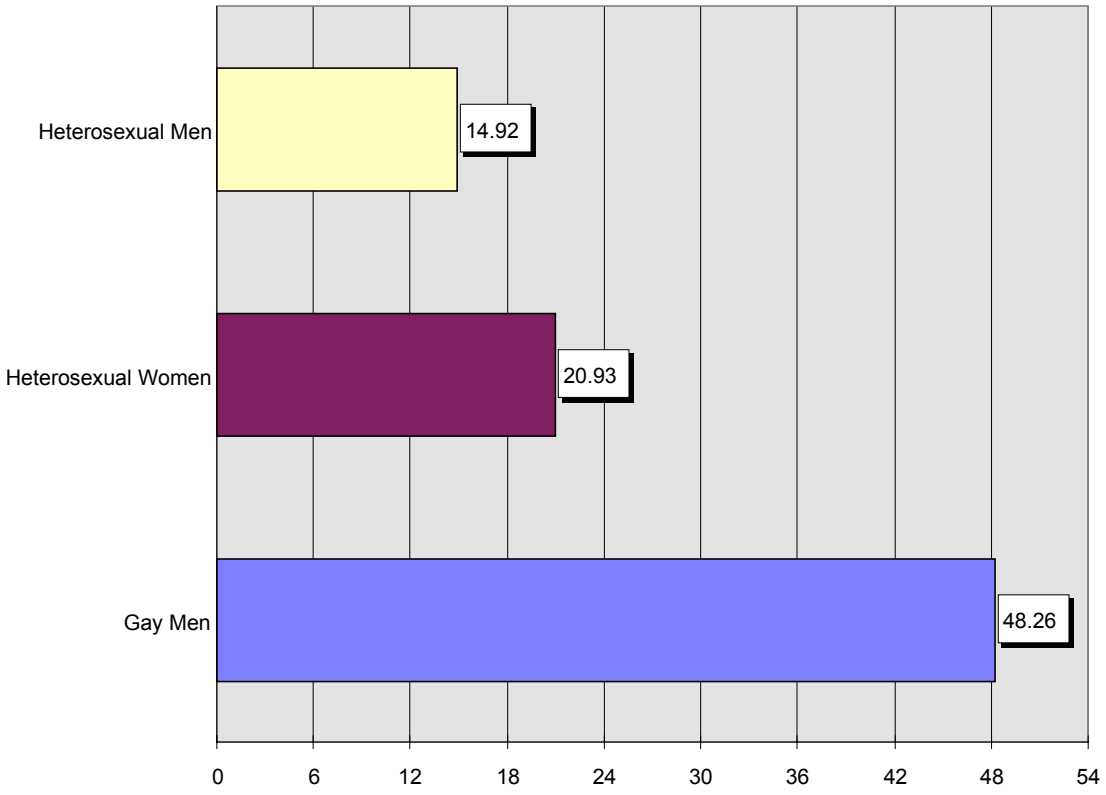
Chart 21: Referral Sources (n=651)



Time between HIV diagnosis and initial intake

Year after year, there have been consistent, marked differences among several client groups in terms of the average number of months between receiving a positive HIV test result and registering for services with AIDS Vancouver. The following graph represents the pattern from 1993 through to the end of March, 1998.

Chart 22: Average Time in Months from Reported Date of Seroconversion or HIV Diagnosis to Intake (n=1320)



As shown by the graph above, gay men on average wait just over four years from the time they seroconvert or test positive until the time they register for services with AIDS Vancouver. In stark contrast, the same waiting period is less than two years for heterosexual women and just over a year for heterosexual men.

One of the factors that may help to explain the comparatively long delay between the time gay men seroconvert or test positive and the time they register for services is that many gay men have access to good health care and informal support networks and so may not feel as pressing a need to connect with the services that AIDS Vancouver offers.

Heterosexual men who are HIV-positive connect with Project Sustain a relatively short time after receiving their diagnosis. Further research is needed to determine exactly why this is. Many of these men live in the Downtown Eastside and have a history of injection drug use. Community outreach efforts by Project Sustain and other HIV/AIDS programs and research projects have made some services more accessible to these men and may help to account for the fact that they register for services with Project Sustain sooner, on average, than their gay male counterparts.

By comparing reported age at seroconversion or first positive test result against age at initial intake, we can begin to build a picture of the task we are facing at Project Sustain. The next three charts show that clients who identify as gay men are generally seroconverting or testing HIV-positive at a younger age than heterosexual men or women. However, given that heterosexual men and women are likely to register for services sooner after seroconversion or an HIV diagnosis, the age profile of all clients at the time of intake tends to look fairly similar.

Chart 23: Reported Age at Seroconversion or HIV Diagnosis and Age at Intake for Heterosexual Women (n=213)

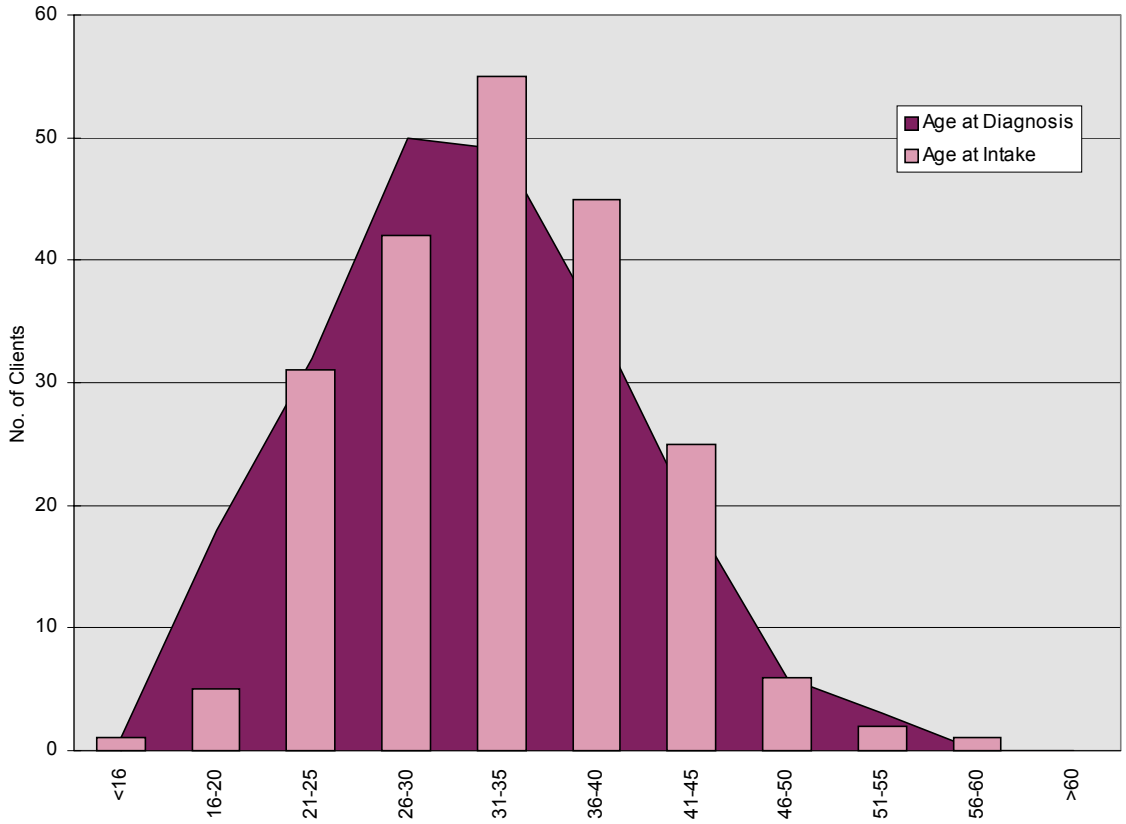


Chart 24: Reported Age at Seroconversion or HIV Diagnosis and Age at Intake for Heterosexual Men (n=453)

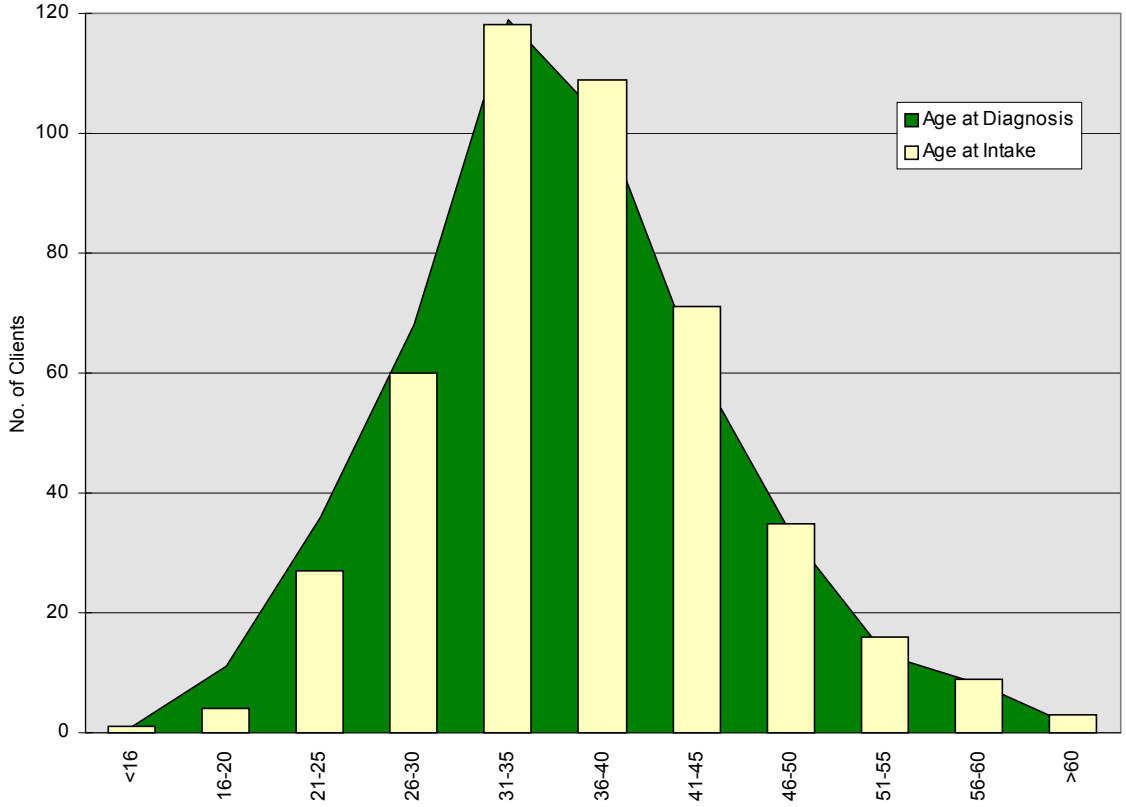
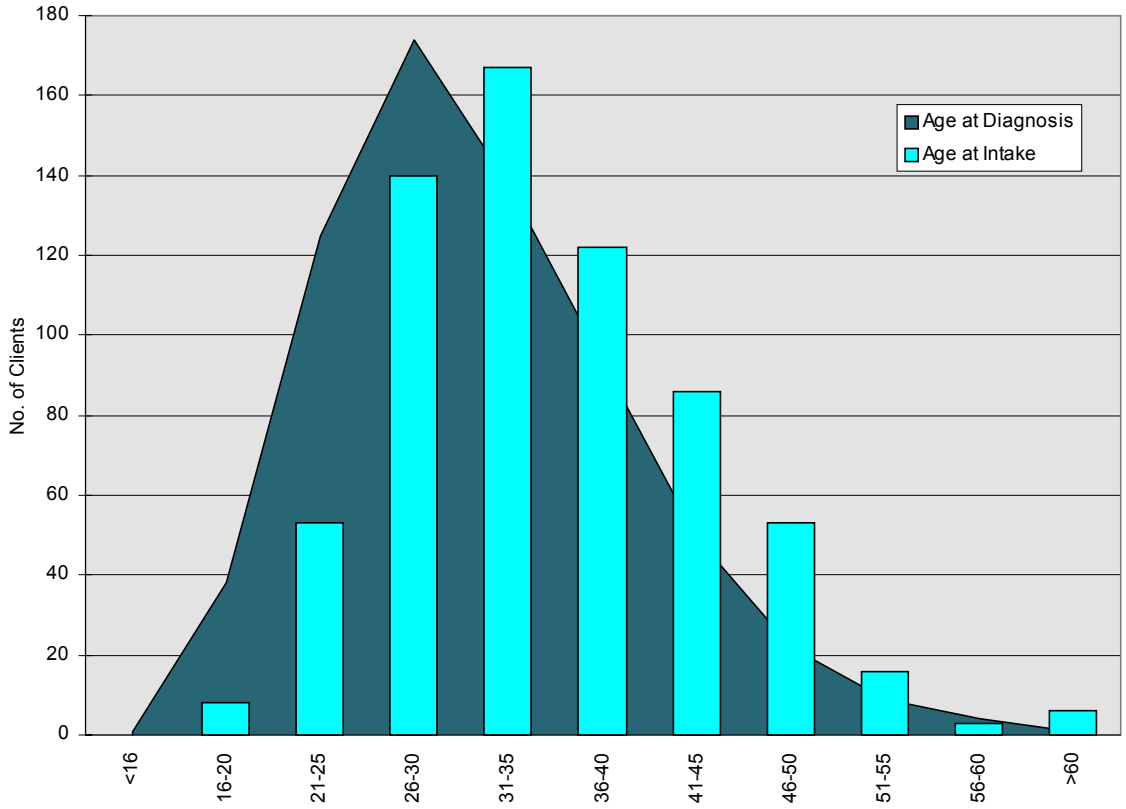


Chart 25: Reported Age at Seroconversion or HIV Diagnosis and Age at Intake for Gay Men (n=654)



Specific program usage patterns

Project Sustain offers a broad range of services, including case management; medical equipment loans; financial assistance; home and hospital visitors; counselling and therapy; volunteer in-home care; and food and nutritional support. This section examines three of these programs in detail.

Counselling

Project Sustain's professional counselling and therapy program offers long-term individual, couple, or family counselling services to persons living with HIV/AIDS whose annual income is below $20,000. Counselling is provided at no charge by volunteers who include registered clinical counsellors, art therapists, and psychologists in private or community practice in Greater Vancouver. This program was developed and expanded as clients requested an opportunity to participate in individual therapy with therapists trained in HIV issues. Project Sustain clients with a limited income who request long-term counselling are matched with therapists who are prepared to commit to a counselling relationship with an AIDS Vancouver client for one year on a pro bono basis. Therapists are screened and complete a two and a half day volunteer orientation

prior to receiving a referral. Clients are matched for particular expertise of therapist, geographical location, and other personal preferences. Therapy sessions are usually held at the therapists' offices, or occasionally at Project Sustain's offices during early evenings or on Saturdays.

Chart 26: Counselling Program Usage by Gender (n=201)

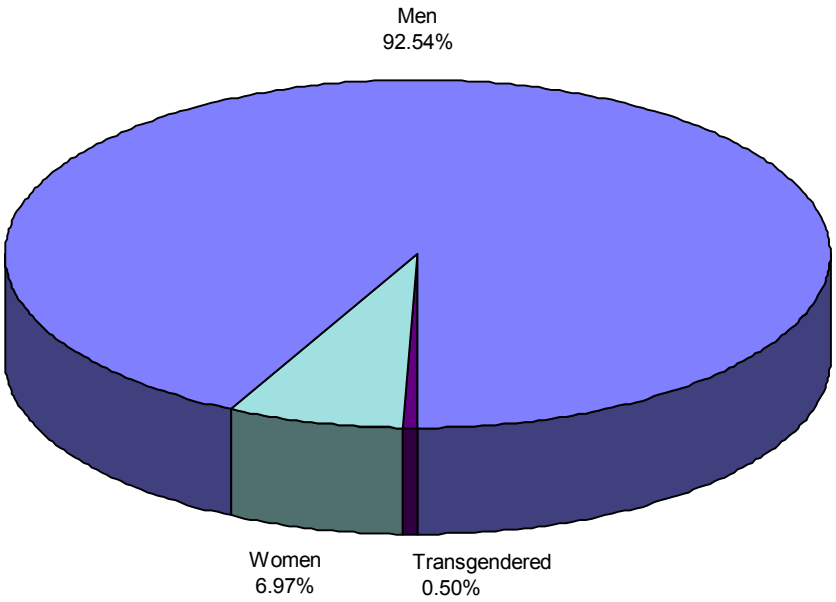
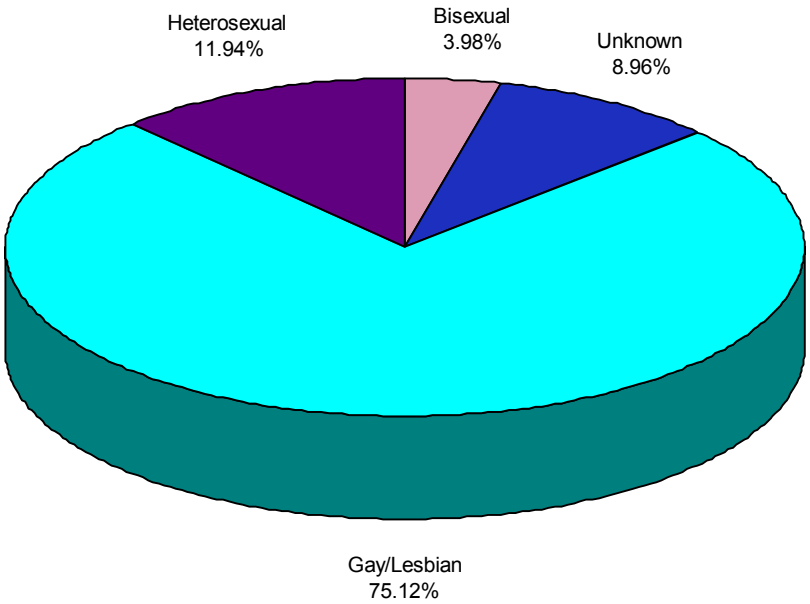


Chart 27: Counselling Program Usage by Sexual Orientation (n=201)



Participation in this program requires a relatively high degree of social organization: stability in housing, nutrition, and income source may contribute to an individual's capacity to attend weekly appointments. Relatively few clients with a history of injection drug use have been placed in this program.

This program is unable to provide psychiatric care or drug and alcohol counselling. In British Columbia, drug and alcohol counselling is provided through the Ministry of Children and Families, although many clients report long delays between the initial referral and a counselling appointment. Psychiatric care is available in emergency situations through referral to resources such as the Psychiatric Assessment Unit at Vancouver Hospital. In non-urgent situations, referral to a psychiatrist can be made, though again waiting lists are long. In the case of serious or chronic mental illness, support is available through Community Mental Health Teams operated by Greater Vancouver Mental Health Services.

Chart 28: Counselling Program Usage by Risk Factor (n=201)

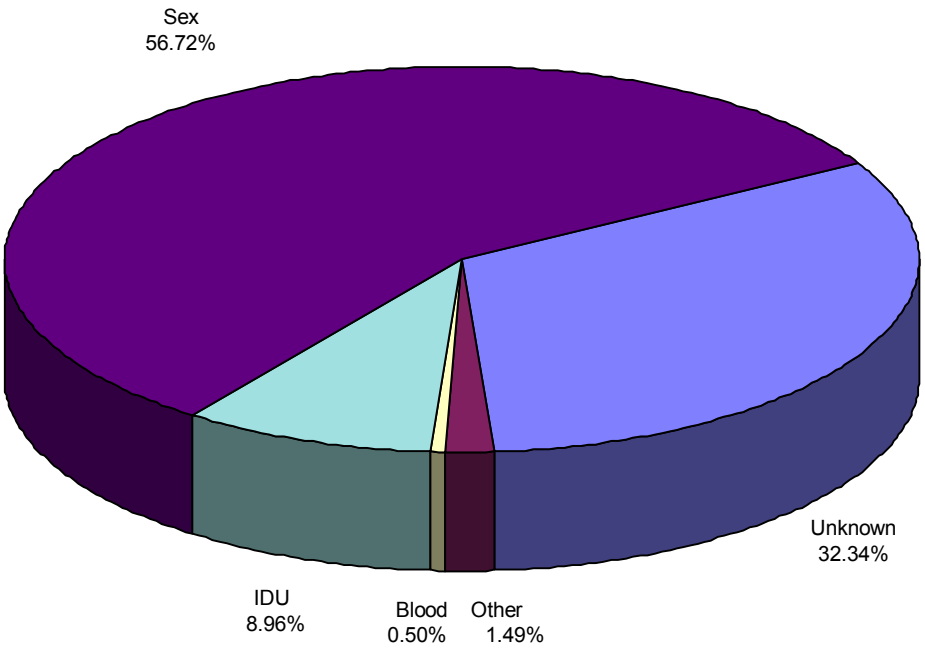
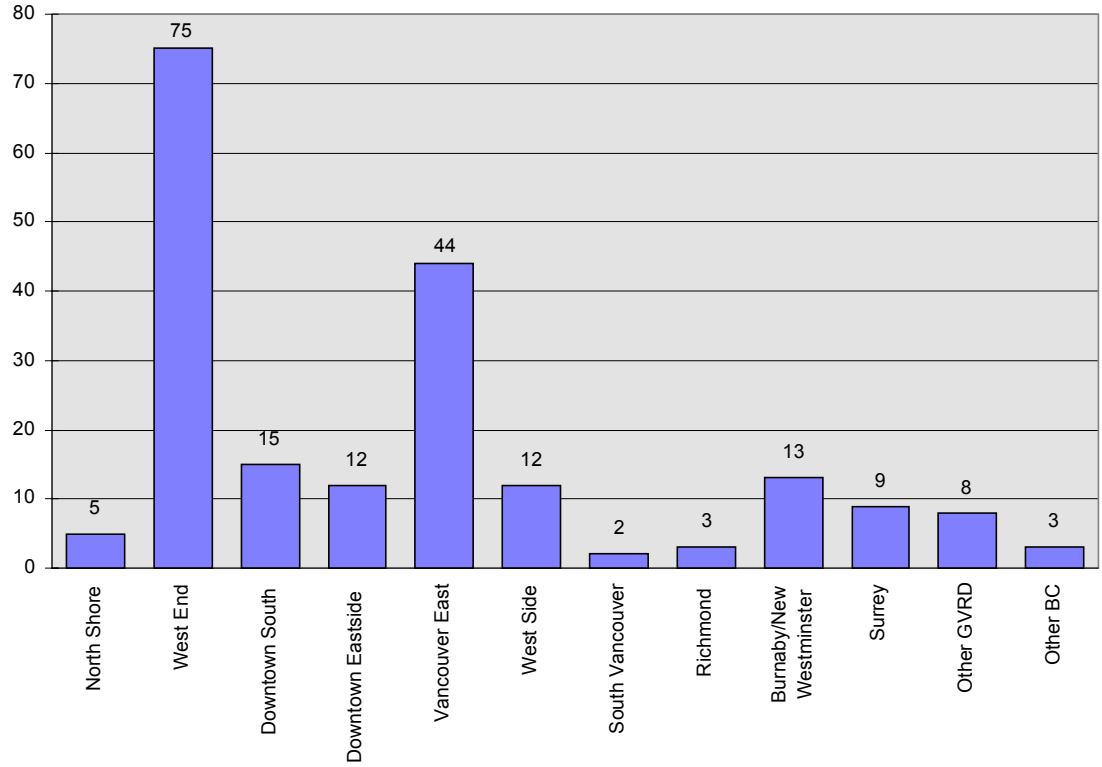


Chart 29: Counselling Program Usage by Area (n=201)



Grocery

Persons living with HIV/AIDS have special nutritional requirements, in addition to basic food needs. The AIDS Vancouver grocery provides supplemental nutrition and some personal hygiene products to persons living with HIV/AIDS whose annual income is below $20,000. The grocery has distributed more than $200,000 worth of food each year since 1995, mostly through a small distribution centre open two days each week. Not all clients who are referred to the grocery use it every week. Average weekly usage generally fluctuates between 400 and 500 clients, though at particularly busy periods as many as 625 individuals a week have used the grocery service.

Chart 30: Grocery Referrals by Gender (n=1638)

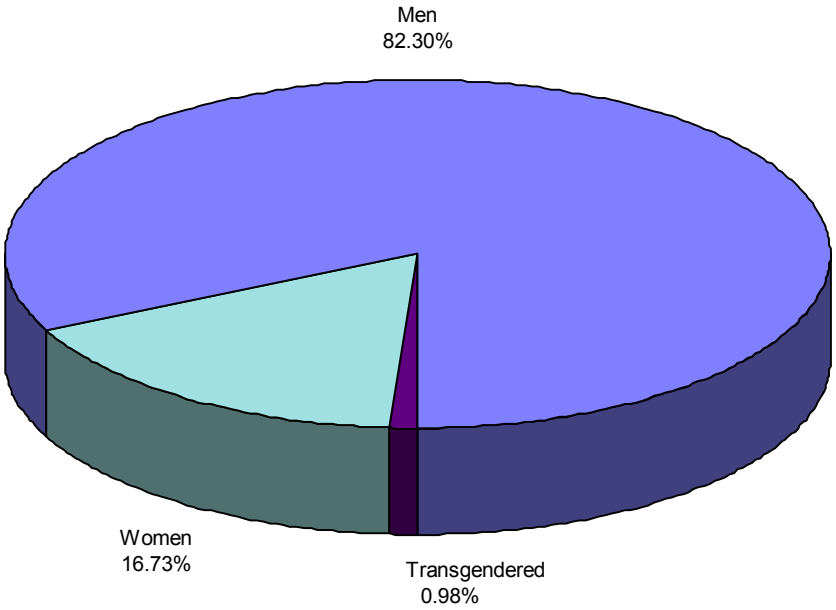
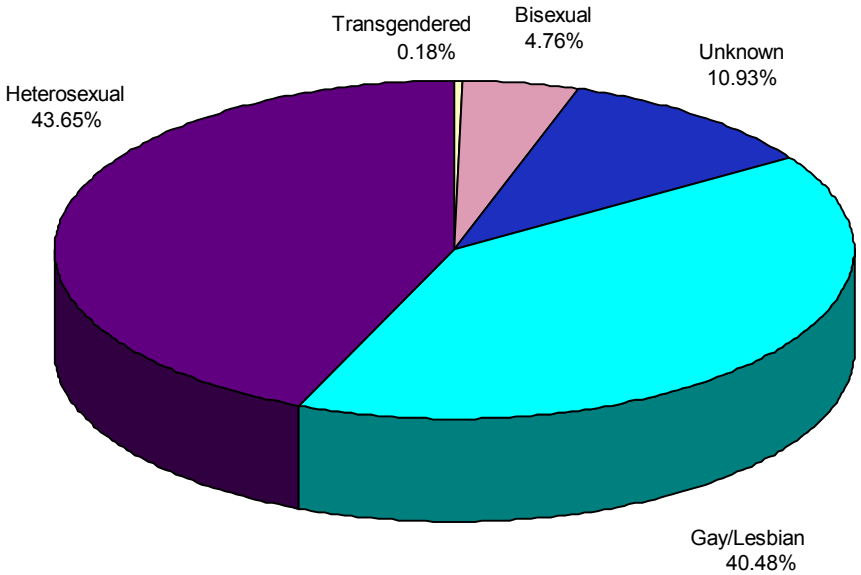
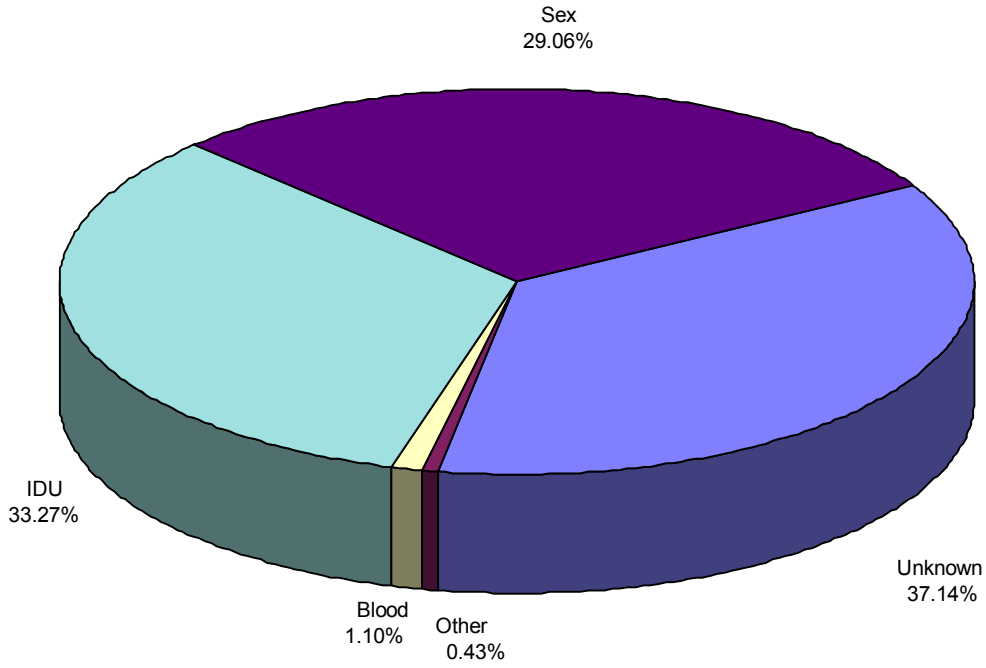


Chart 31: Grocery Referrals by Sexual Orientation (n=1638)



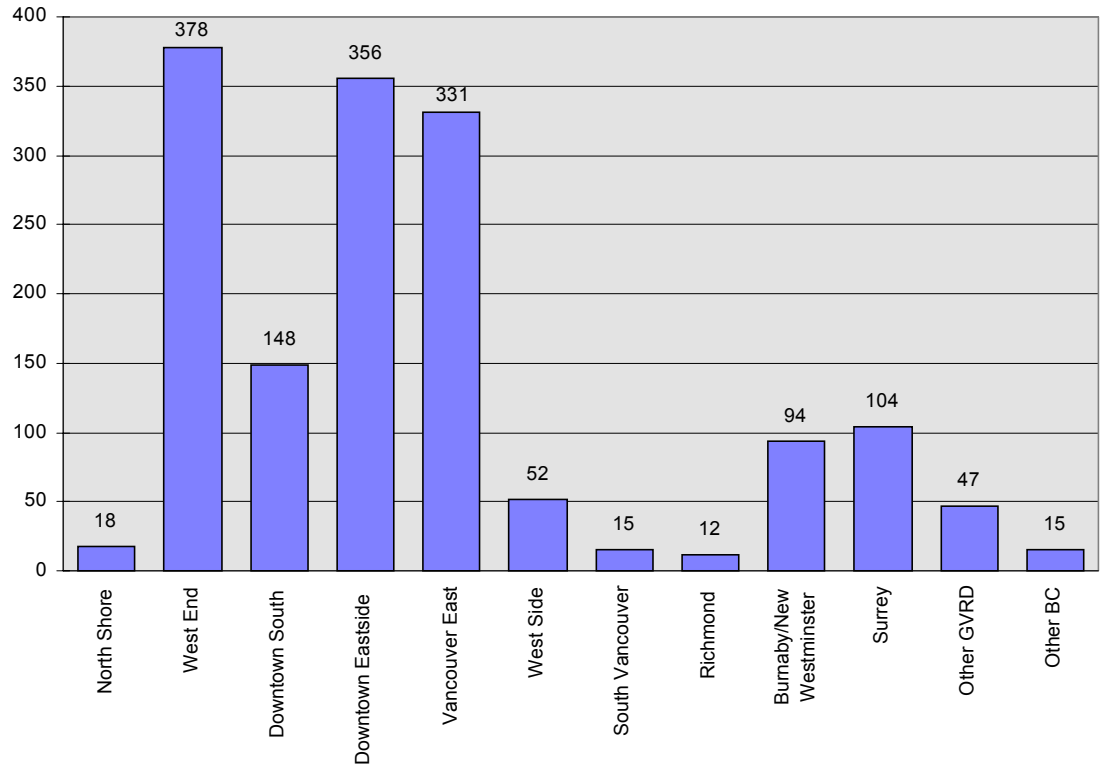
The grocery operates through the generous support of individuals, businesses, community groups, and foundations. The grocery also receives weekly deliveries of supplies from the Vancouver Food Bank.

Chart 32: Grocery Referrals by Risk Factor (n=1638)



The grocery is the program that serves the largest number of Project Sustain clients each week. We were curious to know what effect, if any, the emergence of new risk groups was having on the overall relevance of food and nutrition services, and to better understand the role food and nutrition play in the lives of injection drug users. A separate report, titled *Nutrition, HIV, and Injection Drug Use in Downtown Vancouver*, is being guided by a core group of service users who have a history of injection drug use.

Chart 33: Grocery Referrals by Area (n=1638)



The demographics of grocery usage differ significantly from those of Project Sustain's other support programs. The participation rate of women, heterosexual clients, those with a history of injection drug use, and residents of Vancouver's poorer neighbourhoods is noticeably higher. The grocery is the only Project Sustain program that addresses a basic human need.

Care Teams

Care teams are made up of trained volunteers who provide a combination of companionship, practical assistance, and personal care to people living at home in the Greater Vancouver areas who are in the later stages of the HIV/AIDS continuum. Care teams supplement the long-term care services offered through health departments and are designed to help persons with HIV/AIDS to live at home as long as possible or desired. Clients generally receive support from one to three care team volunteers, although exact numbers vary with client need. Referral sources include Project Sustain case managers, hospital social workers, home care nurses, physicians, and other community agencies.

Chart 34: Care Team Program Usage by Gender (n=102)

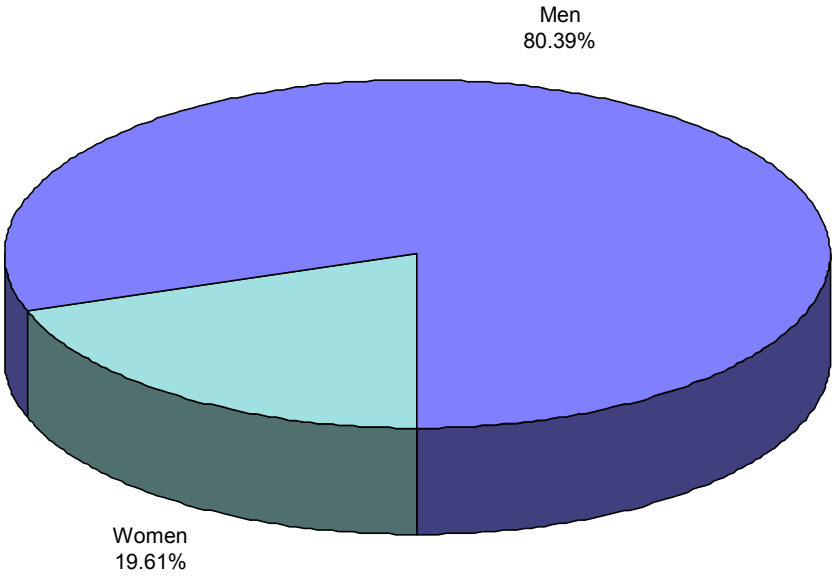
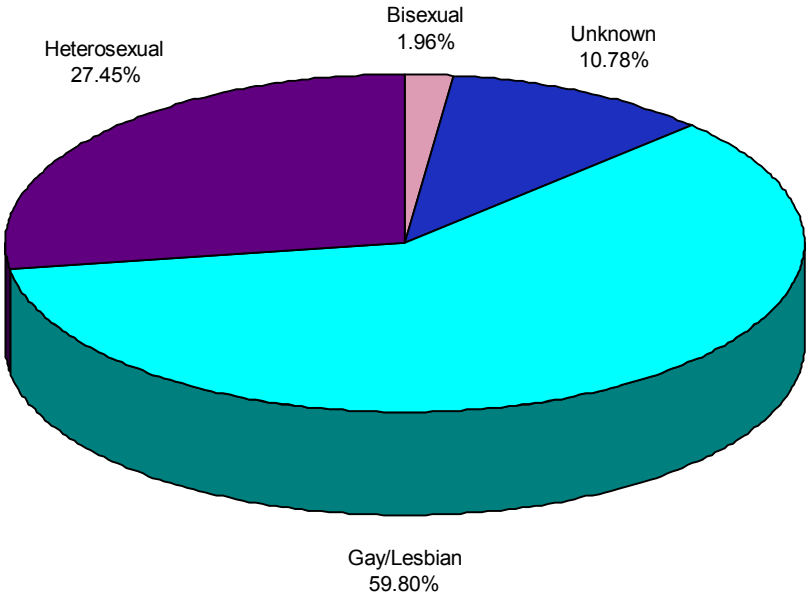


Chart 35: Care Team Program Usage by Sexual Orientation (n=102)



Care team support is an intensive endeavour. It requires a high degree of commitment on the part of volunteer teams, and as HIV treatments improve, care team involvement with an individual client can last a considerable length of time.

Chart 36: Care Team Program Usage by Risk Factor (n=102)

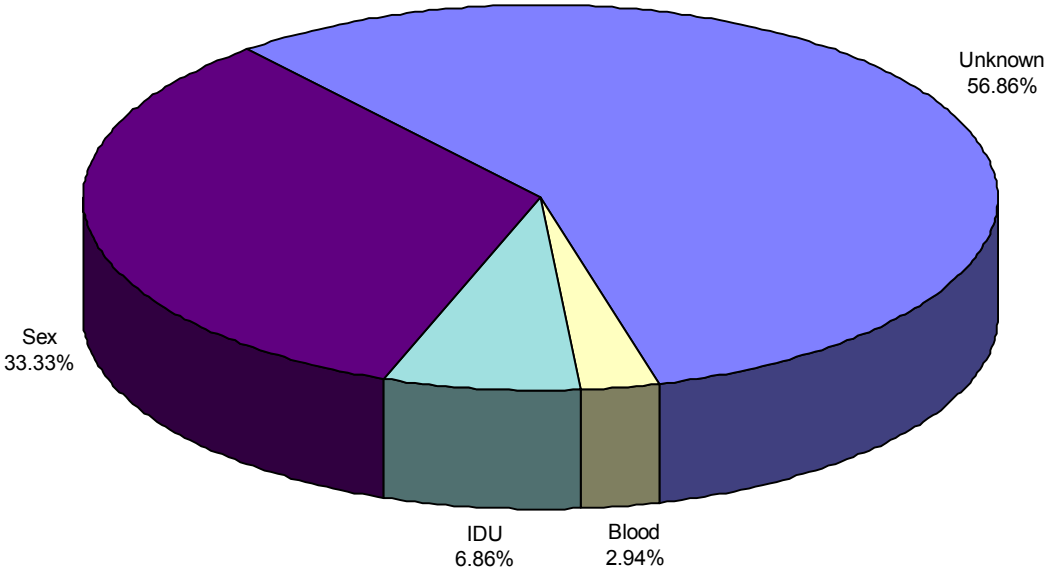
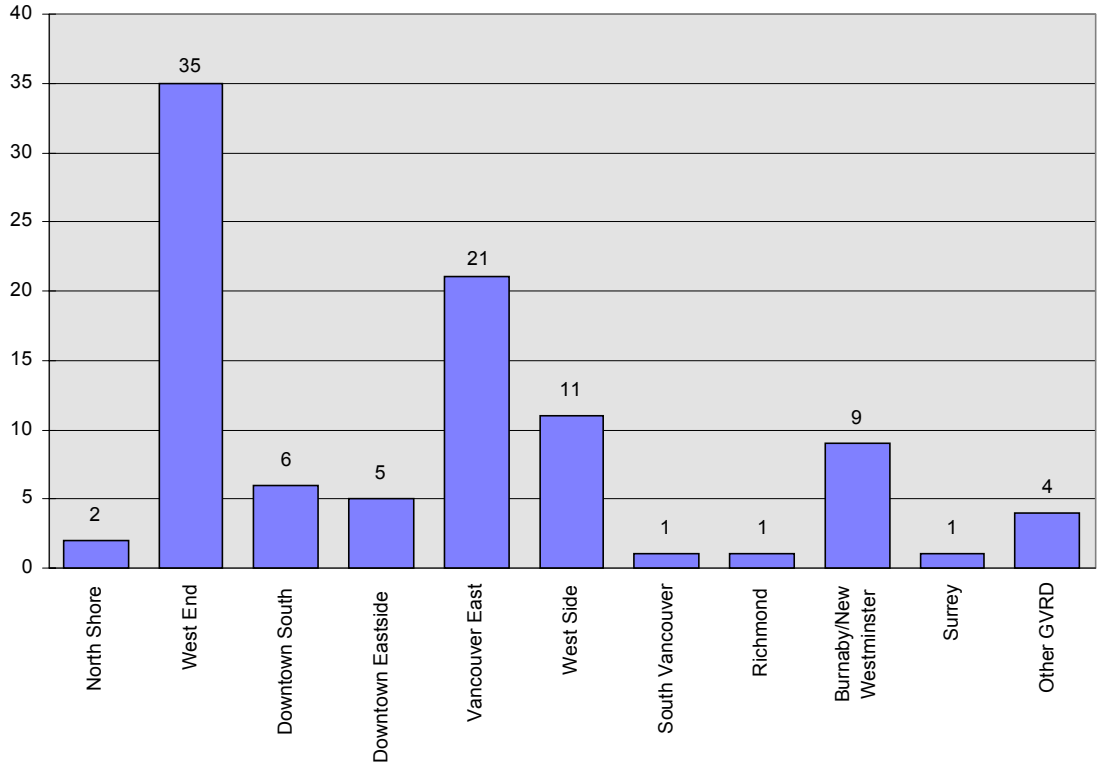


Chart 37: Care Team Program Usage by Area (n=102)



Care team support is fairly evenly distributed throughout the Vancouver area, although relatively few clients living in the Downtown Eastside have received care team support. This may be linked to the substandard and even unsafe housing circumstances that are prevalent in that community. Where a client is living in unsafe conditions, Project Sustain staff will attempt to secure a safer housing situation where volunteer care team and other support services can be provided.

EVALUATION

This project has given the staff at AIDS Vancouver a better idea of what can, and what cannot, be learned from the database we have in place. The primary limitation of the study is the lack of consistently collected data prior to 1992.

Who are we serving, both demographically and geographically?

We are able to answer this question fairly thoroughly. We can now speak with confidence about our clients' age, gender, sexual orientation, area of residence, and (to a lesser extent) reported route of HIV infection.

We cannot, however, provide any statistically sound analysis of our clients' self-identified ethnic and cultural heritage. Many clients are unwilling to provide this information, while others wish to be identified simply as Canadian. Staff and volunteers do not always ask for this information, since its relevance to individual service planning is not readily apparent.

Who are we not serving?

Provincial tracking of HIV antibody testing gives us a good sense of the demographics of this epidemic. By comparing our intake data with BCCDC testing data, we have been able to develop a good picture of those groups we are serving and those we are not.

However, we did not begin recording the route of HIV infection until 1995 and so have not yet collected sufficient data to draw any conclusions with confidence. Furthermore, BCCDC statistics do not pertain to those who move to British Columbia after testing positive for HIV elsewhere.

What factors lead people to our services?

The database is well suited to capturing referral information about those individuals who find themselves confronting a problem, then reaching out to the agency to help address the problem. Not surprisingly, the most common referral sources were hospital social workers, clinic staff, and physicians, with whom AIDS Vancouver has developed a collaborative relationship through the years. Shared programming, the visibility of AIDS Vancouver staff and volunteers, and Project Sustain's ability to respond to basic nutritional and financial needs have all influenced the referral source statistics.

However, not all new clients can identify a single referral source or tell us exactly why they have come to AIDS Vancouver. Some clients talk about having known of AIDS Vancouver's existence for years before finally feeling ready to connect with community services. Others have heard about a particular service such as the Grocery, but are unclear that it is an AIDS Vancouver program. The database in its current form does not capture the more complex social factors that lead people to our services.

Are we accessible to individuals from a wide range of life experiences?

The database is able to give a good picture of accessibility by gender, risk factor, age, orientation and area of residence. It must be recognized, though, that other qualitative tools are required to measure the range of life experience.

Do our services reflect current epidemiology and newly emerging risk groups?

The database is an indispensable tool for these measurements. Specifically, we are able to compare our client group with provincial epidemiological data and create a picture of who we are serving, with one exception: we do not have a good picture of our client group's cultural and ethnic background.

Are some programs limited in the demographic populations they serve?

The simple answer is yes, there are limitations. Long-term counselling program usage, for example, does not match the current demographic profile of Project Sustain clients. The grocery, by contrast, is a program that seems to be highly accessible to the entire range of our clients.

Is there a relationship between program availability and quality and length of life?

We are unable to examine this question, given the data available to us. In terms of length of life, many services have been developed specifically for high need, end stage support. In terms of quality of life, the data do not exist to make this measurement. Clearly, a qualitative approach to this question would be more appropriate.

Are there patterns in service access or usage which could inform future programming?

These are some of the most important and useful results. We find that data exist that allow us to understand who is making use of Project Sustain programs, at what point along the HIV/AIDS continuum they are registering for services, and who is referring clients to us. For example, we find that different demographic groups are apt to connect and register with AIDS Vancouver at different rates subsequent to an HIV diagnosis. Together with BCCDC epidemiological data, this has helped to explain some of the trends we have experienced in recent years and has provided us with valuable information on which to base future programming.

The most significant pattern identified is the contrast between the increasing number of individuals identifying injection drug use as the route of infection, and this group's relatively low participation rate in two of three particular programs examined. This points to the need for further consultation and needs assessment with Project Sustain clients who have a history of injection drug use. A thorough needs assessment may prove useful in determining whether current programs are sufficient, or whether, in fact, new, targeted programs must be developed.

LESSONS LEARNED

In developing the Project Sustain case management database project, we learned several important lessons:

- Our existing data records could be combined and integrated into a useful case management database.
- Data gathering in a service delivery context must be a comprehensible and integral part of individual service planning. Put another way, requests for information that do not appear strictly relevant to individual service planning will be met with scepticism by clients, volunteers, and staff.
- The data gathered can yield useful program planning information. On the basis of information provided by clients, it is possible, for example, to:
    - get an accurate picture of who is using particular services;
    - confirm impressions or dispel myths about who does or does not use a particular program;
    - understand patterns of service use among different risk groups or age groups, to give but two examples.

For AIDS service organizations wishing to develop database analysis capability, we recommend the following:

- Begin by examining existing data records.
- Re-examine confidentiality policies to ensure that individual service planning occurs in a respectful manner.
- Ensure that everyone involved in service delivery has an opportunity to identify information that is already being collected, but not recorded, as an integral part of service planning.
- Canvass the volunteer pool to locate persons with experience in database development. Be cautioned that designing an integrated system to capture data gathered from several diverse programs is a large job. A volunteer team with some professional support may be most appropriate.
- Ensure that the person responsible for computer servicing or network support has a good understanding of the database development process and confidentiality needs, and is able to sensitively assist non-technical users with the software and hardware problems that invariably arise.
- Once a prototype system has been developed, allow it to be used for a reasonable period of time in order to assess which information categories are useful, which are not, and which have been overlooked.
- Ensure that there are parallel methods of qualitative data gathering in place to complement the quantitative data tracked by the integrated case management database.