SHROFF CONSULTING

Setting A New Standard for HIV/AIDS Care: The Dr. Peter AIDS Foundation

Final Report

May 1998
Shroff Consulting

Dr Farah M Shroff
Box 12148 Nelson Square
808 Nelson Street, suite 1716
Vancouver BC
V6Z 2H2
CANADA

Telephone: (604) 221-7660
Fax: (604) 685-8993
Email: fms@ece.ubc.ca
TABLE OF CONTENTS

PREFACE .................................................................................................................. 5

AFFIRMATION .......................................................................................................... 6

EXECUTIVE SUMMARY .......................................................................................... 7
   External Stakeholders’ Perspectives ................................................................. 8
   Participant Perspectives .................................................................................... 9
   Perspectives of PLWAs who are Non-active and Non-Participants of the DPC 10
   Volunteer Perspectives ................................................................................... 10
   Staff Perspectives ............................................................................................ 11
   Conclusions ...................................................................................................... 12

I. INTRODUCTION .................................................................................................... 13

II. THE DAY CENTRE CONCEPT .......................................................................... 14

III. DR PETER CENTRE (DPC) ................................................................................ 16
   A. The DPC’s place in the health care continuum ............................................. 16
   B. Mandate ........................................................................................................ 17
   C. Goals .............................................................................................................. 17
   D. Structure ........................................................................................................ 18
      governance and management structure ......................................................... 18
      Program Features ......................................................................................... 19
   E. Funding ............................................................................................................ 21
   F. Admission Criteria and Process ................................................................. 21

IV. CURRENT ESTIMATED DEMOGRAPHICS OF DPC CLIENTELE ................. 21

THE DR PETER CENTRE QUALITATIVE EVALUATION ..................................... 23
   1.0 OVERVIEW ..................................................................................................... 25
   2.0 INTRODUCTION ............................................................................................. 25
   3.0 RESEARCH PARTICIPANTS ......................................................................... 26
   4.0 METHODOLOGY ............................................................................................ 26
      4.1 Data Collection ............................................................................................ 27
      4.2 Data Analysis ............................................................................................... 28
   5.0 PERCEPTIONS OF EXTERNAL STAKEHOLDERS ..................................... 28
      5.1 General understanding and impressions of external stakeholders regarding the Dr Peter Centre 28
      5.2 Structure ...................................................................................................... 29
         5.2.1 Diffusion of information about the Dr Peter Centre .............................. 29
         5.2.2 Admissions ......................................................................................... 30
         5.2.3 DPC communication with physicians and ASOs and health care agencies 33
         5.2.4 Challenges of a Diverse Population ...................................................... 34
         5.2.5 Hours of operation .............................................................................. 37
         5.2.6 Transportation .................................................................................... 38
         5.2.7 Services and Service Providers ............................................................ 39
         5.2.8 Management and Governance Structures .......................................... 43
<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.3</td>
<td>Process</td>
<td></td>
</tr>
<tr>
<td>5.3.1</td>
<td>Client-centered approach</td>
<td>43</td>
</tr>
<tr>
<td>5.3.2</td>
<td>DPC Collaboration with HIV/AIDS Service Providers</td>
<td>44</td>
</tr>
<tr>
<td>5.3.3</td>
<td>The DPC’s affect on the work of Organizations and Physicians</td>
<td>45</td>
</tr>
<tr>
<td>5.4</td>
<td>Outcome</td>
<td>47</td>
</tr>
<tr>
<td>5.4.1</td>
<td>How well has the DPC achieved its goals?</td>
<td>47</td>
</tr>
<tr>
<td>6.0</td>
<td>CONCLUSION: STRENGTHS, WEAKNESSES AND OPPORTUNITIES FOR IMPROVEMENT</td>
<td>51</td>
</tr>
<tr>
<td></td>
<td>REFERENCES</td>
<td>55</td>
</tr>
<tr>
<td>APPENDIX A</td>
<td>ASOS AND HEALTH CARE AGENCIES</td>
<td>3</td>
</tr>
<tr>
<td>APPENDIX B</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>APPENDIX C</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>APPENDIX D</td>
<td></td>
<td>11</td>
</tr>
<tr>
<td>APPENDIX E</td>
<td>DR. PETER CENTRE FLOOR PLAN</td>
<td>14</td>
</tr>
<tr>
<td>APPENDIX F</td>
<td>ASO AND HEALTH CARE AGENCY RESPONDENTS</td>
<td>14</td>
</tr>
</tbody>
</table>
PREFACE

As a researcher in the area of HIV/AIDS for over a decade, taking up this project has been enormously satisfying, particularly the many weeks I spent doing interviews with the Dr Peter Centre’s participants. I wish to thank them for their friendliness, sense of humor and warmth. I feel enriched after our interactions and have learned a great deal about human struggles, spirit, and hope.

*It is to the Dr Peter Centre participants and other people living with HIV/AIDS that this report is dedicated.*

Being pregnant at the time of the evaluation was a very positive experience for me, as participants and staff at the DPC were always interested in “new developments”.

Despite their busy schedules, staff and management were cooperative and helpful with various aspects of this evaluation.

I wish the DPC continued success in maintaining its cutting-edge programming.

“Dr Farah”

for

Shroff Consulting
AFFIRMATION

I was at Long Beach with some friends. It was warm. The surf was pounding on the sand and I decided to take off on my own for a while. I stood there looking around and thinking, “How much better can it get if it get than this?” I wanted to be able to recapture this moment for future reference because I knew that I would be facing some difficult times. I also wanted to get a sense of being able to draw in some of the forces that were around me to heal myself. So I climbed up on a big rock and laid down in the sun, closed my eyes, and this is what I cam e up with.

I accept and absorb all the strength of the earth to keep my body hard and strong;
I accept and absorb all the energy of the sun to keep my mind sharp and bright;
I accept and absorb all the life force of the ocean to cleanse my body and bring me life;
I accept and absorb all the power of the wind to cleanse my spirit and bring me strength of purpose;
I accept and absorb all the mystery of the heavens, for I am a part of the vast unknown.
I believe God to be all these elements, and the force that unites them;
And from these elements I have come, and to these elements I shall return;
But the energy that is me will not be lost.

BACKGROUND REPORT

EXECUTIVE SUMMARY

The Dr Peter Centre is a day program serving adults living with HIV/AIDS. It provides comfort care to people in high need, with the main goal of fostering their abilities to manage their own care and maximize their health status. Located in downtown Vancouver, the Dr Peter Centre has a staff consisting of qualified professionals in the nursing, therapeutic, psychosocial and recreational arenas.

In the early winter of 1997, The Dr Peter Centre (DPC) contracted Shroff Consulting to conduct an external evaluation of its work. While still early in its existence—less than a year into full operations—the DPC hoped to gain insight into its work through a qualitative evaluation.

The objectives of the evaluation were to:

- determine satisfaction levels of the DPC: of HIV+ people; staff and volunteers at the Centre; AIDS service organizations (ASOs) and health care agencies; and physicians who refer patients to the DPC;
- attempt to articulate how the DPC impacts the health of its clients;
- produce a community document that people living with HIV/AIDS may use to learn about their condition and the treatment experiences of others;
- make recommendations for the improvement of the DPC;
- cover evaluation issues that are not included in the quantitative assessment by the BC Centre for Excellence in HIV/AIDS;
- produce a document that can be used to procure further funding and maintain current funding levels.

Shroff Consulting conducted individual interviews and focus groups with 77 people. Informal discussions, particularly with Dr Peter Centre participants, brought the total number of people consulted for the purposes of this evaluation to approximately 100.

This report is divided into the following parts:

Φ a background description of the Dr Peter Centre
Φ results and analysis of evaluation research carried out with external stakeholders to assess Structure, Process, and Outcome issues at this early stage in the Dr Peter Centre’s existence
BACKGROUND REPORT

Φ results and analysis of evaluation research carried out with participants of the Dr Peter Centre to assess Structure, Process, and Outcome issues at this early stage in the Dr Peter Centre’s existence

Φ results and analysis of evaluation research carried out with people living with HIV/AIDS who have never attended the Dr Peter Centre (to learn why they do not attend) as well as those who have attended and quit or attend sporadically (to learn why they left or do not attend more frequently)

Φ results and analysis of evaluation research carried out with staff and volunteers of the Dr Peter Centre to assess Structure, Process, and Outcome issues at this early stage in the Dr Peter Centre’s existence.

External Stakeholders’ Perspectives

Following background information about the Dr Peter Centre, we discuss perspectives of the External Stakeholders--AIDS service organizations/health care agencies, and physicians who serve DPC participants as well as internal people. Using interviews and focus groups, Shroff Consulting contacted approximately 30 people in these groups to learn, in depth, their perceptions of the DPC’s progress to date.

Overall, external stakeholders are very pleased about the progress of the DPC. They hear consistent reports from DPC participants about the warm, friendly and home-like environment at the DPC. DPC participants have discussed the high quality of the services provided by very skilled staff. External stakeholders have witnessed improvements in DPC participants’ health and well-being, to the point where some participants who were despondent and depressed much of the time have become positive and far more content with their lives. The good food and excellent care have also contributed to weight gain in many DPC participants. Some respondents feel that the DPC is probably decreasing inappropriate hospital admissions due to various factors: many DPC clients may have visited Emergency departments at hospitals when they were not receiving such close care; they receive assistance with managing their medications from DPC staff; they are eating sumptuous and highly nutritious food; they are in recovery from their addiction; and/or they are generally feeling more positive and well as a result of the counseling, therapeutic art, music, massage and other services they receive at the DPC. Many respondents felt that the DPC, as the first service of this sort in Canada, is providing a new and higher standard of HIV/AIDS care and are pleased to be able to refer PLWAs there.

Concerns about the DPC did emerge from discussions with External Stakeholders. A frequently cited issue is one experienced by many HIV/AIDS service organizations: bringing together diverse groups of people who have one commonality--HIV/AIDS--has the potential to create conflicts. We heard of tensions between members of the lesbian/gay/bisexual/transgendered
BACKGROUND REPORT

communities and the heterosexual intravenous drug using communities for example; we also heard of tensions between middle class participants and working class participants. Word of mouth in some parts of the HIV/AIDS community seems to have thus labeled the DPC as a place that is not meant for certain population groups (and this depends on which community with whom one is speaking). Again on the subject of diversity, some respondents voiced a concern for the low numbers of women, First Nations peoples and people of color participants at the DPC. They suggested that more outreach into these communities and hiring more linguistically and racially diverse staff would alleviate some of the ethnoracial gaps.

Most of the suggestions for improving the DPC revolved around increasing its capacity to serve more people for longer periods of time. Increasing the hours of operation, expanding services to include more addictions counseling, taking in more clients and so forth--characterized suggestions for improving the Centre. External stakeholders applauded the DPC’s plans to expand their services to include a residence and thought this would enhance the DPC’s already strong “one stop shopping” service.

Participant Perspectives

We interviewed 22 participants of the DPC and held informal discussions with approximately 15 participants. (At the time of the interviews, there were approximately 83 participants on the DPC’s roster.) Based on this sample pool, the participants of the DPC were generally very satisfied with the Centre. Many of them discussed dramatic changes that had occurred in their lives. For many participants, these changes were linked to recovery from addictions. Participants were celebrating each day that they had been “clean” and the length of time varied from 55 days to 98 days. It is difficult to know the long term impacts of these changes given the short existence of the DPC at this point.

Participants noted other dramatic changes in their health status. The majority reported weight gain, as a result of assistance from the Centre’s nutritionist and from eating the high calorie, nutritious and sumptuous food at the DPC. Other visible improvements in health status were linked, by participants, to acupuncture, massage and other forms of holistic health care available at the DPC. Participants also discussed profound changes in emotional and mental health status as a result of art, music and recreation therapy. Counseling from both the counselors on staff and other staff members was cited by most participants as highly effective for anger management, addictions concerns, and a multitude of other psychological issues. Many participants stated that the DPC filled a major gap in their lives and made them feel cared for; this caring, coupled with all the services, has motivated many participants to want to live, so they take better care.

\[1\] The DPC staff already consists of many women.
of themselves. Based on these assessments, the DPC appears to be very successful as a form of health promotion and disease management.

Virtually all participants who had been hospitalized in the past for HIV/AIDS noted that their participation in the Centre had prevented inappropriate hospitalization. Several participants stated that by becoming more knowledgeable about their health issues, by having access to DPC nurses, and by being more positive about their lives, they avoided going to hospital emergency room. According to many participants, the DPC is fulfilling its goals and exceeding them. In the words of one participant:

Dr. Peter Centre has become the gap in my life, between 9:30 am and 3:30 pm. In a sense, Dr. Peter Centre is my life. It’s my new life that I know and look forward to right now...This place I can be open, be myself as long as I don’t go over the deep end and I respect others’ rights and conditions too...I’m just grateful.

*Perspectives of PLWAs who are Non-active and Non-Participants of the DPC*

Like most of the active participants, those whose frequency of attendance had decreased did not complain about the DPC. Instead, virtually every person we interviewed stated that their low attendance was due to circumstances in their lives, such as not having a great deal of energy, having a job, and other reasons. All the people who had been to the DPC appreciated the high quality of services and the individual attention they received. Similar to many of the active participants, one interviewee resented the drug talk of other participants, as it made her/his recovery process that much more difficult. However, all respondents uniformly noted that they would recommend the DPC to other people.

This investigation made it clear that virtually all people who are fortunate enough to be participants of the DPC generally benefit a great deal. It was also clear that many more people could be benefiting from this unique service. We interviewed PLWAs who had never heard of the DPC and who fit the high needs admissions criteria. While this is the end of the inaugural year of the DPC, and thus early in its existence, the DPC has a great deal of work to do in the coming year. This work will include more outreach and publicity within high needs populations--including women, people of color and First Nations peoples. This would help to inform those who could gain a great deal from participation at the DPC.

*Volunteer Perspectives*

Volunteer respondents were generally very pleased with the Centre and often compared the positive way they were treated at the DPC to other organizations’ poor treatment of volunteers. They were appreciative of the staff, particularly the
Volunteer Coordinator, and stated that if they needed assistance at any time, they received it from staff. They noted that they felt valued and had options for how much involvement they wanted to have at the Centre.

Volunteer respondents felt like they were not aware of many facets of the DPC's operations. For instance, they knew little about the admissions process, management and governance structures. While some of them did not find these gaps in their knowledge to affect their volunteer work, others requested more basic information about the DPC. They also hoped to be able to meet other volunteers for social and networking purposes.

The volunteers with whom we consulted thought that the DPC was generally meeting its goals well. They thought that a place like the DPC has been needed for many years. While other HIV/AIDS service providers struggle to bring together various PLWAs, particularly those from the queer community with heterosexual drug users, the DPC has managed to bring people together relatively harmoniously. One person noted, however, that the DPC has a reputation for working mostly with people from the Downtown Eastside, so this deters some middle class people from even applying.

Increasing the numbers of women participants was one suggestion made by volunteer respondents. More outreach within the HIV/AIDS community in general was also seen as necessary, as many PLWAs have still never heard of the DPC. Also, to further foster independence of participants, more basic skills classes could be offered, such as cooking and sewing.

Volunteer respondents were generally very pleased with the DPC, both as a place to work and as day centre for HIV+ people. All in all, they felt like not only were they giving as volunteers, but they were receiving, both from the Centre and from the experience of being with participants.

**Staff Perspectives**

A majority of full time staff (13) attended the evaluation focus group. Generally, this group voiced an appreciation of the DPC, both in terms of the great benefits for clients and of the productive working environment for themselves. They noted that the DPC has truly created a multidisciplinary staff team and that rapport between them is very comfortable and cooperative.

They feel valued for the work they do and gain tremendous satisfaction from the visible improvements in the health status of the participants. After less than one year of operations, the DPC appears to have created a solid cadre of staff who are highly qualified and skilled, and who genuinely enjoy being at work. Staff credited DPC management for helping to create a flexible and democratically-run work environment.
Staff respondents felt that they were working in an innovative health care setting which was participant-centred in both theory and practice. Many other health and medical facilities are designed to meet the needs of staff first but the DPC has tried hard to put the needs of participants first. The intensity of working within this model, with clients in high need, amongst other factors, has led some staff to feel that they are unable to do everything they would like to do each day because of the many demands placed on them, largely by participants. Some felt they are already at risk of “burn out”. There are currently some mechanisms in place to care for staff’s needs, such as a weekly talking circle, possibilities for attending conferences and training seminars, as well as open access to the Executive Director, who, according to them, is open to making changes to accommodate their needs. One such change that may occur in the near future is the decision to give staff a daily break from the Centre, as currently, they eat lunch and take most of their breaks within the Centre, largely to have enough people available for participants. This may prove to be unsustainable as more people access the Centre and in the future, staff and management may consider working in a unionized environment.

Finally, staff, like all the other groups consulted for this evaluation, were very supportive of the DPC’s leading-edge work and looked forward to continuing to shape DPC programs to even better meet the needs of the high needs PLWAs.

Conclusions

Having spoken to approximately 100 people about the DPC, we have come to the conclusion that it is providing a much needed service in a highly innovative fashion. The DPC must strive to serve an even more diverse population and can achieve this through more outreach and probably by diversifying their staff.

There is no doubt that the DPC has created a new standard of care for people living with chronic and life-threatening illnesses. Other health and medical care facilities could learn a great deal from the democratically organized, multi-disciplinary, and holistic services offered at the DPC. A DPC participant expressed his appreciation:

*Me, I get up in the morning, “Oh goody, I’m going to Dr. Peter Centre today. Yeehah, on the bus on my way up”. That’s what I like about it. It gives me a chance to get off the street, meet people, meet nice people, have something to eat when I feel hungry, and just sort of kick back.*
1. INTRODUCTION

The face of HIV/AIDS (Human Immuno-Virus/Acquired Immune Deficiency Syndrome) continues to change. While People Living with HIV/AIDS (PLWAs) have always belonged to diverse social and economic communities, increasing numbers of marginalized men and women with injection drug use issues, mental illness, and housing problems make the community increasingly diverse. All over the world, HIV/AIDS is becoming known as a “disease of poverty, hunger, and isolation” (Dr Peter AIDS Foundation 1997: 3). Most people living with HIV/AIDS experience a decrease in income as well as a sense of isolation and despair. People who already live in precarious situations with minimal social support systems and financial security are most likely to “remain isolated and unserved” (Horizon Pacific International 1994: 1).

There are at least 10,000 people living with HIV in British Columbia, 85% of whom reside in Vancouver, mostly in the West End and the Downtown Eastside (DTES). The incidence of HIV infection in BC is expected to increase at a rate of 1,500 people per year for the next two or three years, with the majority of new PLWAs identifying themselves as injection drug users (IDUs), young gay men, First Nations peoples and women living in poverty; commercial sex workers and partners of IDUs will also be sero-converting in the near future (Dr Peter AIDS Foundation 1997; O'Shaugnessy 1997). A recent AIDS Update from the BC Centre for Disease Control, reports that 1,854 persons (1,431 males and 406 females) tested newly positive for HIV from 1995 to 1997. An ethnoracial breakdown of the data shows that 1,088 of the new PLWAs were EuroCanadian men and women, 269 aboriginal peoples, 48 people of Hispanic origin, 42 Asians and 40 Black people. The number of officially reported PLWAs in British Columbia stands at a total of 2,499 consisting of 100 women and 2,399 men (BC Centre for Disease Control 1997).

The prevalence of HIV/AIDS has had, and will continue to have, a significant impact on existing health care resources. Inadequate housing, low income, poor nutrition and lack of support contribute to a faster disease progression which in turn leads to an increased demand for acute hospital beds (Horizon Pacific International 1994). Hospital bed days at St. Paul’s Hospital are reported to have increased from 9,669 in 1994/1995 to 10,031 in 1996/1997 (St. Paul’s Hospital 1997). Prolonged periods of illness, an increasing number of people with HIV, and a declining number of caregivers act together to impact upon medical and care delivery systems.

As the population of PLWAs diversifies, needs grow and medical and health treatments ought to adapt to these changing needs. It has become clear that medication and hospital care for acute crises alone cannot serve the needs of people living with HIV/AIDS. A combination of Western medicine and holistic
BACKGROUND REPORT

health care treatments has been shown to assist PLWAs to cope with their conditions. Recent developments in Western medicine have also produced protease inhibitors and other experimental pharmaceutical products, which when taken as a “cocktail” (combination), seem to have made at least a short term dramatic improvement in the health status of some HIV+ people.¹

While post-diagnosis life expectancy may have increased, strategies and therapies to improve vitality and social quality of life are still lacking. Many people continue to suffer from decreased physical capacity and from isolation, alienation, and loss of independence and personal control. People living in poverty, those with mental health imbalances, homeless people, and IDUs, are most vulnerable to these effects as they are least likely to have access to the safe housing, food, clothing, treatment, and social support systems. Additionally, the friends and families of people with HIV/AIDS have felt the burden of care and caregiver burnout has become a significant problem (Horizon Pacific International 1994; Thompson 1990; Strathdee et al. 1997).

The treatment of HIV/AIDS thus calls for an innovative and holistic approach. Cost-effective, supportive community-based programs that offer a comprehensive range of medical, psychosocial and rehabilitative services are needed to enable PLWAs “to live their lives in optimal ‘health’ without stigma” (Horizon Pacific International 1994: 16).

II. THE DAY CENTRE CONCEPT

Given the need for new health care solutions to the issues of HIV/AIDS treatment, “day centers” have emerged in various parts of North America. The philosophy of day treatment programs is based on the notion that HIV/AIDS is a chronic illness with acute episodes rather than a terminal disease. In view of the cyclical and ongoing nature of HIV/AIDS, day centers offer a spectrum of services focused on wellness, self-healing, and comfort in living rather than palliation and preparation for death. They provide a therapeutic environment where individuals can receive the support, training and equipment needed to resume activities of daily living (Thompson 1990). Additionally, day centers strive to create a home-like ambiance in order to promote dignity, autonomy, and physical comfort to those who consistently face progressive losses (Thompson 1990: 29, Architecture 1992). Day centers are heralded for their ability to address the multiple needs of people living with HIV/AIDS (Gutterman 1990; Thompson 1990; Horizon Pacific International 1994).

The Bailey-Boushay House (BBH) in Seattle has become a leading model for the effective management of HIV/AIDS. The Adult Day Health Program at BBH

¹ However, many people are not able to absorb these medications and many others, often those who are multiply disadvantaged due to poverty, addictions, violence, poor housing conditions, and other realities, have relatively short life expectancies from time of diagnosis.
BACKGROUND REPORT

provides optimal health care, opportunities for socialization, and respite for caregivers. In addition, it fosters empowerment by encouraging clients to take control over their lives and their illness. The Bailey-Boushay House offers services to persons who live with HIV/AIDS and are unable to work. It serves all target populations, including women, gay men, and IDUs (Intravenous Drug Users).

The services offered at day centers such as Bailey-Boushay House, the Village Nursing Home in New York City, and St. Peter’s Hospice in Albany New York include:

- food, housing, nursing/medication to meet the basic needs of clients
- mental health services
- environmental support
- spiritual support
- social work
- transportation
- therapeutic recreation such as art and music to help clients express themselves through alternative means
- massage to reduce feelings of isolation and improve body image, circulation, skin health and muscle relaxation
- recreation
- support for care partners and families, including bereavement counseling.

Through their services, day centers reduce isolation as well as maintain and improve the health and well-being of participants. For instance, the provision of nutritious food has enabled clients at Bailey-Boushay and the Village Nursing Home to gain 4-10 pounds in the first month of attendance, which positively affects their health status. Counseling, access to meaningful activities and socialization also benefit participants by helping them cope with their illness and learn to live with physical losses. By re-engaging in activities, participants have reportedly found new meaning and value to daily living as well as a renewed sense of dignity and self-identity. Participants have stated that interactions in day centers have assisted their personal development and transformed their character: they note that they lose their anger and fear and move toward becoming responsive emotional beings. In addition, many clients and families have become HIV/AIDS activists or health educators, and thereby bring their new skills into the community (Thompson 1990; Gutterman 1990; Horizon Pacific International 1994; McNally and Mason Beck).
BACKGROUND REPORT

Day centers also have also been shown to have an impact on the medical system. By teaching daily living skills and fostering independence, they increase the continuity of care between in-patient and home-care settings. Their effects on health and well-being can also potentially reduce the number of acute care hospitalizations per year per PLWA. Moreover, day centers are increasingly regarded as a cost-effective alternative for people living with HIV/AIDS who do not require the intensity of a hospital setting. While daily costs for an acute care hospital bed range from US$800 to US$1000, day centre services range from US$60 to US$135 per day per person.

III. DR PETER CENTRE (DPC)

The Dr Peter AIDS Foundation established the Dr Peter Centre as a means of fulfilling its mission: to provide comfort care through programs that serve adults living with HIV/AIDS. Modeled after the Bailey-Boushay House in Seattle, the DPC embraces a holistic approach by addressing the emotional, psychological, social, physical, spiritual and environmental needs of people living with HIV/AIDS. The services are designed for people with HIV/AIDS who are in high need, including those who are marginalized and difficult to reach. Since April 1997, the Dr Peter Centre has been operating its Day Program in the Comox Building adjacent to St. Paul’s Hospital where it will remain until the new day health centre and residence facilities are built in 1999/2000. The following is a detailed description of the DPC.

A. The DPC’s place in the health care continuum

The Dr Peter Centre is the first of its kind in Canada. Although a number of HIV/AIDS organizations and health care agencies in the province offer services ranging from community care to acute/palliative care, the DPC aims to fill a need not served by these organizations. It is unique in that, under the same roof, it gives clients access to community-based comprehensive integrated services which include emotional support, holistic therapies, recreational therapies, creative outlets, nutrition, clothing, and medication management. The DPC aims to fit within the continuum of services presently available in British Columbia and to fill the gap created by the lack of community care resources, inadequate housing and caregiver burnout (Horizon Pacific International: 1994).

A needs assessment was conducted by Horizon Pacific International (HPI) in 1994 to ensure that the DPC would indeed fill an existing gap in services and to determine the need for, support and use of a day treatment program. HPI undertook a broad-based community consultation consisting of surveys and interviews with three groups: people living with HIV/AIDS who would be

---

1 For a partial list of AIDS service organizations and health care agencies in the lower mainland, please see Appendix A.
eligible for participation in the program; physicians treating people living with HIV/AIDS and who would be in a position of referring them to the centre; and members of ASOs and health care agencies.

The authors of the study found that there was a gap in the continuum of services available to persons living with HIV/AIDS in Vancouver and that the DPC would serve a growing need. Individuals living with HIV/AIDS expressed the need for a day centre which offered nutritious food, counseling, clinical treatments, transportation and a supportive family atmosphere. They also confirmed they would use such services should they became available. Local physicians responded that a day centre would prove beneficial in several ways. Specifically, the majority of physicians believed that the centre would complement both the existing services and the physicians’ own practices, and that it would enhance their capacity to serve their patients’ needs. ASOs and health care agencies were also committed to and fully supportive of the creation of the day centre. The needs assessment paved the way for the Dr Peter Foundation to implement the DPC day program.

B. Mandate

The mandate of the DPC is to assist adults living with HIV/AIDS in achieving and maintaining an optimal level of health while living in the community.

C. Goals

The Dr Peter Centre has four main goals, each of which focus on enhancing the participants’ ability to manage their own care. The goals are:

• to provide appropriate day-centre facilities in order to support HIV-positive people (who attend the Centre) to live independently in the community;

• to promote the efficient use of health care resources and to decrease inappropriate hospital admissions and stays;

• to improve the health status and quality of life of clients; and

• to provide respite for their caregivers.

With these goals in mind, the DPC offers services such as nutrition, stress relief, social life and health counseling in a environment that aims to be warm, respectful and safe. These services are intended to provide structure and stability for participants and essentially “take the chaos out of their lives”\(^1\). Improving the health and quality of life of participants will potentially reduce the demand for acute-care hospital beds (which cost approximately $1,000 a day) and residential

\(^1\) Interview with the Director of the Dr Peter Centre.
beds ($200 a day). At $82 per person per day, the DPC is expected to have a significant impact on the use of medical resources.

D. Structure

governance and management structure

The Dr Peter Foundation is a non-profit society with a Board of Directors. The Board is ultimately accountable and responsible for the fundraising campaign and the operation of the Dr Peter Centre Day Program and future Residence. Board members for 1997/98 include the following people: David Allard, Lawyer--Lawson Lundell Lawson & McIntosh; Susan Gomez, General Manager, Pan Pacific Hotel; Peter Granger, Medical Doctor--Downtown South Community Centre; Andy Hiscox, Urban Planner--City Spaces Consulting; Andrew Johnson, Executive Director--AIDS Vancouver; Dennis MacDonald, Public Relations Professional--BC Cancer Foundation; Tom McAulay, AIDS Advocate; Dale McClanaghan, President & CEO--VanCity Enterprises; David Paperny, Independent Video Producer; Michael Petrie (Chairman), President and Chief Executive Officer--BC Cancer Foundation; Dianne Vernon, President--Vernon Pascoe; Mark Virgin, Lawyer--ICBC. Honorary Members include Bob & Shirley Young (Parents of Dr. Peter Jepson-Young); Nancy Hennessy, Entrepreneur (Sister of Dr. Peter Jepson-Young); Donald Hayes, Hayes Forest Services Ltd.; Jay Wortman, Medical Doctor.

Senior Staff include the Executive Director of the Foundation, the Director of the Dr Peter Centre, and a Financial Manager. The Executive Director supports the Board to ensure that the Foundation is operating well and that communication between the governing committees and the Board is fluid. The Director of the Dr Peter Centre is responsible for the internal operation of the Centre such as staffing, budget management, etc. She reports to the Executive Director. In February 1998, these 2 positions were by 1 person.

An advisory committee provides ongoing support and counsel to the Dr Peter AIDS Foundation regarding the implementation and operation of the Day Program and future combined Day Program and Residence beds. The committee’s membership includes representatives from the following organizations: AIDS Vancouver, BC Centre for Excellence in HIV/AIDS, BC First Nations AIDS Society, BC Persons with AIDS Society. It also includes a Dr Peter Foundation Board Member, the Director, and a participant representative of the Dr Peter Centre, a family practice physician, Greater Vancouver Mental Health Services, Lower Mainland Alcohol and Drug Program, Multi-Diagnosis Committee, St. Paul’s Hospital AIDS Program, Vancouver Richmond Health Board--Burrard and North Health Units, Vancouver Hospital, and the Vancouver Native Health Society.
Program Features

Multidisciplinary staffing plan

Aiming to address the physical and psychosocial aspects of HIV/AIDS and to offer the most holistic and integrated services possible, the DPC staff is composed of an interdisciplinary team of professionals. This team consists of the program director, two nurses, counselors (1.5 Full Time Equivalent (FTE)), recreation therapists (1.6 FTE), a cook, a volunteer coordinator (0.5 FTE), a caretaker (0.75 FTE), a dietitian (0.25 FTE), a music therapist (0.25 FTE), clerical support (1.5 FTE) and casual staff.

Client-centered approach

The DPC professional staff and volunteers work together with the aim of creating a respectful, warm and safe environment for participants. The DPC has embraced an empowerment philosophy that is focused on improving participants’ ability to manage their own care and to increase their involvement in decision-making. Participants are engaged in weekly community meetings with staff members to discuss issues relating to the operation of the Centre such as the selection of activities. They are also given the opportunity to voice their opinions by becoming members of specific committees.

Integrated services

The DPC’s interdisciplinary team coordinates and provides a broad spectrum of integrated services with a view to improving the health and quality of life of people living with HIV/AIDS. The services available to participants include:

• comprehensive nutrition and high calorie diet: continental breakfast, hot lunch and nutritious snacks;

• nursing support in medication management and harm reduction,

• complementary therapies such as acupuncture, aromatherapy, healing touch, massage and relaxation;

• individual and group counseling in mental health, nutrition and chemical dependency;

• respite and support for personal care-givers, partners, family members and friends;

SHROFF CONSULTING
First Nations programming including weekly talking circles

transportation assistance to the Centre for those who need it (by paying for bus tickets or the cost of a handidart van, or, alternatively, through volunteer transportation);

recreation and exercise which includes yoga, swimming, and aquacise;

socialization, structured and unstructured leisure opportunities;

health and leisure education;

individual program planning;

art, music, drama and horticultural programs;

child minding to facilitate women’s participation at the Centre;

social events and gatherings; and

volunteer resources.

As mentioned above, the Dr Peter Centre is planning to relocate in 1999/2000 (across the street from its current address) and offer respite beds and other types of residential care rooms in addition to its day program.

Hours of operation

The DPC is currently open Monday to Friday from 9:30 a.m. to 3:30 p.m. The hours of operation will be extended over time and the residence will eventually be a home for people with HIV/AIDS who require 24-hour nursing care.

Physical features

The interim DPC facility is designed to create a comfortable, warm ambiance and to provide the space for services required to meet client needs. It includes a living room decorated with local artwork, a library, a television lounge equipped with VCR, a cafeteria-style dining room, nap rooms (including one for women only), showers, bathrooms, a laundry room, an art studio, a multi-purpose music/theater/relaxation room, a children’s playroom, lockers for safe storage of belongings, a complementary therapy room for massage and relaxation, a ‘clothing bank’, and treatment rooms which have locked cupboards for storing pharmaceuticals. The DPC is also beginning to encourage participants to utilize the neighboring YMCA (Young Men’s Christian Association) for physical activities.

Please see Appendix E for a floor plan of the DPC.
E. Funding

In 1996, the Government of British Columbia committed $1 million in operating funds for the day program. The DPC recently received $770,000 to build a 10 bed residence for use April 1, 1998. Seven and a half million dollars are required to build new centre. The Dr Peter Foundation expects to raise $2.5 million through its capital fund raising campaign and hopes to receive most of the additional capital funding from the BC Ministry of Health.

F. Admission Criteria and Process

Admission Criteria

The DPC aims to serve adults living with HIV/AIDS who are in “high need”: individuals whose multiple health and social circumstances put them at high risk of deteriorating personal health, and make them more likely to require extensive health care services. In defining “high need”, the DPC takes into account the broad range of factors that impinge on health and well-being. These include coping skills, self-care capacity, personal support networks, other factors such as mental illness or brain injuries, chemical use, hospitalizations, as well as living and economic circumstances.

Referral and Admission Process

Anyone can refer a person to the DPC and self-referrals are encouraged. Following the referral, the potential participant makes an appointment for a tour of the Centre and an hour assessment interview to determine need. Based on this interview as well as contact with the person’s physician and written confirmation of HIV/AIDS and TB (tuberculosis) status, the staff makes a decision regarding admission. Each person is assigned a primary worker within the Centre. Once admitted to the Centre, participants have a one-to-one meeting with their primary worker, and are introduced to each staff and given a participant orientation booklet. The intake counsellor conducts 4 interviews and admits on average 1 participant per week. People who are not accepted into the program are identified as low, medium or high priority rather than being placed on an actual “waiting list”. Due to demand the DPC is only able to accommodate the high need category. They are free to contact the DPC if their situation worsens.

IV. CURRENT ESTIMATED DEMOGRAPHICS OF DPC CLIENTELE

In January 1998, Shroff Consulting requested the DPC for a demographic break-down of their clientele. This request was made in response to comments made by external stakeholders regarding the social identities of DPC clients. While no such formal break-down existed, a DPC staff member conducted a survey amongst
BACKGROUND REPORT

DPC primary workers, asking them to report information that clients had self-disclosed.

The following statistics are estimates on participant demographics in order to provide a preliminary overview. Primary workers were requested to go through their participant lists and note that information which was known to them, either through data collection or open disclosure by the participants themselves.

Table 1: PARTICIPANTS OF THE DR. PETER CENTRE DAY PROGRAM AS OF FEBRUARY 1998

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>TOTAL</th>
<th>PERCENTAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Participants February 1998</td>
<td>83</td>
<td>100%</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male:</td>
<td>67</td>
<td>81%</td>
</tr>
<tr>
<td>Female:</td>
<td>10</td>
<td>12%</td>
</tr>
<tr>
<td>Transgendered Females:</td>
<td>6</td>
<td>7%</td>
</tr>
<tr>
<td>Sexual Orientation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gay:</td>
<td>31</td>
<td>37%</td>
</tr>
<tr>
<td>Bisexual:</td>
<td>4</td>
<td>5%</td>
</tr>
<tr>
<td>Heterosexual:</td>
<td>44</td>
<td>54%</td>
</tr>
<tr>
<td>Race/Ethnic Background</td>
<td></td>
<td></td>
</tr>
<tr>
<td>First Nations:</td>
<td>11</td>
<td>13%</td>
</tr>
<tr>
<td>Caucasian:</td>
<td>70</td>
<td>84%</td>
</tr>
<tr>
<td>Other:</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>Active Chemical Dependency</td>
<td>29</td>
<td>35%</td>
</tr>
<tr>
<td>Recovering from Chemical Dependency</td>
<td>27</td>
<td>33%</td>
</tr>
<tr>
<td>Mental Illness</td>
<td>21</td>
<td>26%</td>
</tr>
<tr>
<td>Physically Disabled</td>
<td>9</td>
<td>11%</td>
</tr>
<tr>
<td>Geographic Area of residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Downtn/Dtn South Downtn East Side</td>
<td>38</td>
<td>46%</td>
</tr>
</tbody>
</table>
**BACKGROUND REPORT**

<table>
<thead>
<tr>
<th></th>
<th>East Vancouver</th>
<th>14</th>
<th>17%</th>
</tr>
</thead>
<tbody>
<tr>
<td>West End</td>
<td>22</td>
<td></td>
<td>26%</td>
</tr>
<tr>
<td>West Side</td>
<td>1</td>
<td></td>
<td>1%</td>
</tr>
<tr>
<td>No Fixed Vancouver Address</td>
<td>2</td>
<td></td>
<td>2%</td>
</tr>
<tr>
<td>Lower Mainland</td>
<td>7</td>
<td></td>
<td>8%</td>
</tr>
<tr>
<td>Participants on Income Assistant</td>
<td>76</td>
<td></td>
<td>91%</td>
</tr>
<tr>
<td>Prison History</td>
<td>32</td>
<td></td>
<td>39%</td>
</tr>
</tbody>
</table>

*Data from self disclosure; not part of standard Program data collection

**THE DR PETER CENTRE QUALITATIVE EVALUATION**

The Dr Peter Foundation requested an external qualitative evaluation—focusing on structure, process and outcome issues--of the Dr Peter Centre day program early in its existence (less than 1 year of full programming) in order to gain insight into the perspectives of external and internal stakeholders regarding the Dr Peter Centre.

The DPC is also working with the BC Centre for Excellence in HIV/AIDS (BCCE) on an on-going quantitative evaluation which will track DPC’s impact on the utilization of other health care resources. The quantitative study is a component of the BCCE Community Research Project initiated to determine the economic impact of HIV/AIDS on the health care system, to measure health status and to analyze the utilization of health care resources. As of November 1997, approximately 52 DPC participants were enrolled in the evaluation. The qualitative evaluation of the DPC is complementary to the BCCE study. Researchers from both the qualitative and quantitative studies have discussed the linkages between the 2 studies and have recognized that the aims and objectives of each study are very different, so the overlap between them is minimal.

The objectives of the qualitative evaluation are to:

- determine satisfaction levels of the DPC: of HIV+ people; staff and volunteers at the Centre; AIDS service organizations (ASOs) and health care agencies; and physicians who refer patients to the DPC;
- attempt to articulate how the DPC impacts the health of its clients;
BACKGROUND REPORT

• produce a community document that people living with HIV/AIDS may use to learn about their condition and the treatment experiences of others;

• make recommendations for the improvement of the DPC;

• cover evaluation issues that are not included in the quantitative assessment by the BC Centre for Excellence in HIV/AIDS.

• produce a document that can be used to procure further funding and maintain current funding levels.
1.0 OVERVIEW

The purpose of this section is to reflect the perspectives of external stakeholders regarding the Dr Peter Centre (DPC) Day Program. The information provided in the section is based on interviews and focus groups conducted between November 1997 and January 1998 with external stakeholders—ASOs, health care agencies and physicians who have clients at the DPC. With the assistance of the DPC, Shroff Consulting contacted 20 ASOs and health care agencies and 31 people within these organizations, as well as 31 physicians, inviting them to participate in the evaluation. Below is an analysis of the views of the 16 ASOs and health care agencies and 7 physicians from British Columbia’s lower mainland who responded.

External stakeholders were generally impressed with the Centre’s evolution to date. They were specifically pleased that the DPC has adopted a holistic and integrated approach to the treatment of HIV/AIDS. By offering nutritious food, medication management, counseling, and alternative therapies under the same roof, the DPC provides a unique and complementary service which fulfills an ever-growing need. In addition, respondents repeatedly commented on the stability, structure and nurturing environment created at the DPC. Through its creative programming and quality of care, the DPC is successfully providing ‘comfort care’ and is well on its way to achieving its four goals.

Respondents were extremely supportive of the DPC and provided only constructive criticism to enable the Centre to further enhance its programming. They suggested the following areas for improvement: increasing hours of operation and intake capacity; increasing outreach to the Downtown Eastside (DTES) and East Vancouver; improving communication and collaboration with ASOs and health care agencies as well as with medical doctors; and expanding programming for the injection drug-using (IDU) community.

2.0 INTRODUCTION

The Dr Peter Centre contracted Shroff Consulting to conduct a qualitative evaluation of its Day Program. Here we provide insight into the perceptions of the Centre’s external stakeholders. The evaluation focused on structure, process and outcome aspects of the DPC. Structure refers to the various resources and linkages required for service delivery. Process elements are the activities or approaches employed to achieve desired outcomes. Outcome aspects refer to the consequences or impacts of services. (For a more detailed discussion of the structure, process and outcome aspects of this evaluation, please refer to section
EXTERIOR STAKEHOLDERS' PERSPECTIVES

4.1 on data collection). The general purpose of this evaluation is to enable the DPC to continue to strengthen its programming.

3.0 RESEARCH PARTICIPANTS

In order to gain a comprehensive understanding of how the HIV/AIDS community and health care agencies perceive the DPC at this early stage of its existence, we chose to interview people who are connected to the DPC but are outside of the Centre. External stakeholders were divided into two groups: physicians who have referred clients to the DPC or who have DPC participants in their care, and local ASOs and health care agencies. Respondents from organizations with the closest relationship to the DPC were considered key informants.

With the assistance of DPC staff and management, we contacted 31 physicians who have clients at the DPC, and 31 people from ASOs and health care agencies. We interviewed a total of 7 physicians and 20 representatives from 16 organizations from November 27, 1997 to January 26, 1998. This section is based on individual interviews with 7 physicians, 3 focus groups with 11 representatives from 10 organizations, 3 individual interviews with representatives from 2 different organizations, and personal and group interviews with 7 key informants from 4 organizations.

4.0 METHODOLOGY

The DPC specifically solicited a qualitative evaluation of their Centre. Qualitative research provides in-depth, rich analysis of phenomena or events. The major components of qualitative research include: data collection, usually arising from interviews and observations; analytical and interpretive procedures that are used to arrive at findings or theories; and written or verbal reports. This type of research approach is applied to the study of organizations, groups, and individuals. Some research areas lend themselves naturally to qualitative research methods, such as uncovering the nature of people’s experiences within an organization or with an illness. Qualitative methods are employed to explore and comprehend what lies behind a phenomenon that is little understood, or to gain deeper insight into something that is already well described. They are carried out by researchers in pairs, teams, or by individual researchers.

In this project, we applied the qualitative research methods of individual face-to-face interviews, individual telephone interviews, small group and individual

1 Please see Appendix F for the [confidential] list of participants.
interviews of key informants, focus groups and participant observation. We also adopted a participatory and collaborative approach to this project. An evaluation committee comprised of the chief researcher, 2 DPC staff (including the Director), participants and board members as well as other related HIV/AIDS experts provided guidance throughout the evaluation process. Committee members were particularly key in identifying potential research participants and helping to develop and revise interview schedules. All research questions were pilot tested.

4.1 Data Collection

Consistent with qualitative research methods, the researchers used semi-structured interviews and focus groups to gather data. The combination of focused and open-ended questions provided the structure necessary to cover evaluation issues without leading or biasing responses. At the same time, the questions were designed to give respondents opportunities to discuss areas of concern to them.

The interview schedules (ie the list of questions) were developed and revised by the research team and the evaluation committee, and were subsequently revised following 3 pilot tests: 2 with physicians and 1 with an HIV+ person who is connected to many AIDS organizations. We designed 3 separate sets of questions to ensure appropriateness and relevance for each group of respondents and for each data collection method. (Please see Appendices B, C, and D for Interview Questions for Physicians, Interview Questions for ASOs and health care agencies, and Focus Group Questions for ASOs and health care agencies).

The interview and focus group guides were divided into 5 parts: introduction (general knowledge and impressions of the DPC), structure, process, outcome, concluding thoughts. The questions in each section aimed to uncover the respondents’ opinions regarding these themes as they relate to the DPC. The first part of the interview aimed to reveal the respondents’ general knowledge and impressions of the DPC. The structure component of the questions was designed to gain an understanding of opinions regarding diffusion of information, the admissions process, Dr Peter Centre communication with external stakeholders, diversity, transportation issues, services and service providers, and governance and management structures. The questions relating to process focused on the DPC approach to care, the collaboration of the DPC with other HIV/AIDS service providers, as well as the impact of the DPC on the respondents’ work. In the last part of the interview, outcome, respondents were asked to discuss the extent to which the DPC has achieved each of its four goals. At the end of each section, an open-ended general question gave respondents the chance to discuss issues that had not yet been addressed. The last questions provided respondents the opportunity to offer suggestions and positive or negative impressions of the Centre. This concluding section was designed to allow respondents to fill in any areas that they may have touched upon lightly, and to summarize positive feedback as well as challenges facing the DPC.
**EXTERNAL STAKEHOLDERS’ PERSPECTIVES**

*Interviews:* All physicians and 3 key informants were interviewed by telephone as this appeared to be the most convenient and effective technique for respondents. One face-to-face group interview was held with a group of key informants. Individual interviews lasted between 10 and 40 minutes while the group interview lasted one hundred minutes.

*Focus Groups:* Two focus groups were held in December 1997 at St. Paul’s Hospital with HIV/AIDS organizational representatives. Another focus group and individual telephone interviews were conducted in January 1998. The focus groups discussions were half an hour to 2 hours in length.

Prior to the interviews and focus groups, respondents were provided with a consent form which they signed, dated and returned to Shroff Consulting. In most cases, respondents were also sent a copy of the questions prior to the interview. All interviews and focus group discussions were tape-recorded. Cassettes and hand-written notes were coded to protect participant identity and ensure confidentiality.

**4.2 Data Analysis**

Qualitative data analysis methods were applied in the analysis of the information gained through interviews and focus groups. The content of each discussion was condensed, coded and organized thematically until all results were displayed on theme charts. Below, these themes are presented to reflect the order in which questions were asked.

**5.0 PERCEPTIONS OF EXTERNAL STAKEHOLDERS**

5.1 General understanding and impressions of external stakeholders regarding the Dr Peter Centre

All respondents generally understood that the Dr Peter Centre is a day centre which provides support for people living with HIV/AIDS who require social and medical assistance. However, in many cases, they were less familiar with the functioning of the DPC, its range of services and service providers, and the admissions process.

By and large, the respondents had extremely positive impressions of the DPC. They commended the DPC for providing a safe and supportive environment for people who may have otherwise remained excluded from service delivery. The organizational representatives applauded the DPC’s success in creating a “home atmosphere”: a relaxing, non-judgmental, comfortable, stable and caring environment where participants can be themselves. Physician respondents placed less emphasis on the nurturing and caring aspects of the DPC environment but consistently commented on the support and stability it offers. All respondents
were confident that the DPC is a unique service that fulfills a growing need in the community. Interviews and focus groups were typified by the following comments:

“We could use more of them, more of that same type of centre. There aren’t enough.”
-organizational representative

“It’s a wonderful example.”
-organizational representative

“It exceeds my expectations in services and benefits.”
-physician

“They are doing a very good job with the resources they have.”
-physician

Several major themes repeated themselves during discussions with external stakeholders. On the one hand, these include the importance of nutritional support and medication management that the DPC is providing and on the other hand, the potential to increase outreach to women and to people in the DTES and East Vancouver.

5.2 Structure

5.2.1 Diffusion of information about the Dr Peter Centre

Information about the Dr Peter Centre has apparently reached the HIV/AIDS community in several ways. Respondents noted that the community was initially informed through the media and the DPC’s consultation process during its implementation stage. Currently, most people in the HIV/AIDS community find out about the Centre through ASOs and health care agencies, physicians, health care professionals, the media, and word of mouth. A representative of a community-based AIDS service organization commented that the DPC has not done enough of “its own work to explain who they are and what they do in a broader sense”. This, he believes, has contributed to the propagation of many commonly held, yet false impressions among HIV+ people, particularly regarding who the DPC services are for and what services it offers. The respondent urged the DPC to send a stronger message promoting its inclusive approach to the HIV/AIDS community. He added that organizations would be willing to support such a message if it were to come from the DPC itself. (Please refer to section 5.2.4 “Challenges of a Diverse Population” for further elaboration on the topic of critical perceptions.)
5.2.2 Admissions

Administrative procedures

Respondents noted that they were aware that the admissions process entailed an assessment interview but were for the most part unclear about the process in general. Amongst physician respondents who had experience in referring clients to the centre, only one physician found the process “complicated, unwieldy, and onerous” and commented that the DPC was not easily accessible, particularly after hours. The others found the intake process fast and easy as they only had to make one telephone call and did not have to act as intermediaries.

Several organizations also found the process effective and straightforward. During one focus group, for instance, a social worker noted:

I was involved in the admission of one of the first 20 participants. I made an appointment and took him to the Centre for the appointment. I wasn’t actually in the room with him during the interview, but he came out pleased. He said he felt welcome.

In a similar vein, a staff member of an HIV/AIDS organization reported, “I brought a person up for an interview. Amazingly, he started the next day. That was wonderful; it was great to see.”

However, organizational members who work extensively with IDUs, people who live on the street, people with mental illnesses, and First Nations people, commented that the interview process was not straightforward for their clients. Their clients may not have the stability, routine or sense of time conducive to making and keeping appointments. They live in unstable and unstructured environments and this, combined with the distance between the DPC and the DTES impedes their access to interviews. Three organizational members noted that clients had finally made it to the DPC but were turned away because they had not made an appointment. One organizational representative remarked that “Someone had come for an interview and was five minutes late and these are people that, well, he had to walk there, he doesn’t have a bus pass or anything and was told: ‘I am sorry, you’re late, we can’t interview you’. And we were horrified.” However, the person added that she “brought it to their [the DPC’s] attention and they dealt with it appropriately, and we haven’t heard of anything like that occurring [again]. I felt that the issue was resolved. They were very receptive.”

The greatest concern voiced amongst respondents regarding the administrative process is that there is a “waiting list” to become a participant. As mentioned in the Background Report, the DPC does not have a “waiting list” per se. Instead, DPC intake personnel place clients on a High, Medium, or Low needs list for categorization and administrative purposes. Clients not admitted are advised to contact the DPC if their situations change. Evidently, clients who do not meet the
admissions criteria think they are on a waiting list, and this impression appears widespread amongst physicians and organizations. In any event, organizational members and physicians are concerned that the DPC admission criteria are extremely difficult to explain, particularly to IDUs. Three respondents now begin their conversations with clients by telling them, “Well, there’s this really great place but there’s a line up so you have to be patient”. One of them added, “That’s a real big problem because we tell people about the centre and then they can’t get in. Explaining lists and schedules and things like that is a bit difficult, especially with injection drug users.”

Respondents were equally concerned about the fact that the DPC sends out letters to notify people of the outcome of assessment interviews. In one focus group where many organizations were represented, there seemed to be consensus that the use of a letter is inappropriate. They stated that their clients were very disturbed when they received the letter informing them their needs were not high enough. One member commented that it had taken her client many months to go for an interview. And although the DPC encouraged him to reapply when his status changes, he is reluctant to do so. Another member stated that it is the duty of the DPC to respond in person: “we go out on a limb to get them to go there... and they put their trust in the program...By giving the response in person, the client can go back with dignity and say ‘my needs have changed’”. These respondents thus felt that a more personal response would also make the process less sterile and further demonstrate the DPC’s commitment to care delivery.

Lastly, the respondents noted that the DPC could improve its communication with them regarding the status of their clients’ applications. One organizational respondent remarked that the DPC “rejection letter” had only been sent to her client’s physician, even though she had made the referral. She subsequently told the DPC it was common courtesy to inform the referring agency but reported that she did not receive any news. Moreover, 2 physicians who had referred clients to the DPC mentioned that they had only received follow-up letters in cases where the client had not met the entrance criteria. They noted that they would have appreciated receiving notice regarding clients who had been accepted.

**Intake capacity**

Several respondents noted that the DPC’s intake capacity was limited and should increase to serve the growing demand. However, they also acknowledged that the DPC was doing its best with limited resources and welcomed the future residence and free-standing DPC as a potential means of increasing its capacity.

**Equity**

The majority of respondents did not have enough information regarding the demographic breakdown of participants on the DPC roster to state whether the DPC’s admissions process is equitable. In fact, they requested that the DPC provide such information. Respondents thought that a large proportion of
EXTERNAL STAKEHOLDERS’ PERSPECTIVES

participants are gay men from the West End and IDUs from the Downtown East Side. They commended the Centre for its acceptance of the IDU population: “It’s nice to know that there’s an organization down here that’s receptive to injection drug users. It’s been a bit of a problem in the past so we consider it a really positive thing.” (organizational representative)

Two physicians commented that the DPC’s outreach to the DTES (Downtown Eastside) had exceeded their expectations. However, one respondent noted that the injection drug-using community is not homogeneous: there are “recovering IDUs” who are receiving treatment, and “chronic IDUs” who are not ready to change. She wondered which section of the IDU (Intravenous Drug Users) community is actually accessing the DPC.

Respondents knew less about the ethnicity and gender of DPC participants. Most however had a sense that women were underrepresented and requested that the DPC increase its outreach to address the issue. Others believed that the DPC is fast-tracking women and viewed this as a positive step. A staff member of an HIV/AIDS organization said, “I know in the past there had been some concerns that there weren’t very many women attending, and I know that was addressed, which was great.” Respondents noted that women tend to access HIV/AIDS services at an advanced stage in their illness, largely due to their caregiving roles within families and other demands on their time. “I know they were looking at trying to increase the number of women in the program so they’re trying to look at having an equitable diversification of their clients.” (organizational representative)

With regards to ethnicity, few respondents knew whether First Nations people were accessing the Centre, and none could say with certainty how many participants were from this community. In addition, one organizational representative was concerned that Hispanic and Asian IDUs, while sero-converting as fast as other IDUs, are not accessing the Centre. Although this may be more related to lack of linguistic diversity within existing staff at the DPC between staff and potential participants than to actual equity in admissions, it raises questions regarding the DPC’s accessibility to people of diverse racial, ethnic, cultural and linguistic backgrounds. However, more outreach to these ethnoracial communities was recommended.

While respondents could not necessarily comment on whether the DPC’s roster was representative of the HIV/AIDS community as a whole, they thought that the DPC based admission on need. Most physicians and several organizational members viewed this as an effective and fair screening criterion. One respondent suggested that the DPC uses “proper clinical judgment and soul searching in order to respond to the highest need in the community”. There seemed to be an understanding that need was reflected in one’s ability to function in the community and manage the illness.
On the other hand, in a focus group where several organizations were represented, members questioned the DPC’s definition of ‘high need’. One person commented that “If it is to be high need on the continuum of care, then I would have thought they would be people who are nearer to the palliative stage and require home support”. Contrary to her expectations, participants are functioning well enough to walk into the Centre. In a group interview, a social worker also felt that ‘high need’ was a rather misleading concept. He mentioned that the DPC is “for those who are one step away from the gutter…Many don’t meet the criteria because they are not out of the gutter yet. You need to be out of crisis to go there”. Moreover, as mentioned above, these clients have difficulty going to the interview and may thus be deterred from accessing services. There seemed to be some debate about the admissions criteria and whether mechanisms are in place to include those who are hardest to reach. One organizational member stated:

My understanding and our team’s understanding is definitely that it should be high need people, you know, as we don’t want people to over-utilize a number of services in the community. We don’t want all the same people to get all the services and other people that could really use them, not get them. So we will discuss with our clients if they bring up the Dr Peter Centre...actually what population it does serve and actually look at what services they have available to them and whether they are an appropriate client for the Dr Peter Centre or, conversely, if the client is in actual fact in need of the Dr Peter Centre.

5.2.3 DPC communication with physicians and ASOs and health care agencies

General communication

On the whole, physicians and HIV/AIDS organizational members deemed that general communication from the DPC was appropriate. Respondents who worked in clinical settings commented that the DPC staff used weekly AIDS care team rounds at St. Paul’s Hospital to make announcements regarding the program. Others commented that advisory committee meetings were also a space for communication.

However, several questions arose during interviews and focus groups regarding DPC services and service providers, the admissions process and criteria, and the demographic breakdown of participants. This suggests that DPC communication regarding its programming could increase in these areas. Several community-based organizations noted that they had not received any information regarding the DPC since its first invitation to visit the facilities. During one focus group, a representative from an organization argued that his staff makes concerted efforts to connect and interact with the DPC, yet the DPC does not appear to be doing the same. Group members suggested that the DPC increase communication by attending community meetings such as existing monthly “brown bag lunches” held for ASOs and health care agencies, for example.
Communication regarding participants

Generally, respondents were satisfied with the DPC’s communication regarding their clients. The majority of respondents reported having been contacted about the clients’ whereabouts or concerns regarding treatment. Nurses and social workers involved in AIDS team care rounds were particularly pleased with the communication. They noted that these rounds gave them the opportunity to discuss the participants’ involvement in the program as well as their health status. Respondents who participated in advisory committee meetings had similar views.

However, several physicians and organizational members reported that communication could be improved. The major concern for physicians was the lack of feedback regarding the health status of their clients. They unanimously requested follow-up in the form of quarterly reviews or monthly updates either by telephone or in writing:

“If my patients are not benefiting from the services, I don’t want to hear it from the patient. I want to hear it from the Centre. I’d appreciate a monthly update to know about the patients’ status, how they are doing, if they have problems, etc.”

“Perhaps they could consider a ‘tick box’ or a routine update sheet that could come out once a month to participants’ physicians, an update on how they’re doing and any questions they have on treatment or care that they might need answered. I’d appreciate that. Not all physicians might appreciate that because it is paperwork, but I would.”

Organizational members were less concerned with this issue as they recognized that the DPC is bound by confidentiality and that any important information should be shared with the doctor or primary caregiver. They further noted that they could contact the DPC on their own initiative if need be.

A more pressing issue for the organizational members was feed-back regarding the involvement of participants. One member had repeatedly requested that the DPC contact her to keep her up to date on the attendance of the people with whom she worked. Despite her efforts, her only communication with the Centre was the one she initiated herself. She was particularly concerned because she had not been notified when one of her clients quit the program. Additionally, several respondents believed that follow-up from the DPC is more forthcoming when community organizations assign their own case managers to follow the participants’ progress than when clients are on their own.

5.2.4 Challenges of a Diverse Population

External stakeholders were asked whether people of diverse backgrounds feel supported and welcome at the DPC. This question stimulated lively discussions regarding how HIV+ people perceive the DPC and the challenges which present themselves when attempting to group people of diverse backgrounds together.
On one hand, respondents recognized that the DPC is working to implement an inclusive approach by creating a non-judgmental, warm and respectful environment. The DPC has created the environment to make people of diverse backgrounds feel welcome and help them find a common bond. As a result, the DPC has, in some situations, fostered trust and understanding amongst the IDU street-involved participants and middle-class non-user participants. In fact, one respondent noted that the DPC is a model that successfully demonstrates the possibility of mixing different communities. Respondents had either heard from their clients, or inferred from their continued participation, that they felt welcome. The DPC was applauded for its sincere efforts to bring people together who may only have one binding factor—a common experience of HIV/AIDS:

“A gay male that attends the Centre was telling me how well he was educated by some of the diverse populations coming in and he felt that it was just a tremendous mix.”

-organizational representative

“It’s offering a kind of model that people didn’t think would work very well because they didn’t think we could mix the IDU, Downtown East Side community with more middle-class people. And the Centre is already proving it can do that very well. It mixes women and Natives and all sorts of people; so, it’s providing a working model that shows these things are possible if you have the right approach from the staff to the participants.”

-key informant

“I know that the Dr Peter Centre has had many discussions about diversity and mutual respect and have worked very hard on that. And my patients have said they feel welcome there.”

-physician

On the other hand, the majority of external stakeholders commented that, although the DPC might in theory have an inclusive approach, this does not necessarily ensure that people of diverse backgrounds feel welcome there. In fact, a major concern of many of the organizational and physician respondents was whether a representative section of society actually makes it to the admissions interviews and stays in the program. As mentioned above, the respondents noted that many of their clients are not functioning well enough to get to the Centre. (This relates to people’s ability to access services and was discussed in the section on admissions.) Of equal concern is that clients are not interested in participating in the DPC. This relates closely to people’s willingness to participate and is largely determined by their perceptions of the DPC.

As mentioned in the section on diffusion of information, many people have strongly ingrained, although possibly mistaken impressions of the DPC, particularly with regards to target clientele. These impressions have an impact on people’s willingness to access the DPC, starting with the assessment interview. When talking to HIV+ people about the DPC, organizations face the challenge of
trying to correct their misperceptions. As one organizational member stated, “the
nub of the conversation is the impression that people carry with them before the
conversation takes place”. These represent a challenge for the DPC in terms of
operationalizing and implementing its inclusive approach. It appears that social
identity, past experiences of clients, and word of mouth strongly shape the
perceptions of the DPC.

Social identity

Apparently the social identity of HIV positive people has a significant impact on
their perceptions of the Dr Peter Centre. Each community has some members who
sense that the DPC is for other people. Some organizational members reported
having heard from middle class gay men that the DPC is for street people.

A nurse who participated in a group interview noted that one of her clients was
reluctant to return to the DPC precisely because there were many participants
who live on the streets. A social worker recalled that a woman was hesitant to go
to the DPC because she felt it was geared largely to men. Yet another
organizational member noted that one client did not feel comfortable at the DPC
and speculated that he had difficulty relating to IDUs or people with mental
health problems.

Many of the social workers and organizations who work in the DTES have heard
clients say the DPC is “another organization that caters to the upper middle class
gay male population”. Comments such as “it’s not for us,” and “they don’t want
people like us” have led organizational members to believe that many of their
clients from the IDU and DTES community feel alienated from the DPC: “A
perception that we hear from many clients is that really only gay men are
welcome there. We still hear a fair amount of that type of feedback.”
(organizational representative) The DPC’s West End location appears to have
reinforced the image that it targets gay men and, for some, may act as a
psychological barrier to participation. This occurs even though, as several
respondents pointed out, the location has benefited the IDU population by giving
them the opportunity to “leave the other world behind” (ie the DTES).

Physicians and organizations also hold their own impressions of the DPC’s target
clientele. These impressions are reinforced by the comments they hear from their
clients. Evidently, some of the external stakeholders are concerned about who
they should refer to the DPC and who will ultimately feel comfortable there. One
physician respondent noted that s/he refers people who will fit into the middle-
class environment.

Location

---

1 The same concern applies to other ASOs and health care agencies in the city.
EXTERNAL STAKEHOLDERS’ PERSPECTIVES

While location was not mentioned in the questions asked of external stakeholders, this issue was raised by many respondents and is thus discussed here. Another factor which influences people’s willingness to access the DPC is the fact that the it is presently located at St. Paul’s Hospital. There appears to be a belief in the HIV/AIDS community that the DPC is “that St. Paul’s agency”. First Nations people, IDUs, and transgendered women may be most reluctant to access services offered in this setting because of previous negative experiences or a general distrust of hospitals. One organizational representative mentioned that “Because the DPC is perceived as part of a larger institution, that is St. Paul’s hospital, they need to work twice as hard to create a separate identity.”

Issues raised by bringing together diverse people

Respondents also identified problems which inevitably arise when people from diverse backgrounds are grouped together. For instance, one physician respondent noted that the congregation of diverse groups of injection drug users may be detrimental to participants who want to change. That is, ‘chronic’ IDUs may pressure recovering IDUs into dropping out of counseling and other activities which help them stay clean.

A problem was also noted with respect to bringing lesbian/gay/bisexual/transgendered and heterosexual people together. Two heterosexual male clients told respondents that men made sexual advances on them. As a result, one client apparently quit the program. The respondent was particularly concerned because the problem was not resolved despite the fact that the client had discussed it with the men who made the advances and a staff member at the DPC. She feels that the Centre is lacking effective mechanisms to deal with problems arising from such conflicts. In contrast, another organizational member firmly believes that the DPC is effectively facilitating diversity through its weekly community meetings and one-to-one counseling that teaches trust, anger control, and behavior change.

It is clear that word of mouth is a powerful means of communication. The above experiences are undoubtedly transmitted to the community and ultimately perpetuate impressions of the Centre, both critical and positive. Respondents commented on the need to increase outreach to diverse populations, specifically women, IDUs, transgendered people, and people of color in order to reinforce the Centre’s inclusive message.

5.2.5 Hours of operation

All respondents agreed that, although the DPC’s hours of operation are appropriate given the organization’s current resource base, it should work towards expanding its hours to weekends and evenings. As one physician commented, “The disease does not work Monday to Friday”. Extending hours would provide further stability, structure, and continuity of care and thereby
enhance participants’ capacity to manage their medications and their illness. Respondents whose clients have substance abuse issues and mental health imbalances confirmed the importance of increasing hours of operation. Their clients have “nowhere to go for support on weekends” and some may be tempted “to go back to their ‘old life’ [of drug use]”. Offering services during weekends would both serve a growing need and fill a gap in service provision in the lower mainland where most organizations are open weekdays only. One medical doctor reported that “A couple of people have said they would like weekend services, at least some services, because otherwise they are on their own. And for those who are using the Centre for help with medication management, it’s a two day gap for them. So it would be helpful [for the DPC to be open on the weekend].”

One respondent also noted that the DPC must at some point consider longer hours in order to respond to the increasing complexity of the epidemic. She explained that the treatment of AIDS must adapt not only to new drug therapies, but to issues related to mental health, drug use and HIV, to the changing demographics of AIDS, and to increasingly finite resources. As many pointed out, the DPC is attempting to respond to changing needs through its programming, and expanding its hours of operation would further reflect this commitment. On the other hand, the shorter hours have facilitated the daily staff briefing and debriefing sessions which ultimately enable the service providers to maintain an active therapeutic environment.

Organizational members also commented that more information regarding the personal caregivers was in fact needed to determine the appropriateness of the current hours of operation. He emphasized the importance of knowing how many participants have personal caregivers and whether or not these caregivers have full-time employment. The hours of operation should be discussed and adapted to reflect this information. Thus, they should take into account the work schedules of personal caregivers, many of whom might work evenings and weekends. By opening later during the week and over the weekends, the Centre could offer additional respite and support to personal caregivers.

5.2.6 Transportation

Respondents were asked whether participants find it easy or difficult to get to the DPC. To this, five respondents responded that it did not seem to be an issue for their clients. Most respondents, however, had a clear position regarding transportation to the DPC. Some reported that their participants found it easy to get to the DPC: they could either take public transportation or walk. In fact, one physician noted that walking to the DPC had actually proven beneficial for the participant as it was his only source of exercise.

The majority of respondents, particularly those working with participants from the DTES and East Vancouver, responded that it is difficult for clients to access the
EXTERNAL STAKEHOLDERS' PERSPECTIVES

Centre. Many were unaware that the DPC assists with transportation by providing bus tickets or a handidart transfer service for those in need. As a result, they were concerned that the commute to and from the Centre was both too costly and too difficult for those who are sick or otherwise too weak to walk or take the bus:

Although I know the Centre provides transportation, sometimes they just don’t feel well enough to go. I wonder if a little more proactive program like the volunteers saying ‘well, I’ll come and pick you up’ might help them go. Because once they are there it would be very helpful to them. More can be done in terms of proactivity to pick them up and this may be simply by means of a car, by picking them up.

-physician

Most of the respondents who did know about the bus passes and tickets, thought it was a useful strategy. However, one person suggested that participants may ultimately sell the tickets rather than use them to get to the DPC.

Several nurses and social workers from an AIDS care unit raised a separate issue concerning transportation. They noted that wheel-chair bound in-patients had difficulty accessing the DPC from their rooms at St. Paul’s Hospital because there is no direct route from the wards. In order to enable and encourage participants to access services, respondents suggested that the DPC develop a volunteer-based transportation program and make the new facilities wheelchair accessible from Comox Street.

5.2.7 Services and Service Providers

Range and quality of services

External stakeholders were clearly impressed by the services at the DPC. They were extremely pleased with the DPC’s holistic, integrated approach to the treatment of HIV/AIDS and its “one-stop shopping” convenience. Respondents unanimously felt that the range and quality of services were excellent and helpful. The highest ranking in terms of quality and benefit to participants (based on respondents’ personal opinion and client feedback) were: nutritious food, medication management and nursing services, counseling, and arts and crafts (including First Nations crafts). A physician reflected, “It’s very important to have alternative and complementary medicine or practices available because they are very beneficial. So, yes, I think that the services they offer, the counseling, the massage, the artistic programs are very beneficial to a person’s well-being as a whole.”

Although the general feedback concerning services was very positive, a number of respondents were concerned that many of the services offered were centred on the tastes of the middle-class West End community. While horticulture may be appropriate for the general HIV population, one physician and representatives from several organizations did not see what use their clients might have for it, for
instance. One organization member pointed out that the highest priority for IDUs is food and that nutrition may in fact be their only interest in the program:

I understand that some of the staff are frustrated that they come and eat and run...They really want participants to take advantage of the services, the art and music. But, that’s just not a priority for some people. For the participants that we send up, the main priority is food and maybe laundry, but they’re not really thinking beyond that and they shouldn’t be expected to. Injection drug users can’t stick around. If you have a habit and if they’re trying to respect the Centre and they’re not going to be using there, they can only stay so long. Maybe more education in that community [ie the DPC staff] would serve them a little bit better. Like, in understanding that schedules and time and expectations about clients should be different and maybe they shouldn’t have so many expectations about the clients... The staff shouldn’t feel that frustration and that they’re being used because they’re just there to provide food. They are providing an essential service for these people and they shouldn’t feel bad that people do eat and run.

-organizational representative

Most sero-converters are currently coming from the IDU community and several respondents were concerned that the DPC services did not reflect this trend. For instance, one respondent noted that the DPC had hired an art therapist yet did not have an alcohol and drug counselor on staff. Although many respondents were unaware of what the DPC provides in terms of mental health therapy, life skills and housing assistance, their sense was that alcohol and drug services are critical and should be included in programming. They repeatedly commented on the need for harm reduction approaches, as well as detoxification and follow-up services for IDUs who are attempting to “stay clean”. Two respondents stated that the DPC could continue to respond to changing needs and offer more stability by offering methadone therapy.

With regards to the usefulness of services for caregivers, respondents were unable to comment. They were unaware of what services were offered and how they were being accessed, and noted that the majority of their clients did not have personal caregivers.

In addition to mental health therapy, life skills, housing assistance and detoxification support, the respondents suggested that the following services would be beneficial additions to the DPC programming:

• support system for staff and volunteers to prevent burnout
• support group for personal caregivers
• residence (respondents confirmed that this is a necessary evolution for the DPC)
EXTERNAL STAKEHOLDERS' PERSPECTIVES

• activities offered outside the DPC
• education regarding palliative care
• hostel-type intermediate facility with nursing supervision
• bedrooms for relatives who have come from out of town for participants in palliative care
• expanded programming in areas necessary to maximize health: such as daily living and housing
• transportation services for those who cannot otherwise access the Centre
• engaging participants in selling crafts that they have made, to fundraise for the DPC.

Service Providers

Overall, external stakeholders were impressed with the quality, skill level and competence of service providers they knew at the DPC. The majority of respondents had been in contact with only one service provider (generally, a counselor, a nurse, a social worker or intake personnel), and commented that they were highly competent professionals with skills suited to the environment. However, they had little knowledge of the professional background and skill level of other service providers.

The organizations and physicians who had the most contact with, or who had the most feedback about service providers, added that together they form a supportive multidisciplinary team. In addition to representing a broad range of disciplines, the DPC service providers are “the ultimate interdisciplinary team” of professionals who mutually respect each other’s knowledge and experience. Rather than succumb to professional territorialism, they learn and share experiences. And while their backgrounds may vary, they adopt similar approaches to caring for people with HIV/AIDS. As a team, they have been able to create what one respondent called a “very sophisticated therapeutic environment…and this speaks for their quality and professional background”. More praise for the staff:

“The quality of care is excellent.”
-organizational representative

“The respect they give to clients is exceptional.”
-organizational representative

“The nursing staff is excellent.”
-physician

1 The DPC has already begun to accesses services in the community such as the YMCA for physical exercise.
“I heard the nursing staff was really good.”
- organizational representative

“The one taking care of my patient is very good with him.”
- physician

“I think the direction often comes from the leadership that is given. And I think that the staff have worked together remarkably to establish a very nice feeling, a very comfortable feeling for everybody, a very respectful, safe comfortable environment.”
- organizational representative

“They’re very friendly and very helpful.”
- organizational representative

Respondents also complimented the service providers for their ability to create a supportive, caring and respectful environment. This, combined with their non-judgmental and highly respectful attitude towards the participants, is such that “you can feel the comfort zone because of the staff” and this environment has apparently had many positive impacts on participants (as will be seen in the section on outcomes).

While the respondents’ impression of service providers was generally very positive, they felt that hiring the following service providers would enhance the DPC day centre:

- staff proficient in Spanish, French, Vietnamese, and Cantonese
- drug and alcohol counselor
- pharmacist to dispense antiretrovirals and methadone
- more counselors
- social worker
- staff with expertise/background in harm reduction and IDUs living with HIV.

When asked whether the DPC services are based on the best available evidence, most respondents agreed that the Centre’s approach to the treatment of HIV/AIDS is based on the experience of other successful day centers such as Bailey-Boushay and the New York Village Nursing Home. The director of an agency was pleased at how successfully the DPC had replicated the two models and adapted them to local needs. Other organizational interviewees thought the DPC was based on research on the benefits of complementary therapies and on the relationship between determinants of health such as shelter and nutrition on health and well-being.
5.2.8 Management and Governance Structures

For lack of information, almost half of the respondents were unable to comment on the management and governance structures of the DPC.

There was consensus amongst other respondents that the DPC is running extremely well. One physician noted he was impressed with the board of directors, while others commented that the leadership, specifically the Director, is doing an excellent job. They were further impressed with the Director’s commitment to community consultation, particularly prior to and during the implementation of the day centre. They commended the governors and managers of the DPC for commissioning this evaluation and for including them.

5.3 Process

5.3.1 Client-centered approach

There appeared to be consensus that the DPC’s approach is based on reciprocal respect and horizontal relationships. Unlike the dominant medical system in which control lies within professional hands, the DPC strives to create a partnership with participants and encourages them to take control over their lives and their illness. The implementation of health promotion and harm reduction concepts supports participants as well as their families to feel self-reliant.

Except for one organizational member who noted that the DPC activities are not centred on the needs of IDUs, all respondents agreed that the DPC adopts a client-centered and participatory approach. This approach manifests itself in two ways. First, participants are partners in their own care. They are not forced to participate in particular treatments or activities, but rather are provided with choices about their care.

Second, participants are involved in setting policies and practices at the DPC. By participating in community meetings (weekly gatherings for participants, staff and volunteers at the DPC) and DPC committees, they are engaged in decision-making regarding the design and evaluation of activities. These same meetings provide the opportunity for participants to solve problems amongst themselves and identify their needs. DPC participants also sit on hiring committees of the Centre. Respondents agreed that the participants’ needs and voices were brought into the design of the centre, and that the “work is centered around the participant’s needs rather than the needs of staff”. As a result, the DPC has inculcated a sense of ownership in its participants—a feeling that it is “the clients’ program”.
5.3.2 DPC Collaboration with HIV/AIDS Service Providers

The interviewees were asked to comment on whether the DPC collaborates with other HIV/AIDS service providers to ensure services are complimentary and continuous. The majority of physician respondents did not know enough about the DPC’s collaboration efforts to provide an answer. Other stakeholders held different views in this regard.

The majority of remaining respondents agreed that the DPC has made concerted efforts to collaborate with other service providers by inviting them to participate in committees or other meetings and by becoming involved in community meetings. Service providers are represented on the DPC advisory committee, and this encourages agencies to coordinate care. Many people also spoke of the DPC’s openness to hearing about problems and to resolving them in a collaborative manner. There was a strong sense that partnerships have formed between the DPC and other service providers.

Another means by which the DPC collaborates is through the weekly AIDS care team rounds at St. Paul’s Hospital (mentioned previously). Respondents who attend these rounds spoke highly of the DPC’s involvement as it stimulates discussions about discharge planning and subsequent care options. Ultimately, this collaboration has created a bridge between hospital and community settings by involving clients in the day program before they are discharged. Nonetheless, a senior staff member at one AIDS care unit would like to see even stronger linkages with the DPC. Although the AIDS ward has an acute care focus and the DPC has a community care approach, both organizations deal with similar cultural and protocol issues and could thus learn from one another. S/he suggested that the collaboration with the DPC could be enhanced if the DPC attended the ward’s own AIDS rounds to discuss the status of clients and their appropriateness for the day program. In addition, the respondent felt that the DPC could also educate the staff about issues pertaining to the DPC such as eligibility, policies and practices.

During one focus group where several community-based organizations were represented, people commented that the collaboration between St. Paul’s and the DPC was undoubtedly facilitated by geographical proximity and that collaboration with their organizations could be improved. One member suggested that the DPC needs to show more ‘connectedness’ with community organizations if it wants to gain their trust. An important way of collaborating would be to work together in case planning. While he recognized that his organization also had a role to play in fostering collaboration, he had the sense that until now, the onus seemed to rest disproportionately on his staff. He suggested that ‘true collaboration’ would be in place when the DPC and community organizations “connected with case planning”.

With regards to the DPC’s place within the continuum of HIV/AIDS services in the lower mainland and in the province, most respondents reported that the DPC
provides complementary services and fills a growing need. For physicians, it offers the mental and social support which they are unable to provide in their practice. And although there is some overlap with other services available in the lower mainland, such as meals, counseling, and alternative therapies, the DPC complements these services by offering a comprehensive program. By providing medical as well as mental, emotional and social support, the DPC has the potential to deal with a crisis situation better than organizations which offer only psychosocial support. One respondent commented that “there has been a lot of pain and suffering experienced due to lack of such services”.

In addition to providing a unique service, the DPC also offers services to those who have “fallen through the cracks”. Two organizations working in the DTES commented that they would prefer to send their clients to the DPC precisely because it accepts IDUs.

Thus, all respondents perceive the DPC as a valuable and essential resource. However, while all organizations agreed that the DPC fills a gap in services, organizational representatives in two focus groups argued that it did not fit into the continuum of care in the entire lower mainland area. Given that they felt more outreach is needed in the DTES and East Vancouver, they argued that the DPC undoubtedly plays a limited role in surrounding areas such as Chilliwack and Richmond, and even less in other parts of the province.

5.3.3 The DPC’s effect on the work of Organizations and Physicians

Respondents were asked to identify how the DPC has affected their work. Two organizational representatives felt the DPC had not affected them in any way because few of their clients access the centre. The most common response amongst other respondents was that the DPC represents another resource for them to use. They can refer their clients to the DPC or ask the Centre for information regarding other services available in the community or any other HIV/AIDS related questions:

“It provides a resource for our clients--a place for them to go to. Especially those people who can’t fit into any service area. The DPC seems to fill a niche that otherwise no one else is fitting into. So, it’s extremely good.”

- key informant

“I’m not all aware that aware of all the services available. It’s easy to send them to the DPC and they can refer them to other services if they can’t take them there.”

- physician

Over half of the physician respondents noted that the DPC helps them provide care for and manage their “difficult” patients; that is, those whose multiple problems such as substance abuse, mental illness, or housing make them less
likely to follow drug therapy or seek support. By helping DPC participants to follow medical treatment instructions, the DPC may ultimately prevent or detect the onset of a crisis. Physician respondents feel comfortable knowing their patients are well fed and have their medication monitored. One physician explained:

It makes me feel more comfortable actually. Because I don’t have to see patients as often. We have a very busy practice here. And I know that they are being looked after. And if there is a concern, I will be notified or they’ll be encouraged to come and see me. So, it’s a comfort thing for me. I also know they gain weight, their medications are monitored if they want. It just makes me feel better.

Similarly, organizational members also commented on the comfort they feel in sending their clients to the DPC or informing them of the services:

“It’s nice to have a place where I can send people and I feel comfortable that they are going to get what we tell them they are going to get.”

“It provides hope for many of the patients I see. It is a big fear for a lot of people. They worry about what is going to happen in the next few years. Sometimes explaining the services available calms people down and gives them emotional support as well. So, to me there is a lot of hope when I introduce the program.”

One organizational member also commented that the DPC provides a model for ASOs and health care agencies:

It’s a check point in terms of what we need to strive towards when dealing with individuals and the services they receive in our agencies. I am grateful it’s there because of our clients and the high level of needs they have… One thing we keep hearing is the comparison. They use the Dr Peter Centre and they compare the services. And you hear them talk: ‘well we get this at the Dr Peter Centre and we don’t get that over there. So, it’s a checkpoint for us.

In a similar vein, the executive director of a community-based AIDS organization noted that the DPC gives other services a model towards which to strive. She added that she was grateful that the DPC is there for her clients. A nurse commented that she is able to provide hope for clients and calm them down by describing the services available to them through the DPC. Lastly, one respondent, who teaches at the University of British Columbia, is pleased that the DPC has been receptive to students who go there to observe.
5.4 Outcome

5.4.1 How well has the DPC achieved its goals?

All respondents were very impressed with the impact the DPC has had on their clients and were confident that the DPC has been successful in achieving its goals. The following is the list of goals and responses from research participants. The four goals are separate yet very closely interrelated. The factors listed below are thus also connected and mutually reinforcing.

To provide appropriate day centre facilities in order to support HIV+ people (who attend the centre) to live independently in the community

In order to answer the question, one organizational representative stated he would need to know if the DPC has staff that are dedicated to work on aspects which help people live independently. One physician also abstained from responding. However, other respondents answered that without a doubt, the DPC has enabled participants to live independently in the community. They identified four main mechanisms through which the DPC is attaining this goal: 1) the creation of a stable, structured and safe environment, 2) helping participants take control over their lives and illnesses; 3) education in life skills such as socializing and 4) nutritional support.

⇒ stability, structure, and safety

Respondents noted that the DPC gives structure and stability to peoples’ lives. One organizational member noted that “it’s a place they can go to every day…it almost feels like a job, and that’s a lot for people who don’t have a lot of structure in their lives...Some even say they are ‘Dr Petered out’ and need a day off.” By participating in the day program, clients add some normalcy to their lives and gain a sense of purpose and a reason to live. Another respondent remembers a client saying “Six months ago I was going in circles, I was spinning. Now I have a life.” As a result, participants “become more in tune with themselves and can function at a higher level”. Apparently one participant has returned to work.

In addition, the DPC is a safe place where people can go to relax and escape the difficult influences in their lives. A nurse and two social workers recalled that one woman attended the Centre five days a week and was ultimately able to stay off drugs.

⇒ control

As mentioned above, the Dr Peter Centre adopts a highly participatory, client-centred approach to care. By promoting participant involvement in decision making regarding their treatment and Centre activities, the DPC fosters client empowerment. One organizational respondent felt that, “The DPC doesn’t hold their hand all the time. It gives them a
chance to get their life and their health in order and helps them help themselves.”

The non-judgmental, caring, and respectful environment, along with the sense of purpose mentioned above, supports clients to develop the self-esteem and dignity necessary to take charge of their lives and care for themselves. One organizational member noted that “You first realize you are worth something and you deserve something. When that’s built and you finally realize it, you cope much better in an environment that was probably quite harsh prior to having those skills. People who felt they were non-people now have an identity.”

⇒ education

The education provided at the Dr Peter Centre is invaluable in helping clients lead more independent lives. They learn coping and behavioral skills which enable them to deal with their illness without anger, drugs or violence. The clients also learn about their illness and drug therapies, and learn to manage both on their own. In addition, the DPC teaches life skills such as hygiene and proper nutrition which enable them to function better in the community.

⇒ socializing

Most physician respondents emphasized the importance of socializing and peer support in assisting clients to live independently in the community. Getting out of the house, seeing people and gaining the support of their peers enables clients to cope with their illness and has a tremendous impact on their social well-being. Moreover, the socialization skills they learn help them participate in community life. One physician respondent noted a remarkable transformation in a client who had never left the house until he started going to the DPC: “He used to be a loner. Now he goes to the DPC every day. It is important for him to interact with other HIV+ people.”

⇒ nutritional support

Finally, several interviewees noted that nutritional support has been influential in enabling clients to live independently. One physician noted that his/her client often remarks on the high quality of the food. Several others echoed comments they had heard from DPC participants about the deliciousness of the cuisine:

“He says the food is great.”
-physician

“The food program is excellent.”
-physician

“The meals are highly beneficial. People rely on the food.”
-organizational member

To maximize the health of the HIV+ people who attend the centre
EXTERNAL STAKEHOLDERS’ PERSPECTIVES

All respondents were of the opinion that the DPC has helped to maximize the health of the participants. The broad spectrum of services at the DPC act together to improve health and well-being. The DPC provides a safe, caring environment which facilitates the delivery of care, and, the creative programming helps participants to keep their mind off their illness. One physician noted, “It helps improve the health of participants. Most of my patients are IV drug users. The Dr Peter Centre helps them get stable and this impacts on their health because it’s easier for them to take their medication.”

The most influential factors in maximizing health were nutritional support, medication management, education, and a caring environment.

⇒ nutritional support
   By far, the best, and most often cited evidence of increased health status was the weight gain noted in participants. All the organizations commented on the impact of a stable and nutritious diet in maximizing the health of HIV/AIDS patients.

⇒ nursing support and medication management
   Because the DPC has a nursing staff, the participants can get assistance in diagnosis and treatment when needed; interviewees were clear that the nursing support was complementing other medical services the participants were receiving and was not redundant. The Dr Peter Centre has also created an environment conducive to increasing medical cooperation amongst participants: it provides education about drug therapies and assistance in managing medication, as well as offers the support, stability, caring, and food required to maintain a strict medication regimen. One organizational member noted that medication management is a stepping stone to many health improvements.

⇒ education, counseling and support
   Through education, counseling and support regarding a number of issues relating to HIV/AIDS, participants have learned to manage and cope with their illness. Respondents noted that this has had a positive impact on their psychological well-being and quality of life. They also remarked that counseling in drug use has helped participants stay clean, which also acts to maximize health.

⇒ caring environment
   Respondents reported that the nurturing and caring environment created by the DPC staff has had a significant impact on participants’ social well-being. When clients are surrounded by caring people who are willing to help and who take their needs seriously, the clients also learn to take their own needs seriously and value their lives. This, together with the independence, sense of purpose, and social support noted above, gives them the confidence and desire to take care of themselves.
To decrease inappropriate hospital admissions and stays of people living with HIV who attend the Centre

When asked whether the DPC has contributed to decreasing inappropriate hospital admissions and stays of people living with HIV, all respondents felt they needed data to provide an evidence-based answer. In addition, they found it difficult to isolate the DPC from factors such as new drug therapies or other available services which may also have an impact on hospital admissions. Nonetheless, many respondents responded intuitively. They assumed that the increased health status noted above would ultimately decrease the illnesses participants would experience, and should lend itself to lowering hospital admissions. Moreover, the staff at the DPC may detect disease earlier and treatment can therefore be administered before hospitalization is required. Conversely, one physician suggested that in some cases, early detection can also lead to an increase in “appropriate” admissions.

Social workers and nurses at an AIDS care health unit were able to identify at least one person who has not been readmitted to the hospital since she became involved in the DPC. They have also noted a trend of clients returning to the hospital when they stop participating in the DPC. A nurse also confirmed that PLWAs are being referred to the DPC instead of the Health Unit and that the use of the Unit’s Home Support Workers may also ultimately decline.

The executive director of a community organization explained that previously, people accessed the emergency room because they were not involved in any other services. Even though their visit may have been for drug seeking purposes, the hospital was a safe environment and they were off the streets. Although the respondent did not feel these admissions were necessarily “inappropriate”, she noted that as clients become involved in the DPC, they use it as their base and phase out visits to the emergency room. Thus, the DPC’s presence in the community also provides an alternative to hospital settings.

The following quotations typify the respondents’ thoughts on this issue:

“I think to really analyze that you would have to look at hospital admissions. But, the very fact that they are getting the nutritional support, the assistance with their medication management and some behavioral management is going to enhance their physical status and that should certainly lend itself to decrease the different illnesses that they would experience.”

-organizational representative

“If you are looking at the number of ER visits, why were those people using the Emergency Department? In most cases it’s because they
EXTERIOR STAKEHOLDERS’ PERSPECTIVES

didn’t have anywhere else to go and they weren’t connected, the hospital was a safe environment even if it was for drug seeking behavior, it was still almost like a home. As they become incorporated in the Dr Peter Centre, they tend to use it as their base and phase out their emergency visits, and possibly they’re getting earlier treatment because of the comprehensive care at the Dr Peter Centre, so their admissions are being decreased. But we don’t have an appropriate database to give you all the particulars.”

-organizational representative

“It gives us another place to refer people to instead of the hospital.”

-physician

“People can certainly detect early symptoms, and you know you can’t make the horse drink the water, but I think it’s very beneficial.”

-organizational representative

To support the personal caregivers of the participants of the Dr Peter Centre

The respondents had difficulty commenting on the impact of the DPC on personal caregivers for two reasons. First, almost all respondents reported that their clients did not have personal caregivers, and thus had no feedback on which to base their answer. Second, several respondents had limited knowledge of the counseling and support services the DPC offers caregivers and the extent to which they are accessed. Respondents felt they needed more information on the caregivers, particularly regarding their work schedules and the services they access. Despite the fact that they could not offer an informed answer, one quarter of the respondents felt the Dr Peter Centre must be supporting caregivers if only by virtue of the respite it offers.

6.0 CONCLUSION: STRENGTHS, WEAKNESSES AND OPPORTUNITIES FOR IMPROVEMENT

In conclusion, external stakeholders were extremely optimistic about the DPC’s work and future potential. They were impressed with quality of services and service providers and noted the remarkable speed with which the Centre had evolved. They used descriptors such as “fabulous,” “excellent”, “impressive” when describing the Centre and unanimously perceived it as a highly needed and valuable resource. Respondents commended the DPC for its flexibility and urged it to continue adapting to the constant changes inherent in the reality of HIV/AIDS. They were extremely supportive of the DPC and wished to see the
EXTERNAL STAKEHOLDERS’ PERSPECTIVES

Centre continue to expand and improve its services. As a result, they generally provided positive and constructive criticisms.

Strengths

While each respondent prioritized different areas of the DPC’s work, the most valuable aspects of the Centre, according to external stakeholders, appeared to be:

- Nutritional support
- High quality of care
- Medication management
- Counseling, support, and stability
- The creation of linkages and continuity of care between the hospital and the community
- The availability of a new resource and an alternative to hospitalization

The respondents also applauded the DPC’s decision to conduct an evaluation early in its existence as it attests to the Centre’s commitment to quality of care. They recommended subsequent evaluations once the residence beds are in place.¹

Weaknesses and opportunities for improvement

The most commonly cited suggestions for the DPC were:

- a need to do outreach to diverse communities
- a need for staff who are fluent in Chinese, French, Spanish and Vietnamese as well as staff who are skilled in working in the areas of social work and substance abuse
- expanding its hours of operation
- increasing its intake capacity
- improved communication with stakeholders, particularly medical doctors.

These suggestions for improvement were made with the understanding that the DPC is conducting the program as best as it can given present funding and space restrictions and considering it is in its first stage of development. In summary, the top areas for improvement are as follows:

Increase outreach to diverse communities

¹ With respect to the next phases of this evaluation, representatives from several organizations urged Shroff Consulting to include the voices of HIV+ people who may be eligible to participate in the DPC but are not accessing services. Two organizations offered to help identify potential participants. One member suggested that community organizations could administer a simple questionnaire to their clients; and, in fact, brought a sample to the focus group and offered to facilitate the process.
EXTERNAL STAKEHOLDERS’ PERSPECTIVES

Interviewees were under the impression that the DPC could do more outreach to peoples of color, and women. Additionally, the majority of the organizations felt that more work is required to incorporate the Downtown Eastside and East Vancouver communities into the program. Specifically, the DPC could increase its outreach and provide more information about its program, sensitize staff to the characteristics and needs of the drug using community, develop new strategies to meet those needs, place more emphasis on detoxification programs and counseling, and potentially open another centre in the Downtown Eastside or East Vancouver.

Diversifying Staffing

Interviewees urged the DPC to hire staff with Spanish, French, Chinese, and Vietnamese language abilities to make the program more accessible to people of color living with HIV/AIDS. An organizational representative felt that, “There are no non-English speaking staff members and we have a number of Hispanic and Asian participants that we would like to see access the Dr Peter Centre and we think they would be good for the Centre, but they are not able to [access it] because of language barriers.”

Additionally, given that the IDU community is accessing the DPC, some respondents felt it was important for the DPC to hire a substance abuse counselor and social worker. The majority of physicians and one organization’s representative commented on the need for a pharmacist to dispense medications and provide directly observed therapy. Finally, several organizations suggested implementing a volunteer-based transportation service.

Expand hours of operation

There appeared to be consensus that ideally, the DPC should operate 7 days a week and offer services during the evening.

Increase intake capacity

Approximately one quarter of respondents felt that the DPC should ultimately increase its intake capacity. They welcomed the new building and residence as a potential move in that direction.

Increase communication with physicians and organizations

Physicians and organizations saw the need for increased communication in the following areas:

• monthly or quarterly updates to physicians regarding the health status and involvement of clients in the DPC;
• communication about the status of client applications (negative or positive) to the referring organization or physician;
• information regarding the admissions process;
EXTERNAL STAKEHOLDERS' PERSPECTIVES

• information regarding the day program in general;
• information regarding the demographic breakdown of participants.

Increase collaboration with organizations
Respondents in focus groups and interviews representing eight organizations suggested that the DPC could increase its collaboration with other HIV/AIDS service providers.

Other suggestions included
• developing a hostel-type intermediate facility with nursing supervision
• providing bedrooms for relatives who have come from out of town for participants in palliative care
• expanding programming in issues necessary to maximize health: daily living, housing
• developing more mechanisms to cope with diversity
• increasing activities outside the DPC.

These constructive suggestions will hopefully assist the DPC in reaching its full potential. At this point, however, external stakeholders’ sentiments may be aptly summarized by the following commentaries:

“It gives people a purpose. It’s somewhere to come. It’s a place that they’re welcomed. It occupies a huge part of their day which is maybe spent in other unsafe activities. I think it’s just wonderful.”

-organizational representative

The DPC gives my patient a reason to get up in the morning. If he didn’t have a reason to go out, he’d stay at home. I hadn’t anticipated how well the Centre would give my patient the desire to live again.

-Physician
REFERENCES


Dr Peter AIDS Foundation (1997). “Dr Peter Centre Project Fact Sheet”, Dr Peter AIDS Foundation, Vancouver.


McNally, Len and Leah Mason Beck (date not recorded). “A Chronic Care Approach to Health and Social Services for People with AIDS”.

O’Shaugnessy, Michael (1997). Minutes of a presentation by Dr. Michael O’Shaugnessy, Director of the BC Centre for Excellence in HIV/AIDS, to the Dr Peter AIDS Foundation Board of Directors, Vancouver.


APPENDICES
APPENDIX A
ASOS AND HEALTH CARE AGENCIES

The following is a partial list and description of HIV/AIDS service organizations and health care agencies in the lower mainland. A number of hospitals, clinics, and organizations serving the HIV/AIDS population in Vancouver are not mentioned here. Those listed below exemplify the diverse and complementary nature of resources available.

**AIDS Vancouver** offers a comprehensive program of community and client support and education. Its program includes the Care teams, counseling, grocery store, the Training Institute, medical equipment loans, support and advocacy and legal aid. AIDS Vancouver has representation on the Dr Peter Centre Advisory Committee and the Dr Peter Foundation Board of Directors.

**BC Centre for Excellence in HIV/AIDS (BCCE)** In addition to conducting epidemiological, economic and virological research and professional education, the Centre offers AIDS related treatment at no charge to all people with HIV/AIDS in BC. The BCCE has a representative on the Dr Peter Centre Advisory Committee.

**BC Persons with AIDS Society (BCPWA)** provides support and advocacy for people living with HIV/AIDS. Among other projects, the BCPWA offers art therapy, support groups, legal assistance, nutrition and peer counseling, resource information, a newsletter ad the Positive Living Manual. Through its Complementary Health fund, the BCPWA also provides funding for members to receive treatment not covered by the British Columbia medical insurance plan. The BCPWA is represented on the DPC Advisory Committee and the Dr Peter Foundation Board of Directors.

**Friends for Life** provides spiritual, emotional and psychological support to people with life threatening illness including HIV/AIDS. Friends for Life presently runs 50 programs including group and individual support, massage, body work, and social programming such as meal programs and counseling.

**Pacific AIDS Resource Centre (PARC)** was established in 1992 by the BCPWA, AIDS Vancouver and the Positive Women’s Network in an effort to provide a ‘one stop’ facility for persons with HIV/AIDS. Together, the three participating organizations provide health promotion services and facilitate the delivery of high quality, comprehensive integrated and accessible health care to HIV affected communities of BC.

**Positive Women’s Network** provides support and advocacy services to women throughout British Columbia, including information and referral, drop-in counseling, quarterly retreats, magazines, education and awareness.
St. Paul’s Hospital is the principal treatment centre for HIV/AIDS in the province. Through its HIV Disease Program, it “promotes the health of persons affected with HIV/AIDS through care, support, research and education” (Horizon Pacific International 1994: 31). The St. Paul’s AIDS Program is a member of the Dr Peter Centre Advisory Committee.

Vancouver/Richmond Health Department Continuing Care Division includes visiting home care, nursing and rehabilitation therapy services, case management, home support services, and residential care. Together, its Burrard-West End and North Health Units serve the largest numbers of BC residents with AIDS. Both Units have membership on the DPC Advisory Committee.
APPENDIX B

QUALITATIVE EVALUATION OF THE DR. PETER CENTRE

Questions for Physicians

1. Introduction

A. Please tell me briefly what you know about the Dr. Peter Centre.

B. Approximately how many of your patients attend the Dr. Peter Centre?

C. At this early stage of the Dr. Peter Centre’s existence, what are your general impressions of the Centre?

2. Structure

A. How do most people in the HIV/AIDS community, especially HIV+ people, find out about the Dr. Peter Centre?

B. Have you ever referred someone living with HIV to the Dr. Peter Centre?

If Yes-- If so, you know that the Dr Peter Centre is currently serving HIV+ people in high need. Please comment on the admissions process. (Do you think the admissions process is relatively straightforward? Is the process equitable in terms of who gets in?)

If Not--why not?

C. In general, how well does the Dr Peter Centre communicate with you? (Do you have any feedback about the contact between you and the Dr Peter Centre?)

D. How well does the Dr Peter Centre communicate with you about the health status of your patients there?

E. The diversity of the AIDS community involves many groups of people, including lesbians/gays/bisexuals/transsexuals, First Nations peoples, people of color, marginalized women, people who live on the street, those with addictions, people living in poverty as well as middle class people, and others. In your view, do people of diverse backgrounds feel supported and welcome at the Centre? Please explain.

F. Currently the Centre is open five days a week from 9:30 am to 3:30 pm. Are the hours of operation appropriate in your view? Please explain.
G. Do your patients find it easy or difficult to get to the Centre? Please explain.

H. The following services are currently offered at The Dr Peter Centre: hot meals and nutritious snacks; nursing support in medication management and harm reduction; individual and group counseling in mental health, nutrition, and chemical dependency; health and leisure education; individual program planning; art, music, drama, writing and horticulture programs; recreation and exercise; socialization, structured and unstructured leisure opportunities; complementary therapies such as aromatherapy, healing touch, massage and relaxation; respite and support for partners, family members and friends; transportation assistance to the Centre for those who need it; and volunteer resources.

Please comment on the quality and range of services provided. (Are they appropriate and helpful to your patients? to the informal caregivers and partners/families of your patients? Are there any services missing in your view?)

I. Please comment on the range and skills of service providers at the Dr Peter Centre. (Is there an appropriate use of providers with various skills--in the medical, recreational and therapeutic areas?)

J. In your view, are the programs offered by the Dr Peter Centre designed on the basis of the best available evidence? Please explain.

K. Are there any aspects of the governing or management structures of the Dr Peter Centre that you wish to discuss?

L. Are there any other aspects of the structure of the Dr Peter Centre that you would like to discuss?

3. Process

A. In your view, are the services at the Dr Peter Centre adequately centred on the participants? Please elaborate. (Do you believe that participants are active partners in their own care? Do you sense that participants are involved in setting policies and practices at the Dr Peter Centre?)

B. Does the Dr Peter Centre collaborate with other HIV/AIDS service providers, including physicians, to ensure services are complimentary and continuous? (Does it fit well into the continuum of HIV/AIDS services in the lower mainland and in the province?)

C. How does the Dr Peter Centre affect the work you do? (Has the Centre had an impact that you did not anticipate it would?)
D. Are there any other aspects of the process by which the Dr Peter Centre operates that you would like to discuss?

4. Outcome

The mission of the Dr Peter AIDS Foundation is to provide *comfort care* through programs that serve adults living with HIV/AIDS. Under this broad mission, the Dr Peter Centre has 4 main goals--focused on fostering participants’ abilities to manage their own care. I will name each goal and would like your opinions about how well the Centre, at this early stage, has reached these goals:

A. To provide appropriate day-centre facilities, in order to support HIV+ people (who attend the Centre) to live independently in the community.

B. To decrease inappropriate hospital admissions and stays of people living with HIV (who attend the Centre).

C. To maximize the health of the HIV+ people who attend the Centre. (In what ways do you think these services have helped people? What have participants gained from the Dr Peter Centre? Has the Dr Peter Centre affected health and well-being? If so, how?)

D. To support the personal care givers of the participants of the Dr Peter Centre.

E. Please name the most useful and the least useful aspects of the Dr Peter Centre. Please explain.

F. Do you have any suggestions for how the Dr Peter Centre can improve? Feel free to be as general or specific as you like.

G. Do you have anything else you would like to tell me about your impressions of the Dr Peter Centre--positive or negative?

Thank you very much.

© SHROFF CONSULTING 1997
APPENDIX C

QUALITATIVE EVALUATION OF THE DR. PETER CENTER

Questions for ASOs and health care agencies

1. Introduction

A. Please tell me briefly what you know about the Dr Peter Centre.

B. Approximately how many people do you know/work with who attend the Dr Peter Centre?

C. At this early stage of the Dr Peter Centre’s existence, what are your general impressions of the Centre?

2. Structure

A. How do most people in the HIV/AIDS community, especially HIV+ people, find out about the Dr Peter Centre?

B. Have you ever told an HIV+ person about the Dr Peter Centre? Yes--If so, you know that the Dr Peter Centre is currently serving HIV+ people in high need. Please comment on the admissions process. (Do you think the admissions process is relatively straightforward? Is the process equitable in terms of who gets in?) No--If not, why not?

C. In general, how well does the Dr Peter Centre communicate with your agency? (Do you have any feedback about the contact between your agency and the Dr Peter Centre?)

D. How well does the Dr Peter Centre communicate with your agency about the health status of Dr Peter Centre participants you know?

E. The diversity of the AIDS community involves many groups of people, including lesbians/gays/bisexuals/transsexuals, First Nations peoples, people of color, marginalized women, people who live on the street, those with addictions, people living in poverty as well as middle class people, and others. In your view, do people of diverse backgrounds feel supported and welcome at the Centre? Please explain.

F. The Centre is currently open from 9:30 am to 3:30 pm. Are the hours of operation appropriate in your view? Please explain.
G. Do the people you know find it easy or difficult to get to the Centre? Please explain.

H. The following services are currently offered at The Dr Peter Centre: hot meals and nutritious snacks; nursing support in medication management and harm reduction; individual and group counseling in mental health, nutrition, and chemical dependency; health and leisure education; individual program planning; art, music, drama, writing and horticulture programs; recreation and exercise; socialization, structured and unstructured leisure opportunities; complementary therapies such as aromatherapy, healing touch, massage and relaxation; respite and support for partners, family members and friends; transportation assistance to the Centre for those who need it; and volunteer resources.

Please comment on the quality and range of services provided. (Are they appropriate and helpful to the participants you know? to the informal caregivers and partners/families of participants? Are there any services missing in your view?)

I. Please comment on the range and skills of service providers at the Dr Peter Centre. (Is there an appropriate use of providers with various skills—in the medical, recreational and therapeutic areas?)

J. In your view, are the programs offered by the Dr Peter Centre designed on the basis of the best available evidence? Please explain.

K. Are there any aspects of the governing or management structures of the Dr Peter Centre that you wish to discuss?

L. Are there any other aspects of the structure of the Dr Peter Centre that you would like to discuss?

3. Process

A. In your view, are the services at the Dr Peter Centre adequately centered on the participants? Please elaborate. (Do you believe that participants are active partners in their own care? Do you sense that participants are involved in setting policies and practices at the Dr Peter Centre?)

B. Does the Dr Peter Centre collaborate with other HIV/AIDS service providers to ensure services are complimentary and continuous? (Does it fit well into the continuum of HIV/AIDS services in the lower mainland and in the province?)
C. How does the Dr Peter Centre affect the work you do? (Has the Centre had an impact that you did not anticipate it would?)

D. Are there any other aspects of the process through which the Dr Peter Centre operates that you would like to discuss?

4. Outcome

The mission of the Dr Peter AIDS Foundation is to provide comfort care through programs that serve adults living with HIV/AIDS. Under this broad mission, the Dr Peter Centre has 4 main goals--focused on fostering participants’ abilities to manage their own care. I will name each goal and would like your opinions about how well the Centre, at this early stage, has reached these goals:

A. To provide appropriate day-center facilities, in order to support HIV+ people (who attend the Centre) to live independently in the community.
B. To decrease inappropriate hospital admissions and stays of people living with HIV (who attend the Centre).
C. To maximize the health of the HIV+ people who attend the Centre. (In what ways do you think these services have helped people? What have participants gained from the Dr Peter Centre? Has the Dr Peter Centre affected health and well-being? If so, how?)
D. To support the personal care givers of the participants of the Dr Peter Centre.

E. Please name the most useful and the least useful aspects of the Dr Peter Centre. Please explain.

F. Do you have any suggestions for how the Dr Peter Centre can improve? Feel free to be as general or specific as you like.

G. Do you have anything else you would like to tell me about your impressions of the Dr Peter Centre--positive or negative?

Thank you very much.

© SHROFF CONSULTING 1997
APPENDIC D

FOCUS GROUP QUESTIONS FOR ASOS AND HEALTH CARE AGENCIES

QUALITATIVE EVALUATION OF THE DR PETER CENTER

1. Introduction

A. At this early stage of the Dr Peter Centre’s existence, what are your general impressions of the Centre?

2. Structure

A. How do most people in the HIV/AIDS community, especially HIV+ people, find out about the Dr Peter Centre?

B. Have you ever told an HIV+ person about the Dr Peter Centre? Yes—If so, you know that the Dr Peter Centre is currently serving HIV+ people in high need. Please comment on the admissions process. (Do you think the admissions process is relatively straightforward? Is the process equitable in terms of who gets in?) No—If not, why not?

C. In general, how well does the Dr Peter Centre communicate with your agency? (Do you have any feedback about the contact between your agency and the Dr Peter Centre?)

D. How well does the Dr Peter Centre communicate with your agency about the health status of Dr Peter Centre participants you know?

E. The diversity of the AIDS community involves many groups of people, including lesbians/gays/bisexuals/transsexuals, First Nations peoples, people of color, marginalized women, people who live on the street, those with addictions, people living in poverty as well as middle class people, and others. In your view, do people of diverse backgrounds feel supported and welcome at the Centre? Please explain.

F. The Centre is currently open from 9:30 am to 3:30 pm. Are the hours of operation appropriate in your view? Please explain.

G. Do the people you know find it easy or difficult to get to the Centre? Please explain.
H. The following services are currently offered at The Dr Peter Centre: hot meals and nutritious snacks; nursing support in medication management and harm reduction; individual and group counseling in mental health, nutrition, and chemical dependency; health and leisure education; individual program planning; art, music, drama, writing and horticulture programs; recreation and exercise; socialization, structured and unstructured leisure opportunities; complementary therapies such as aromatherapy, healing touch, massage and relaxation; respite and support for partners, family members and friends; transportation assistance to the Centre for those who need it; and volunteer resources.

Please comment on the quality and range of services provided. (Are they appropriate and helpful to the participants you know? to the informal caregivers and partners/families of participants? Are there any services missing in your view?)

I. Please comment on the range and skills of service providers at the Dr Peter Centre.
(Is there an appropriate use of providers with various skills--in the medical, recreational and therapeutic areas?)

J. In your view, are the programs offered by the Dr Peter Centre designed on the basis of the best available evidence? Please explain.

K. Are there any aspects of the governing or management structures of the Dr Peter Centre that you wish to discuss?

L. Are there any other aspects of the structure of the Dr Peter Centre that you would like to discuss?

---

3. Process

A. In your view, are the services at the Dr Peter Centre adequately centered on the participants? Please elaborate.
(Do you believe that participants are active partners in their own care? Do you sense that participants are involved in setting policies and practices at the Dr Peter Centre?)

B. Does the Dr Peter Centre collaborate with other HIV/AIDS service providers to ensure services are complimentary and continuous? (Does it fit well into the continuum of HIV/AIDS services in the lower mainland and in the province?)

C. How does the Dr Peter Centre affect the work you do? (Has the Centre had an impact that you did not anticipate it would?)
D. Are there any other aspects of the process through which the Dr Peter Centre operates that you would like to discuss?

4. Outcome

The mission of the Dr Peter AIDS Foundation is to provide comfort care through programs that serve adults living with HIV/AIDS. Under this broad mission, the Dr Peter Centre has 4 main goals--focused on fostering participants’ abilities to manage their own care. I will name each goal and would like your opinions about how well the Centre, at this early stage, has reached these goals: A. To provide appropriate day-center facilities, in order to support HIV+ people (who attend the Centre) to live independently in the community.
B. To decrease inappropriate hospital admissions and stays of people living with HIV (who attend the Centre).
C. To maximize the health of the HIV+ people who attend the Centre. (In what ways do you think these services have helped people? What have participants gained from the Dr Peter Centre? Has the Dr Peter Centre affected health and well-being? If so, how?)
D. To support the personal care givers of the participants of the Dr Peter Centre.

E. Please name the most useful and the least useful aspects of the Dr Peter Centre. Please explain.

F. Do you have any suggestions for how the Dr Peter Centre can improve? Feel free to be as general or specific as you like.

G. Do you have anything else you would like to tell me about your impressions of the Dr Peter Centre--positive or negative?

Thank you very much.

© SHROFF CONSULTING 1997
APPENDIX E  DR. PETER CENTRE FLOOR PLAN

APPENDIX F  ASO AND HEALTH CARE AGENCY RESPONDENTS

Total number of participants: 28
Total number of organizations represented: 16
**Key Informant Interviews**: 7 participants

- St. Paul’s Hospital - 1 representative
- St. Paul’s Hospital - Unit 10C: 4 representatives
- St. Paul’s Hospital - HIV/AIDS Program: 1 representative
- BC Centre for Excellence in HIV/AIDS: 1 representative

**Focus Group #1**: 2 participants

- Vancouver Richmond Health Board Continuing Care Staff, Burrard Health Unit - 1 representative
- ACT Team (Greater Vancouver Mental Health) - 1 representative

**Focus Group #2**: 2 participants

- Vancouver Native Health Society - 1 representative
- VIDUS Project - 1 representative

**Focus Group #3**: 7 participants

- St. Paul’s Hospital Immuno Deficiency Clinic - 1 representative
- AIDS Vancouver - 1 representative
- BC Persons With AIDS Society - 1 representative
- High Risk Project Society - 1 representative
- Greater Vancouver Mental Health Services - 1 representative
- Street Nurse Program - 2 representatives

**Individual Interviews with Organizations**: 3 participants

- Vancouver Hospital - 1 representative
- Friends for Life - 2 representatives

**Individual Interviews with Physicians**: 7 participants

7 physicians practicing in the lower mainland