

Hooking Up **TO SOCIAL SERVICES**

A Report on the Barriers
People Living with HIV/AIDS
Face Accessing Social Services

ERIC MYKHAILOVSKIY

Community AIDS Treatment Information Exchange

GEORGE W. SMITH

Ontario Institute for Studies in Education

March, 1994

ISBN 1-896135-04-8

Additional copies available from:

CATIE

Community AIDS Treatment Information
Exchange (CATIE)

Réseau Communautaire D'Info-Traitements
SIDA (RCITS)

517 College Street, Ste. 420, Toronto, Ontario
Canada M6G 4A2

(416) 944-1916

or

1-800-263-1638

Canadian Cataloguing in Publication Data

Mykhalovskiy, Eric, 1963-

Hooking up to social services: a report on
the barriers people living with HIV/AIDS face
accessing social services

ISBN 1-896135-02-1

1. AIDS (Disease) - Patients - Services for -
Ontario. I. Smith, George W. (George William),
1935- . II. Community AIDS Treatment
Information Exchange. III. Title.

RC607.A26M85 1994 362.1'969792'009713541
C94-930682-7

COPYRIGHT ©1993 by Ontario Institute for
Studies in Education (OISE)

All rights reserved. No part of this publication
may be reproduced in any form or language
without written permission from the publisher.

ISBN 1-896135-04-8

Printed by CATIE - Community AIDS Treatment
Information Exchange, Toronto, Ontario
Canada

*This report is dedicated to Barry James Way (1962 - 1993),
person living with HIV/AIDS and AIDS activist, who fought hard
to improve access to social services for people living with
HIV/AIDS.*

Acknowledgements

We would like to express our gratitude to the individuals whose assistance helped enhance this report in innumerable ways.

We are particularly indebted to the people living with HIV/AIDS (PHAs) we interviewed, who gave generously of their time and spoke candidly about matters that were often difficult. Without them there would be no report. We would also like to thank the individuals we interviewed who worked in AIDS service organizations, government agencies, health services and other organizations involved in "hooking up" PHAs to social services.

We would like to express our appreciation to our technical advisory committee members who gave valuable guidance with respect to the intellectual direction of the report. Our discussions with Dorothy Smith were particularly helpful for clarifying our analysis of research findings. We also gratefully thank the members of our community advisory committee with whom we met on numerous occasions throughout the research project. They generously facilitated the organization of interviews with PHAs and contributed important insights and criticisms to our analysis. We would also like to thank Caralee Price for her skilful management of the administrative aspects of the research project. With great care and precision, B. J. Cooke, Ruth Nieboer, Riva Love and Less Tager transcribed our interview tapes.

During the early phases of our research, our discussions with Carol-Anne O'Brien, Robb Travers and Laurie Bell gave us an opportunity to air methodological issues and test out preliminary research findings. We would also like to thank Sarah Forer, Darien Taylor, Rebecca Bloomsfield, John Hammond, Carol-Anne O'Brien, Liza McCoy and Frank Chester who gave valuable feedback to earlier versions of this report. Lastly, we thank Lesbians, Gays and Bisexuals of U of T for their generous loan of office space and Joel Rotstein for donating his time to produce the report's cover.

During the final phase of our research, George Smith became ill. Consequently, the majority of this report was written by Eric Mykhalovskiy.

Technical Advisory Committee

Eugenia Moreno
Executive Director
Canadian Association of
Social Workers

Gillian Walker
Director
School of Social Work
Carleton University

Dorothy Smith
Department of Sociology
Ontario Institute for
Studies in Education

Community Advisory Committee

Scott Beveridge
Street Outreach Services
Toronto, Ontario

Mary Grondin
Department of Public Health
Toronto, Ontario

Scott Bowler
Department of Social Work
Sunnybrook Health Centre
North York, Ontario

Wayne Hellard
Community AIDS Treatment
Information Exchange
Toronto, Ontario

Dionne Falconer
Black Coalition for
AIDS Prevention
Toronto, Ontario

Doreh Mohsenzadeh
Hemophilia Ontario*
Toronto, Ontario

Wayne Fitton
AIDS Committee of Toronto
Toronto, Ontario

Carol Polych
Etobicoke, Ontario

Mark Frearno
AIDS ACTION NOW!
Toronto, Ontario

Joanne Solarski
HIV Clinic
St. Michael's Hospital
Toronto, Ontario

Jim Gaylord
Toronto PWA Foundation
Toronto, Ontario

*At the time our research was conducted

Table of Contents

Executive Summary\Sommaire	
I.	Introduction 1
	"Hooking Up" as a Social Process 1
	Structure of the Report 1
	How We Conducted our Research 2
II.	The Work PHAs do to "Hook Up" to Social Services 6
	Health, HIV+ Status and Leaving Work 7
	Accessing Income Assistance and Housing 12
	Accessing Home Care 19
III.	Making the Connections: A Strategy for Action 23
	The Social Relations of "Hooking Up" 23
	1. The Stigma of HIV/AIDS 24
	2. 'Case Management' and Advocacy 29
	3. Knowledge about Social Services 34
	Social Service Agencies 38
	4. Income Assistance Programs 38
	5. Housing 42
	6. Home Care 48
	Other Institutional Sites of "Hooking Up" 54
	7. HIV Clinics 54
	8. Prisons 55
	9. Drug Treatment Programs 58
IV.	Closing Summary 62

Executive Summary

This report is about access to social services for those of us living with HIV/AIDS.

The information provided in this report was obtained from 120 interviews conducted in Toronto in three phases. In the first phase, we interviewed 70 PHAs who made their lives under different conditions of gender, race, class, sexual orientation, age, and ethnicity. Next we interviewed 40 individuals from a range of community-based agencies and health services including AIDS services organizations, hospital HIV clinics, organizations serving street youth, HIV primary care physicians' offices, hemophilia organizations and supportive housing facilities, among others. Lastly we interviewed 10 government workers responsible for the delivery of social services to PHAs.

A major finding of this research is that the process through which PHAs "hook up" to social services is a highly social one. This is contrary to what we call the official view of "hooking up." According to this view, "hooking up" is a straightforward matter of contacting the proper government office, filling in the right forms and meeting the relevant eligibility criteria.

Examining "hooking up" to social services as a social process directs attention to the human effort and activity that go into accessing social services. This report focuses mainly on the work PHAs do to access social services. A vital finding is that the work PHAs must do to "hook up" is shaped by their class, race, ethnocultural background, gender and sexual orientation.

Time and again, the PHAs we interviewed spoke about the difficulties they experienced in accessing social services. They often described the process as exhausting and confusing. Our research revealed numerous barriers preventing smooth access to social services for PHAs including: (1) problems that occur within the extended social relations that shape the "hooking up" process, particularly those of stigma, 'case management' and advocacy, and knowledge; (2) more specific problems in the organization of social services including programs of income assistance, housing and home care; (3) difficulties in the way other institutional sites important for "hooking up" are set up and run. These sites include hospital HIV clinics, prisons and drug treatment centres.

Research Findings

- **The stigma of HIV/AIDS is the most serious and complex barrier for PHAs "hooking up" to social services.** While all PHAs experience the stigma of HIV/AIDS, it is felt most profoundly by hemophiliacs, street youth, Native peoples, heterosexual men and women, drug users, prisoners, marginalized gay men, members of ethnic and racial

communities and others not well-connected with the lesbian and gay community. For these individuals, the fear of being publicly known as HIV+ can lead to extreme social isolation and severe emotional stress. Under these circumstances, "hooking up" is done in isolation from networks of knowledge and support that facilitate PHAs' access to social services.

- **PHAs who do not connect with AIDS service organizations experience serious difficulties "hooking up" to social services.** AIDS service organizations (ASOs) provide 'case management' and individual and institutional advocacy which interface between the lives and needs of PHAs and the rules and procedures of social service agencies. These services expedite access to social services in innumerable ways. At the same time, lack of resources means that ASOs are often forced to carry them out on an ad hoc basis. It is also extremely rare for 'case management' and advocacy to be offered to PHAs as a program of support, in the way counselling services are, for example. All of this produces uneven advocacy and 'case management' for PHAs, both within and across the AIDS service organizations that serve them.

- **Lack of knowledge about social services is a serious barrier to "hooking up."** Very few people know how social services actually work. There is also a serious dearth of accessible print information that describes how to access them. Confusion about social services is common among PHAs, workers in community-based organizations, health care workers and social service workers themselves, all of whom have difficulty developing and maintaining knowledge about social services.

- **Delays in the receipt of income assistance and in the transfer of applications from General Welfare Assistance to Family Benefits Assistance create problems for PHAs.** In part, these delays result from the extreme difficulty of establishing regular contact with welfare workers and errors made in applications. The social relations noted above also complicate access to programs of income assistance. Because of the low levels of support provided and delays in receiving them, accessing welfare and Family Benefits Assistance triggers a slide into poverty for many PHAs.

- **Provincially-subsidized housing and supportive housing are both set up in ways that exclude certain groups of PHAs from being housed.** Application procedures which identify certain individuals as 'unfit tenants' can prevent PHAs who are street youth, homeless, ill, or who have crime, drug use or psychiatric histories from accessing provincially-subsidized housing. The shared living circumstances and limited staffing of supportive housing facilities can also produce access problems for PHAs who come to be seen as 'difficult' or 'different.' These PHAs are denied an opportunity to establish a stable physical and social context in which to maintain their health and access community-based and other support services. Far too many are forced to live in rooming houses, hostels or other housing that is unsafe, overcrowded and unhealthy.

- **Many PHAs have difficulty accessing the home care services they require.** The Ontario Home Care Program does not function as a stand-alone service. Only middle-class PHAs who are able to supplement the hours of care they receive under the Program with private nursing or care teams organized through AIDS service organizations and private support networks are able to die comfortably in their homes. PHAs who do not have wide friendship networks, who are not connected with ASOs, who have low incomes or unstable housing face extreme difficulties accessing home care. The actual organization of home care services, particularly the eligibility procedures for homemaking services, the nature of assessments, the delivery of complex care and the difficulty of knowing how home care works also produce problems for PHAs who wish to access this service.
- **Hospital HIV clinics can be problematic sites of "hooking up" for heterosexual PHAs, particularly those from ethnocultural communities.** Hospital HIV clinics are often the only AIDS-related organizations with which these PHAs are connected. These individuals must "hook up" to social services within the professional and medical relations characteristic of these settings. The tendency for clinic social work services to emphasize therapeutic practice over practical assistance with accessing social services and the lack of translation services can produce "hooking up" problems for some clients of hospital HIV clinics.
- **PHAs living in prisons face serious problems "hooking up" to social services.** Lack of knowledge about AIDS and isolation from other PHAs severely restricts their opportunities for learning how to live with HIV infection and access social services. Many PHAs in prison are caught up in a pattern of repeated temporary incarcerations. This disrupts the 'case management' efforts of AIDS workers they may have connected with and produces a cycle of continual application, cessation and reapplication for welfare or Family Benefits Assistance. These disruptions create delays in accessing income assistance which, at times, are further complicated by jurisdictional disputes between different government ministries.
- **PHAs who are drug users face particular barriers in accessing social services.** Many PHAs who are drug users are unable to take on the work of "hooking up" to social services in earnest until they control or stop their drug use. The dearth of drug and alcohol treatment programs and certain features of their organization, particularly forced disclosure of HIV+ status and sexual orientation, often discourage their use. This can have serious consequences for drug users' ability to access social services.

Recommendations

This report offers a strategy for action designed to alleviate the many barriers which create problems for PHAs and others involved in the work of "hooking up" to social services. The strategy for action serves as a framework for responding to the difficulties and inequities that PHAs face in "hooking up" to social services. While it is based in research on the organization of "hooking up"

within a large urban centre, many of its suggestions pertain to other areas of the country. The main recommendations it puts forward are summarized below.

The Social Relations of "Hooking Up"

1. **Governments, AIDS service organizations and public health authorities should work together to eradicate the stigma of HIV/AIDS.** This initiative should target a wide range of constituencies including, among others, health care workers, homemakers working in home care services, ethnocultural communities, people of colour, hemophiliacs, heterosexual men and women, Native peoples, street youth and the lesbian and gay community. It should include the use of AIDS in the workplace programs and the vigorous prosecution of human rights complaints.
2. **The provincial government should make funds available to establish a coordinated system of 'case management' and advocacy services for PHAs.** This initiative should involve the strengthening of existing 'case management' and advocacy services in AIDS service organizations as well as the establishment of a parallel system of independent community-based advocacy and 'case management' services for PHAs who do not use ASOs.
3. **Information about social service access and delivery must be produced and made available to PHAs, workers in AIDS service organizations, social services, health services and prisons.** This initiative should include the incorporation of "hooking up" information as a standard part of post-test counselling procedures. It should also include in-service training programs on access to government income assistance programs, housing and home care, for workers in government and community-based agencies. Manuals and other guides on how to access social services should also be produced for PHAs.

Social Service Agencies

4. **The provincial government must establish ease of access to adequate levels of income assistance for all PHAs.** It should end the two-tiered system of income assistance in Ontario. The provincial government should also provide access to social services through on-site intake at AIDS service organizations, HIV clinics and other organizations working with PHAs. Drug cards should be made available to PHAs and others living with catastrophic illnesses, who do not have private health insurance, so that they are not forced into the social service system in order to access drug treatments they cannot afford.
5. **The provincial government, AIDS service organizations and other community-based organizations must ensure that all PHAs can "hook up" to housing that meets their needs.** The provincial government should establish an emergency housing fund and portable rent subsidy program for PHAs, as well as emergency interim housing for poorer PHAs. Supportive housing facilities must be organized and funded so that 'hard-to-house' PHAs can access them.

6. All PHAs who want to die in a home should be able to "hook up" to home care. PHAs need to know the eligibility criteria and assessment procedures for home care, including complex care. In addition, eligibility for homemaking services should not be contingent on a PHA's need for professional home care services. Primary care-givers must have improved access to respite care. Moreover, the federal government should develop an unemployment insurance program of income support, similar to maternity leave, for primary care-givers designated by PHAs. The provincial government should also fund the further establishment of chronic care and palliative care programs for PHAs.

Other Institutional Sites

7. **Assessment of PHAs' social service needs should become a standard part of hospital HIV clinics' intake procedures and ongoing client evaluation.** HIV clinics should also make professional translation services available to PHAs who need them.
8. **The conditions under which PHAs in prison "hook up" to social services upon release should be improved.** Discharge planning for HIV+ prisoners should include assistance with accessing social services. In addition, PHAs receiving Family Benefits Assistance (FBA) prior to entering prison should be able to maintain their comfort allowance and their access to drugs covered under FBA. They should also have access to HIV primary care physicians, because of the vital role these doctors play in "hooking up" PHAs to social services.
9. **The flexibility and availability of drug treatment programs used by PHAs should be improved.** Existing alcohol and drug treatment facilities should establish programs that respond to the varied needs of PHAs. These should involve the use of therapeutic models that do not force the disclosure of HIV+ status or sexual orientation and the introduction of therapeutic models based on harm reduction.

Sommaire

Le présent rapport traite de l'accessibilité des services sociaux pour les membres de notre société qui sont séropositifs ou sidéens.

Nous vous présentons ici les résultats des entrevues que nous avons menées à Toronto. Les 120 personnes interviewées appartenaient à l'une ou l'autre des trois catégories suivantes : les séropositifs et les sidatiques des deux sexes, de différentes races, classes sociales, orientations sexuelles et origines ethniques et d'âges différents (70 personnes); le personnel et les bénévoles des organismes communautaires et des services de santé, y compris les organismes de services reliés au sida, les cliniques de dépistage des hôpitaux, les organismes à l'intention des jeunes de la rue, les soins de première ligne, les groupes d'hémophiles et les maisons d'accueil pour personnes atteintes du sida (40 personnes); enfin, les fonctionnaires chargés d'offrir des services sociaux aux séropositifs et aux sidéens et sidéennes (10 personnes).

Une des principales conclusions de cette étude est que, pour les séropositifs et les sidéens et sidéennes, « se brancher » sur les services sociaux est une démarche essentiellement sociale. Ce qui contredit la définition officielle, selon laquelle cette démarche est strictement administrative : communiquer avec l'instance visée, remplir les formulaires nécessaires et répondre aux critères d'admissibilité pertinents.

Lorsqu'on examine cette démarche sous l'angle social, on souligne, en fait, l'effort et l'énergie qu'y consacrent ces personnes. Voilà le principal sujet du présent rapport. Fait important à signaler : les efforts des séropositifs et des sidéens et sidéennes pour « se brancher » sur les services sociaux varient en fonction de leur classe sociale, de leur race, de leurs origines ethnoculturelles, de leur sexe et de leur orientation sexuelle.

Les séropositifs et les sidéens et sidéennes interviewés ont indiqué, à maintes reprises, combien il leur est difficile de « se brancher » sur les services sociaux. C'est une démarche épuisante et frustrante, ont-ils répété. Notre recherche nous a d'ailleurs permis d'isoler plusieurs des obstacles qui compliquent l'accès des séropositifs et des sidéens et sidéennes aux services sociaux, notamment : 1) les difficultés qui surgissent au sein du réseau social élargi et qui transforment cette démarche, plus particulièrement, la stigmatisation du sida, la « gestion de cas » et la défense ainsi que la connaissance de la maladie; 2) des problèmes plus précis en matière d'organisation des services sociaux, notamment les programmes de supplément au revenu, de logement et de soins à domicile; 3) les problèmes reliés au fonctionnement des autres organismes qui jouent un rôle important dans cette démarche. Il s'agit, entre autres, des cliniques de dépistage des hôpitaux, des prisons et des centres de désintoxication.

Conclusions

- **La stigmatisation du sida est le plus grave et le plus complexe des obstacles auxquels sont confrontés les séropositifs et les sidéens et sidéennes qui cherchent à « se brancher » sur les services sociaux.** Même si la société stigmatise toute personne atteinte du VIH ou du sida, certains groupes ressentent cette hostilité de façon plus aiguë : les hémophiles, les jeunes de la rue, les Autochtones, les hétérosexuels des deux sexes, les consommateurs et consommatrices de drogues, les détenus des deux sexes, les gays marginalisés, les membres de groupes ethniques et raciaux et quiconque n'a pas de liens solides avec la communauté gay et lesbienne. Pour ces personnes, en effet, la crainte d'être reconnue publiquement comme porteur du VIH peut se traduire par un isolement extrême et une tension affective élevée. Cette situation les isole des réseaux de connaissances et d'appui qui, normalement, facilitent l'accès des séropositifs et des sidéens et sidéennes aux services sociaux.
- **Les séropositifs et les sidéens et sidéennes qui n'ont pas de contacts avec les organismes de services reliés au sida éprouvent de sérieuses difficultés à « se brancher » sur les services sociaux.** Le rôle des organismes de services reliés au sida consiste à gérer des cas et à intervenir auprès des individus et des organismes qui s'interposent entre les besoins des séropositifs et des sidéens et sidéennes et les règles et procédures des organismes de services sociaux. Ces démarches facilitent grandement l'accès aux services sociaux, et ce, d'innombrables façons. Or, faute de fonds, ces organismes doivent souvent offrir ces services de manière ponctuelle. En outre, la « gestion de cas » et la défense des droits sont rarement proposées comme des programmes d'aide, à l'instar, par exemple, des services de counselling. Le résultat : une prestation irrégulière des services de défense et de « gestion de cas », tant au sein des organismes de services reliés au sida qu'à l'extérieur.
- **Le manque de connaissances au sujet des services sociaux entrave le recours à ces services.** Seules quelques personnes connaissent bien les rouages des services sociaux. L'on constate, par ailleurs, une grave pénurie de documents écrits sur l'accès à ces services. Il règne une grande confusion à leur égard tant chez les séropositifs et les sidéens et sidéennes que chez les travailleuses et travailleurs sociaux et les intervenants des organismes communautaires et des services de santé. Tous et toutes éprouvent quelque difficulté à acquérir les connaissances nécessaires et à les garder à jour.
- **Les séropositifs et les sidéens et sidéennes éprouvent des difficultés lorsque leurs prestations de supplément au revenu tardent à arriver et qu'on ne transfère pas rapidement leurs demandes d'aide sociale au Programme de prestations familiales.**

Ces retards découlent, en partie, de l'absence de contacts suivis avec les travailleuses et travailleurs sociaux et des erreurs commises sur les demandes. Et le réseau social décrit précédemment complique également l'accès aux programmes de supplément au revenu. Ainsi, étant donné le faible soutien accordé par le gouvernement et les retards mis à expédier les prestations, bon nombre de séropositifs et de sidéens et sidéennes se retrouvent sous le seuil de la pauvreté lorsqu'ils deviennent prestataires de l'aide sociale ou familiale.

- **Les critères d'admission aux logements sociaux et aux maisons d'accueil excluent des catégories de séropositifs et de sidéens et sidéennes.** Les procédures d'admission pour les logements sociaux qui classent certaines personnes dans la catégorie « locataires indésirables » peuvent effectivement exclure les jeunes de la rue, les sans-abri, les malades, les criminels, les consommateurs de drogues ou les patients psychiatriques qui sont porteurs du VIH ou qui ont le sida. Ces personnes éprouvent aussi des difficultés dans les maisons d'accueil en raison de la vie communale et du personnel restreint. Elles acquièrent peu à peu un statut de personnes « difficiles » ou « différentes ». En somme, on prive les séropositifs et les sidéens et sidéennes de la possibilité de se créer un environnement physique et social stable où ils pourraient surveiller leur état de santé et se prévaloir des services d'appui offerts par la communauté et d'autres organismes. Trop de séropositifs et de sidéens et sidéennes doivent habiter des pensions, des foyers ou d'autres types de logements peu sécuritaires, surpeuplés et malsains.
- **Un grand nombre de séropositifs et de sidéens et sidéennes ne reçoivent pas les services de soins à domicile dont ils ont besoin.** Le Programme ontarien de soins à domicile ne suffit pas à lui seul. En effet, pour pouvoir mourir chez soi, les séropositifs et les sidéens et sidéennes doivent recevoir davantage de soins que leur accorde ce programme. Or, seules les personnes de la classe moyenne peuvent se permettre des services infirmiers privés ou les soins offerts par les organismes de services reliés au sida et les réseaux d'entraide privés. Les autres, c'est-à-dire ceux et celles qui n'ont pas beaucoup d'amis et d'amies, qui n'ont aucun contact avec les organismes de services reliés au sida, qui ont un faible revenu ou n'ont pas d'adresse fixe, éprouvent d'énormes difficultés à obtenir des services de soins à domicile. Du reste, l'organisation même de ces services, particulièrement les critères d'admissibilité à l'aide familiale, la nature des évaluations, la prestation de soins complexes et la difficulté à découvrir comment fonctionnent ces services, constituent d'autres obstacles pour ceux et celles qui désirent « s'y brancher ».
- **Les cliniques de dépistage des hôpitaux compliquent le recours aux services sociaux, particulièrement dans le cas des hétérosexuels des deux sexes porteurs du VIH ou atteints du sida, surtout ceux et celles qui appartiennent à un groupe ethnoculturel.** Les cliniques de dépistage constituent souvent l'unique lien qu'ont ces personnes avec des organismes œuvrant dans le domaine du sida. Aussi, pour « se brancher » sur les services sociaux doivent-elles se plier aux règles professionnelles et médicales en vigueur.

Or, les services sociaux des hôpitaux ont tendance à privilégier les traitements plutôt que les conseils pratiques sur l'obtention de services sociaux, ce qui représente un obstacle pour certains de leurs patients et patientes, de même que la rareté des services d'interprétation.

- **Les détenus porteurs du VIH ou atteints du sida sont presque entièrement coupés des services sociaux.** En effet, le manque de connaissances sur le sida et l'isolement réduisent considérablement les occasions d'apprendre ce qu'est la séropositivité et comment « se brancher » sur les services sociaux. Par ailleurs, bon nombre de séropositifs et de sidéens et sidéennes sont régulièrement incarcérés pour des périodes plus ou moins longues. Ce cycle contrecarre les efforts entrepris par les intervenants auxquels ils se seraient adressés pour obtenir des prestations d'aide sociale ou familiales. Un cercle vicieux se crée donc : demande de prestations — arrêt des versements — nouvelle demande. Or, ces perturbations occasionnent des retards dans l'obtention d'un supplément au revenu, retards que compliquent davantage, parfois, les conflits d'attribution entre les divers ministères.
- **Les séropositifs et les sidéens et sidéennes qui font usage de drogues sont confrontés à des obstacles particuliers.** Bon nombre d'usagers et d'usagères de drogues atteints du sida ou séropositifs ne peuvent entreprendre sérieusement les démarches visant à « se brancher » sur les services sociaux sans d'abord maîtriser ou cesser leur consommation de drogues. Or, la pénurie de programmes de désintoxication et certaines de leurs caractéristiques — notamment, la divulgation obligatoire de la séropositivité et de l'orientation sexuelle — en découragent plus d'un. Ce qui nuit considérablement, parfois, à la capacité des personnes consommatrices de drogues à obtenir des services sociaux.

Recommandations

Le présent rapport renferme un plan d'action visant à réduire les nombreux obstacles auxquels sont confrontés les séropositifs et les sidéens et sidéennes ainsi que les personnes qui les aident à « se brancher » sur les services sociaux. L'objectif du plan d'action est de résoudre les problèmes et de corriger les inégalités auxquels font face les séropositifs et les sidéens et sidéennes qui cherchent à « se brancher » sur les services sociaux. Bien que la démarche proposée convienne mieux aux grands centres urbains, certaines de ses composantes se prêtent à d'autres milieux. Voici un résumé des principales recommandations :

La dimension sociale du recours aux services sociaux

1. **Les gouvernements, les organismes de services reliés au sida et les bureaux d'hygiène publique devront collaborer à enrayer la stigmatisation du sida.** Cette mesure s'appliquera à un large éventail d'intervenants, dont les travailleuses et travailleurs de la santé, le personnel des services de soins à

domicile, les groupes ethnoculturels, les personnes de couleur, les hémophiles, les hétérosexuels des deux sexes, les Autochtones, les jeunes de la rue et la communauté gay et lesbienne. Cette initiative consistera, entre autres, à offrir des programmes de sensibilisation sur le sida en milieu de travail et à régler les cas de violation des droits de la personne.

2. **Le gouvernement provincial devra financer la création d'un système coordonné de « gestion de cas » et de services de défense à l'intention des séropositifs et des sidéens et sidéennes.** Il s'agirait, d'une part, de renforcer les services qui existent actuellement dans les organismes de services reliés au sida et, d'autre part, de créer un système parallèle de services communautaires de défense et de « gestion de cas » à l'intention des séropositifs et des sidéens et sidéennes qui ne se sont pas « branchés » sur ces organismes.
3. **Il faudra produire des documents sur l'accès aux services sociaux et leur prestation et les distribuer aux séropositifs et aux sidéens et sidéennes ainsi qu'au personnel des organismes de services reliés au sida, des services sociaux, des services de santé et des prisons.** Cela comprendra, notamment, l'ajout de renseignements sur comment « se brancher » sur les services sociaux aux procédures de counselling post-dépistage; des programmes de formation internes à l'intention des fonctionnaires et du personnel des groupes communautaires en matière d'admissibilité aux programmes gouvernementaux de supplément au revenu, de logement et de soins à domicile; et, finalement, la production de manuels et de guides sur l'accès aux services sociaux à l'intention des séropositifs et des sidéens et sidéennes.

Les organismes de services sociaux

4. **Le gouvernement provincial devra simplifier l'accès des séropositifs et des sidéens et sidéennes aux programmes d'aide sociale. Il doit aussi leur offrir un revenu adéquat.** Le gouvernement devra abolir le système d'aide sociale à deux niveaux en Ontario. Il devra également faciliter l'accès aux services sociaux par le biais des organismes qui aident les séropositifs et les sidéens et sidéennes (organismes de services, cliniques, etc.). On donnera une carte-médicaments aux séropositifs et aux sidéens et sidéennes ainsi qu'aux personnes atteintes de maladies graves qui n'ont pas d'assurance-santé individuelle. On évitera ainsi que ces personnes soient obligées de recourir à l'aide sociale afin d'obtenir les médicaments qu'elles ne peuvent se permettre.
5. **Le gouvernement provincial, les organismes de services reliés au sida et les autres associations communautaires devront s'assurer que tous les séropositifs et les sidéens et sidéennes disposent d'un logement qui réponde à leurs besoins.** La province devra créer un fonds de secours et un

programme de subventions au logement temporaires à l'intention des séropositifs et des sidéens et sidéennes. Elle devra aussi mettre en œuvre un programme de logements temporaires à l'intention des séropositifs et des sidéennes et sidéens plus démunis. Il importera, par ailleurs, de mettre sur pied et de financer des maisons d'accueil à l'intention des séropositifs et des sidéens et sidéennes « plus difficiles à loger ».

6. **Tous les séropositifs et les sidéens et sidéennes qui veulent mourir à la maison devraient recevoir des soins à domicile.** Il convient de renseigner ces personnes sur les critères d'admissibilité et les procédures d'évaluation en matière de soins à domicile, y compris les soins complexes. En outre, le besoin de soins à domicile professionnels ne doit pas influencer sur l'admissibilité aux services d'aide familiale. Le personnel soignant de première ligne doit avoir un meilleur accès aux soins de relève. Par ailleurs, le fédéral devra créer un programme de supplément au revenu — analogue aux prestations versées lors des congés de maternité par le département de l'assurance-chômage — à l'intention des personnes désignées par les séropositifs et les sidéens et sidéennes pour leur dispenser des soins. Enfin, le gouvernement provincial devra financer la mise sur pied de nouveaux programmes de soins palliatifs et de soins aux malades chroniques.

Les autres organismes

7. **L'évaluation des besoins des séropositifs et des sidéens et sidéennes en matière de services sociaux devrait désormais faire partie des procédures d'admission habituelles des cliniques et de l'évaluation continue des patients.** Les cliniques devront également offrir des services d'interprétation aux séropositifs et aux sidéens et sidéennes qui en ont besoin.
8. **Il faudra améliorer les conditions dans lesquelles les détenus et détenues « se branchent » sur les services sociaux.** Il faut préparer les personnes séropositives, avant leur libération, à « se brancher » sur les services sociaux. Par ailleurs, ceux et celles qui touchaient des prestations familiales avant d'être incarcérés devront continuer de recevoir leur allocation pour menues dépenses et les médicaments auxquels ils ont droit. Ils devront aussi pouvoir consulter des sidologues de première ligne, car ces spécialistes aident grandement les séropositifs et les sidéens et sidéennes à « se brancher » sur les services sociaux.
9. **Il faudra assouplir les programmes de désintoxication offerts aux séropositifs et aux sidéens et sidéennes et les rendre plus accessibles.** Les centres de désintoxication devront créer des programmes qui répondent aux divers besoins des séropositifs et des sidéens et sidéennes. Il s'agit, notamment, d'adopter des traitements qui n'exigent pas de divulguer la séropositivité ou l'orientation sexuelle et d'offrir des traitements qui visent à réduire la souffrance.

I. Introduction

"Hooking Up" As A Social Process

Accessing or "hooking up" to social services can be viewed as a straightforward process of contacting the proper government office, filling in the right forms, and meeting the eligibility criteria. We call this the official view of "hooking up." It is a view that is presumed in legislation and built into the application forms and work of government offices.

This report takes a different approach. It looks at "hooking up" as a social process. This view focuses attention on the human effort and activity that go into accessing social services. In the context of AIDS, it emphasizes how "hooking up" is done by people living with HIV/AIDS (PHAs) and by others working in community-based organizations, health services and government offices.

The process through which PHAs "hook up" to social services takes the form of a coordinated series of activities linking together three sites where the work of "hooking up" goes on. These are: 1) the social context of the day-to-day work PHAs do to "hook up;" 2) the sites of 'case management' and advocacy work conducted in community-based organizations; and 3) the various sites of government work where the determination of eligibility and the delivery of social services takes place. To illustrate, a PHA's efforts to apply for non-profit housing often must be coordinated with advocacy work done by a counsellor in an AIDS service organization who helps manage this process and with work done by a worker in a government office concerned with the person's eligibility. Under the right conditions, these activities, going on in different places and at different times, come together to "hook up" the individual to the housing she or he needs.

Unfortunately, "hooking up" to social services rarely works this smoothly. For the PHAs we interviewed, it was often a confusing and exhausting process, complicated by a variety of problems. This report focuses on the difficulties PHAs experience in accessing social services. Its goal is to describe the barriers PHAs face as they go about the work of "hooking up" to social services.

Structure Of The Report

Following this introduction, the second section of the report examines how the social locations of PHAs create barriers in accessing social services. Social location is a term we use to refer to how people's lives are shaped by a variety of social relations such as sexual orientation, class, race, gender, ethnicity and HIV status. At times, we also speak of these forms of social organization as a person's "background," "situation," or "circumstances." This section of the

report describes the key aspects of the work PHAs do to "hook up" to social services. Moreover, it shows how this work and the larger courses of action PHAs follow in order to access social services differ, depending on PHAs' circumstances. In this way, it emphasizes how the social locations of PHAs are a source of the inequities they face in accessing social services.

The third section of the report expands on the second by drawing attention to how barriers arise in "hooking up," when the lives of PHAs run counter to or do not "fit" with the way social services and other organizations involved in "hooking up" are set up and run. We refer to these barriers as organizational problems. This section of the report examines three social contexts where barriers to "hooking up" arise. First, are the extended social relations which shape the "hooking up" process, particularly those of stigma, 'case management' and advocacy, and knowledge. Second, is the site of work going on in specific social services, including income assistance programs, housing and home care. Last, is the site of work occurring in other institutions important for "hooking up" to social services, particularly HIV clinics, prisons, and drug treatment centres.

The third section of the report takes the form of a strategy for action which responds to the difficulties and inequities that PHAs face in "hooking up" to social services. It contains a series of recommendations designed to alleviate the access problems which arise in the three social contexts mentioned above. The strategy for action was produced for PHAs, AIDS activists and others concerned with improving the conditions under which PHAs live. It is based on research about how "hooking up" takes place in a particular context, namely that of a major urban centre with a large lesbian and gay community, numerous AIDS service organizations and an ethnically and racially diverse population. Metro Toronto is also where half of PHAs in Ontario live. Relations that shape the "hooking up" process for PHAs in other areas may be different. At the same time, there should be similarities. As such, the strategy for action and its more specific recommendations have a relevance that transcends a local context.

How We Conducted Our Research

In examining how PHAs "hook up" to social services, we set about determining how they and others go about this process. For one thing, we came to see that whether or not PHAs could "hook up" to social services very much depended on how these services met their needs and how they were made available. For example, some forms of drug rehabilitation based on the 12-step model often discourage PHAs from "hooking up" to these services. It was also the case that the almost total lack of facilities in Toronto for PHAs with dementia meant that these people were unable to "hook up" to the services they desperately needed. Over the course of our research we also became interested in how PHAs' experiences of "hooking up" are shaped by the social relations of class, ethnicity, gender and race, and by those relations ordinarily referred to as the "medical model." We wanted to know the barriers to prompt and effortless access to social services for PHAs. For example, how is it that in trying to get social services, some PHAs "fall through the cracks?"

We searched for answers to these and similar questions by conducting an institutional ethnography¹ of three sites of work that shape PHAs' access to social services. These sites include the work done by PHAs to access social services, the work of individuals in community-based agencies and health services to manage the "hooking up" process and the work done by individuals in government offices. We explored the work that goes on in these sites through a process of interviewing described below.

Phase 1 - Interviewing PHAs

In the first and largest phase of our research we interviewed 70 PHAs about the work they do to get income assistance, housing, home care or drug rehabilitation. We were unable to fully investigate other social services relevant to the lives of PHAs. These include child care, child welfare agencies and legal services. We could see that women with children might have unique experiences "hooking up" to social services. However, we were unable to investigate these experiences because access to these families was virtually impossible.

Our interviews began with gay men referred to us by local AIDS service organizations. As we spoke with them, we came to understand how their access to social services was facilitated by AIDS service organizations in the lesbian and gay community. This told us something important about the social organization of "hooking up" for PHAs who were gay. At the same time, it made us aware of the need to speak with PHAs whose access to social services was organized differently.

In order to do this, we needed to move beyond our own social location as middle-class, white, gay male researchers. We also had to alter the practices that organized our research. In part, this involved changing how we got our informants. We wanted to include PHAs who did not use AIDS service organizations. But designing a research practice inclusive of the diversity of PHAs raised other, more difficult problems. For example, we had to wrestle with ideas and practices which, from our vantage point, restricted the possibility of dialogue with people whose social identities were different from our own. In other instances, we had to respond to a mistrust and wariness of research. This was a problem we often faced when approaching PHAs and AIDS workers who had previously taken part in research projects. Many of them told us about research that was intrusive, that treated PHAs, or certain of them, as "tokens" or that offered little practical benefit in return for participation. Lastly, as we reached out to PHAs outside the lesbian and gay community, we confronted the stigma of AIDS. We needed to develop ways to respect and respond to the social isolation and other conditions experienced by PHAs who live out their lives in relation to this stigma.

¹ Institutional ethnography is a research strategy developed by sociologist Dorothy Smith. This method of research investigates a "section" of the social world from the standpoint of the organization of the work of those who produce it. This kind of ethnography takes as its focus the complex of relations in which this local world is embedded. It seeks to describe the extended social relations involved in the production of local events and activities. (see Smith, D.E. 1987. *The Everyday World as Problematic: A Feminist Sociology*. Toronto: University of Toronto Press.)

Reorganizing our research in response to these problems was made easier by the support of numerous community-based organizations. In the end, we were able to implement a research strategy that incorporated the experiences of a wide range of PHAs. We were successful in connecting with people of colour, drug users, people whose first language is not English (as well as people who did not speak English), gay men, refugees, people who had lived in prisons, street youth, women, homeless people and heterosexual men. We were less effective in reaching deaf people; women with children, hemophiliacs and Native peoples. Unfortunately, we were unable to interview any lesbians or Asians. This report must be read in light of these successes and failures.

The work we did to reach out to various PHAs at the start of our research was very important. It shaped and located our inquiry in a particular way. Starting from the experiences of PHAs meant that our research was not framed by the relevances of universities, governments or other sites of professional research. Also, our efforts were not directed at testing social science theories or producing knowledge used by government and the medical profession to manage and direct the lives of PHAs.

Phase 2 - Interviews In Community-based Organizations and Health Services

In the second phase of our research we interviewed 40 individuals from community-based agencies and health services about the work they do to facilitate PHAs' access to social services. Organizing these interviews was relatively easy in comparison to those conducted with PHAs. Problems of access, for example, did not arise. One challenge we did face was focusing these interviews on the actual face-to-face work that agency workers did with PHAs. Workers with professional training often preferred to talk about their work in abstract, professional terms. However, in order to understand how "hooking up" actually worked, we needed to move beyond professional accounts to find out about the details of their day-to-day work with PHAs.

The knowledge we gained from our interviews with PHAs was important for organizing our second phase of research. Specifically, we had seen how PHAs from varied social locations connected with different types of organizations as part of "hooking up" to social services. In order to fully explore this second site of work involved in the "hooking up" process, we needed to interview people from a range of organizations. While we started with various AIDS service organizations based in the lesbian and gay community, we quickly extended our efforts to include hospital HIV clinics, services for street youth, hemophilia organizations, Native organizations, STD clinics, supportive housing, a needle exchange, a public health department, doctors' offices, a women's hostel, community health centres, churches, legal clinics, drug treatment facilities and others.

Phase 3 - Interviewing Government Workers

In the third and final phase of our research we interviewed people in government about their work of "hooking up" PHAs to social services. Our concern was to understand the every day work they do to determine and manage eligibility for and entitlement to social services. We wanted to know how they

processed PHA applications for social services and how various documents, ranging from legislation to office forms, coordinated their work. The individuals we interviewed worked in programs of income assistance (General Welfare Assistance and Family Benefits Assistance), the Home Care Program and housing programs of the provincial government.

Throughout this report we quote from what people told us in interviews. These were taped and transcribed. The purpose of the quotations is to show how "hooking up" takes place. As part of the ethical review for this project, we agreed to guarantee anonymity to the people we talked with. We have taken a number of steps to do this. At times, we have changed the names of people and places mentioned by interviewees. Also, where necessary, we have altered background information that could be used to identify an individual. Each interviewee is referred to as "INT," short form for "interviewee." If there is more than one interviewee, the first is called "INT1" and the second is identified as "INT2." We intend these procedures to make it difficult to identify a particular person because of what might appear as his or her continued presence in this report. Likewise, we have used generic names for social services such as "welfare" or "home care," rather than the names of particular agencies. Throughout the report, we use "EM" and "GS" to identify ourselves as speakers.

II. The Work PHAs do to "Hook Up" to Social Services

For most PHAs, "hooking up" to social services is not easy or straightforward. Rather, it is complex, ongoing and involves a great deal of work. This section describes the work PHAs do to access social services. It shows how that work and the overall courses of action PHAs follow to "hook up" to social services vary with their social locations.

Describing the work that PHAs do to "hook up" in relation to their social locations reveals the disparities and inequalities they face in this process. For example, it was a general finding of our research that formerly middle-class, gay PHAs who lived in downtown Toronto faced fewer obstacles in "hooking up" to social services than other PHAs we interviewed. The latter, including drug users, Native peoples, street youth, people of colour, homeless people, heterosexual men and women, people who did not speak English, marginalized gay men, refugees, people who had lived in prisons and others were socially located in ways that made "hooking up" to social services difficult. This section examines how barriers in accessing social services are produced in the social relations of class, gender, race, sexual orientation, and ethnicity that shape the daily lives of PHAs. An important theme of this section is that successfully "hooking up" to social services depends on knowledge about how social services work. This knowledge and the ability to access it depends on a PHA's social location. Social relations are important for shaping PHAs' opportunities for networking and sharing information about "hooking up."

PHAs enter the work of "hooking up" from a myriad of social locations. Depending on their circumstances, they must deal with different social service needs at different times and with different resources. Often they must manage access to more than one social service at a time. All of this renders the description of their work in "hooking up" to social services difficult.

Our interviews did, however, indicate certain commonalities with respect to PHAs' experiences of "hooking up." For example, for nearly all the PHAs we interviewed, accessing social services was central to the changing circumstances of daily life brought on by their HIV+ status. In our conversations with PHAs, we also came to see how certain experiences required them to begin the actual work of "hooking up." The most important of these were a decline in health, learning about one's HIV+ status and leaving work. Variations in these experiences represented different starting points from which PHAs carried out the work of "hooking up." While there was no simple temporal uniformity to the processes through which PHAs accessed social services, they regularly spoke with us about accessing General Welfare Assistance (welfare), Family Benefits Assistance (Family Benefits or FBA), housing and, for those who became ill, home care.

Health, HIV+ Status and Leaving Work

For most PHAs we spoke with, "hooking up" to social services was part of a larger story connected to the state of their health. The relationship between "hooking up" and health was important in many respects. In the first place, a decline in health often brought on the work of accessing social services. Changes in the conditions of one's health also triggered the need for ongoing access to new services, such as different housing arrangements or home care. For many of the PHAs we interviewed, ill health further complicated the already difficult process of "hooking up:"

INT: ... I was doing my home visit from my worker sometime in June.... for FBA. I think it was, the middle of June. I can't remember the exact date.... I had a doctor's appointment that day and I got up that day and I was feeling, you know, just like shit. Into the doctor, she goes over me and says "Well, you've got pneumonia, not pneumocystis, just plain ordinary pneumonia. Go home, relax, take it easy, take the antibiotic prescribed." I get home and there's a card from the FBA maintenance worker hanging on my door. It says, "I'll be back next Friday." Well, the following Friday I was in all day except an hour and a half or so to go to my doctor again. Today I got a nasty letter saying "We haven't been able to contact you so we're going to cut you off unless you send us a letter telling us why you couldn't be contacted." I'm annoyed at this in more ways than one. I mean I didn't have to come home from having been told to go home and lay down, you've got pneumonia and find a social service worker card stuck in my door. Because my blood pressure and my heart rate and everything else just went right through the roof.

Time and again, the PHAs we interviewed spoke about how illness made the work of "hooking up" more difficult. Trying to make phone calls when sick, coordinating doctor's appointments with meetings with social service workers or standing in line while suffering from extreme fatigue were just some of the ways this occurred. Of course, the situation was even worse for those PHAs who first learned they were HIV+ when they became sick.

Learning About One's HIV+ Status

The PHAs we interviewed found out they were HIV+ in different ways. Particularly important for the later work of "hooking up" were the differences in circumstances which led some PHAs to test for HIV antibodies early, and others not. Our research revealed the stigma of HIV/AIDS to be an important way these differences are organized. The stigma of HIV/AIDS is produced in relation to epidemiological risk group categories. PHAs' experiences of stigma are also shaped by their connections with the lesbian and gay community. The stigma of HIV/AIDS operates in such a way that certain people, primarily heterosexuals, do not see themselves to be at risk for HIV infection. Many of these individuals have little connection to the lesbian and gay community or other communities in which knowledge about AIDS circulates freely. One heterosexual man living with HIV spoke about the way AIDS entered into his conversations with friends:

EM: Did the people that you hung around with, did they know about HIV and AIDS at all, or were they sources of knowledge for you?

INT: I would say, for the most part, it doesn't come up. Except when it first came out, everybody was talking about AIDS and it was, obviously at that time, everybody thought it's a gay disease, and you know, there was really crude jokes, people laughing at a gay couple sitting down drinking a bottle of wine, holding hands while they both jumped out the window. You know. There were jokes about that. And uh, I feel bad that I was one of the people who laughed at that, at the time. But for the most part, there's still that stigma of it being a gay disease.

AIDS was produced as a disease of 'other people' in the everyday interactions he had with friends. It was not personally relevant in the way it was for many of the gay men we interviewed. The kind of "talk" and knowledge about AIDS that circulated within his friendship network did not include information about early HIV antibody testing. In the context of his daily life, that information was not readily available, nor understood to have a direct bearing on his life.

AIDS entered into daily life in similar ways for many other PHAs we interviewed, particularly women, and members of ethnocultural communities, especially those who did not speak English. The possibility of being HIV+ was extremely remote to them. Simply put, it was something they rarely thought about. As such, they only found out they were HIV+ by chance or once they became ill. There were those, for example, who only learned of their HIV+ status after giving blood. Others we interviewed, found out at hospital while recovering from an AIDS-defining illness such as PCP (pneumocystis carinii pneumonia) or after giving birth.

The conditions under which these PHAs discovered they were HIV+ complicated their "hooking up" process in many ways. For some, the news of their HIV+ status came as a complete shock. This often precipitated periods of extreme emotional difficulty. A woman living with HIV we interviewed told us about her situation:

INT: See like, I just, like I never got it [HIV] in Toronto. I went to New York and I got it from New York.... I was in jail in New York.... and they told me, so I went to the hospital--a doctor's, like a hospital and they test you every time you go to jail if you got any virus or anything.... Yeah, and I got uh, uh.... I'm like "No I don't...." [EM: Was there a lot of stress when you found out? To try to deal with it, was it, did it make you feel like sad or unhappy?] Yeah. Unhappy and hurt. And I say to myself, "Why me?" Nobody else, "Why me?" That's what I thought, nobody had it, only me had it.... I knew I had it, but I didn't want to believe it.... Really, I don't know how to put it. And I had nobody in New York for me to talk about it.

Other PHAs we spoke with, who were in similar circumstances, came to experience themselves as HIV+ individuals under conditions of extreme stigma and social isolation. Often the work of "hooking up" to social services could not begin until these problems were addressed. The situation for those who learned they were HIV+ as a result of illness was even worse. In the first place, they had

to go about the work of "hooking up" while ill. In addition, they faced drastic life changes--learning they were HIV+, being sick, needing to leave work and access social assistance--all in a short space of time.

By contrast, many of the gay men we interviewed discovered they were HIV+ under circumstances that afforded better opportunities for "hooking up" to social services. We do not mean to suggest that dealing with an HIV diagnosis was easy for the gay men we interviewed, nor that they all tested early in their infection. This was not the case. What we do wish to emphasize is how their involvement with the lesbian and gay community produced conditions for learning about their HIV infection, including early testing, that facilitated the process of "hooking up" to social services. One HIV+ gay man we interviewed spoke about the circumstances under which he tested this way:

INT: Well officially I found out, I guess it's about a year and a half ago. But I've always suspected that I was, because I've been out [openly gay] for 12 years.... Part of the reason why I got tested was a number of people that I had slept with in the past had passed away.... The thing was that when most of my friends who died of AIDS--I wasn't fully aware that I was HIV+. I suspected! There's a difference of feeling you're HIV+ and then when you find out. It kind of helps a little bit though, you sort of assume.

Dealing with an HIV+ test result was not easy for this man. At the same time, however, getting tested was something he had thought about for some time. He was able to make a decision about it after considering that many of his friends and sex partners were HIV+ and that he might also be. For him and other gay men we interviewed, AIDS was more often a part of daily life--something they read about or talked about with friends. Gay men had better access to knowledge about AIDS. They were also more likely to know people who were HIV+. They had easier access to information about the value of early testing and were more likely to understand it as personally relevant. As such, gay men were more often "productive" in the conditions through which they learned they were HIV+, by planning and deciding to test. This often meant that positive test results were less traumatic. Positive test results were also experienced with less stigma. Testing early also offered the time to plan a response to an HIV+ diagnosis, including when and how to access social services. This was facilitated by easier access to AIDS service organizations of the lesbian and gay community which offer assistance in "hooking up."

Leaving Work and Class Relations

In our interviews with PHAs we also came to see how the ways they made a living and the conditions under which they left work influenced how they accessed social services. These conversations were important for showing the impact of class relations on the work of "hooking up."

We found striking class differences in what happened to PHAs as a consequence of leaving work. The most important of these was organized by access to private insurance benefits. PHAs securely anchored in the middle class would often have long-term disability and extended health care benefits.

These provisions alleviated their need to access government programs of income assistance and helped ease the disruptions in their lives brought on by the loss of employment. For example, the income provided through long-term disability benefits helped pay the rent and, as such, these PHAs did not have to face leaving their homes. Health benefits also paid for drugs and extra nursing care at home when it was needed. This meant they were more able to remain in their homes and die comfortably in them than poorer PHAs on Family Benefits Assistance.

Most of the PHAs we interviewed did not have jobs that offered these kinds of benefits. Many of the working-class PHAs we spoke with were employed in the service sector or held other low-paying jobs with little security or health care benefits. We also interviewed PHAs who were self-employed or who worked on a contract basis. When they could no longer work, they were not eligible for unemployment insurance benefits; nor did they have long-term disability benefits. For these individuals, leaving work set in motion a course of action very different from that experienced by middle-class PHAs. Among the changes they faced were a slide into poverty and a reorganization of their lives in relation to government programs of support. The levels of income assistance provided under welfare and FBA made it very difficult for these PHAs to make ends meet:

INT: I've been on FBA for about a year now. [GS: What happens to your life as you continue on it? Do you get used to it?] You get used to doing without things, you get used to not going to... having to watch every penny that you spend, too. I mean there's a lot that I'd like to do, but I just don't do it. I mean I, I don't skimp on the groceries.... I know how important reasonable levels of nutrition are. But I buy new clothes extremely rarely. It's a matter of expense and money. I've got like two pairs of shoes and that's it for footwear. And I mean if I decide I wanted to go visit my parents, just outside of Sudbury, well then, I've got to make sure that I don't, I don't do other things, because the cost of getting up and back is... [GS: Pretty expensive?] Even to do it by bus.... I mean you can survive on what FBA pays, but you can't live on it. And if you have any additional expenses beyond the basics of food, clothing and shelter--you just can't make it.

For some PHAs, low levels of income assistance and delays in receiving them meant that they fell behind in rent and lost their homes. Many were also forced into a disruptive series of new housing arrangements in order to accommodate changes in the conditions of their illness. Poorer PHAs, particularly sex trade workers, some drug users and others without a history of formal employment often found this latter process difficult to manage. This was partly because they could be classified as 'difficult'² or 'hard-to-house' under the application procedures for supportive or provincially subsidized housing.

² Throughout this report we hold words and terms in single quotes to highlight their location in social relations that manage and regulate the lives of PHAs.

The Negotiated Character of Leaving Work

Our research also showed the way particular circumstances under which PHAs left work had an impact on how they "hooked up" to social services. These circumstances were themselves shaped by class and other social relations. The most important were whether leaving work had a negotiated character and the extent to which it was a source of anxiety for PHAs.

For almost all the PHAs we spoke with, leaving work was associated with ill health. Beyond this, PHAs left work through highly varied courses of action. An important part of this variation was the extent to which leaving work was planned. A small number of PHAs we interviewed were able to plan leaving work far in advance. These individuals often knew of their HIV+ status before the onset of illness. Most were also connected with HIV primary care physicians and AIDS service organizations. Some also had supportive employers. For these individuals, leaving work was the outcome of a process of consultation and discussion with physicians, lovers, family members, AIDS workers and others. This helped to organize and facilitate the decision to leave work and eased the transition to living on social assistance.

Leaving work did not have this negotiated character for most of the PHAs we interviewed. For example, some of the PHAs we spoke with were dismissed from their jobs when they missed too many work days because of illness. Others were fired as a consequence of outright AIDS discrimination. We interviewed a bisexual man of colour living with HIV who described the circumstances under which he left work this way:

INT: ...I got on Unemployment Insurance as a result of losing my job which I think was because of my HIV status. [GS: Oh, could you explain that?] Well, you get sick. I was off for two months and then I got better and I went to the hospital and I went back to work after two months and they fired me within a month. I can't think of any other reason.... [GS: What happened when you got sick? What were your symptoms?] I had pneumonia.... I was in hospital for approximately three weeks but, total, I was off work for two months. [GS: Did your employer know you were HIV+ ?] Well they knew I was sick. When I was in the hospital I remember my manager asking for my doctor's number but I don't think he would have given out that information. I don't know if they could have gotten it from that. Because they probably just assumed, being that they know that I'm bisexual. They probably just assumed, 'cause I had a lot of obvious symptoms.... They claimed... well, I was working in retail, right, they claimed that I stole two dollars. Two dollars! I've been working for them for two years, I do cash at nights, deposit it in the bank, I put in thousands of dollars in the bank, what's two dollars? Plus I didn't take it from the cash register. So my social worker suggested I should see a lawyer and file a discrimination complaint... a wrongful dismissal.

Others we interviewed feared disclosing their HIV status or homosexuality to their employers and left work without accessing the benefits to which they were entitled. All of these PHAs had very little control over the processes through which they left work. As such, they were unable to "ease

into" living on social assistance and, instead, experienced it as a disruptive and abrupt change in the circumstances of their lives.

These conditions often added to the anxiety with which PHAs experienced leaving work. Some of the PHAs we interviewed were anxious about making the transition to income assistance, because they considered leaving work a marker of disease progression. Others had difficulty leaving work because of their commitment to a career or to the "work ethic:"

INT: My work... I've always been... 20 hour days, you know, as best I can. I've always had the energy to do that and give it 100%. I stopped working when I came to Toronto a year ago and I have the desire to go back but I know I can't. I've tried, you know, part-time things and... [EM: How did that work? Can you tell us how... what that was like?] I pushed myself too hard because I didn't want to be--what's the word--an invalid... didn't like the idea of first of all, being on the government payroll. I didn't like nobody, anyone helping me. I've always been self-supporting since I was 15 years old.... [EM: So you tried part-time work. What happened then? Can you tell us what was happening when you decided to stop work?] I pushed myself too hard and I ended up with PCP. I had drained my system so bad. I wasn't eating. I was working literally 17 to 18 hour days. I was covering things up, you know. I figured working I didn't have to think about it. And I did, I went overboard. I worked 7 days a week. I managed a business that was the worst business I could have been in. It is very high stress, a very unhealthy environment, very bad.... You know, my thing was that I had a job to do, I was under a contract, I had to do it. It's my belief that I pushed myself and I pushed myself to the point where I woke up one day and I couldn't stand up and I couldn't get out of bed. I was running a fever to where it all boiled down to an ambulance came and got me and that was it.

The PHA quoted above illustrates, in a dramatic way, how the difficulties some PHAs experience with leaving work can complicate the "hooking up" process. Like other PHAs we interviewed, his capacity to work was central to his self-identity. Not being able to work represented a painful shift in how he understood himself. It reminded him of his deteriorating health. It made him feel unable to look after himself, or as he says, like an "invalid." His situation was further complicated by seeing the transition to social assistance as demeaning. This was also true of many of the recent immigrants and first-time recipients we interviewed. Overall, his circumstances were not unusual. In his case, they dangerously prolonged his stay at work, so that he was forced to begin the work of "hooking up" from the hospital.

Accessing Income Assistance and Housing

For most of the PHAs we interviewed, programs of income assistance were the easiest of social services to access. At the same time, "hooking up" to welfare or Family Benefits Assistance was rarely straightforward or easy. The most common complaint we heard about these programs concerned the low levels of support provided and delays in receiving them. The latter often

occurred because of errors in applications, difficulties in establishing regular contact with welfare workers and problems in the transfer of applications from General Welfare Assistance to Family Benefits Assistance.

The work of accessing income assistance is different for each PHA depending on his or her situation. One of the PHAs we interviewed described how he "hooked up" to Family Benefits Assistance in the following way:

INT: Basically, I went through my social worker. When I quit my job, I went on welfare and I was waiting for unemployment and then I applied to Family Benefits through her. She sort of asked me all the questions.... At that time I was quite... I was pretty sick.... [EM: Did you get like a home visit? What actually happened?] Okay, I phoned them and then they came and I explained the situation--that I was HIV+ and I wanted to apply for Family Benefits. And she just asked me a whole bunch of questions and just told me that it would take from three to four months. She asked me for a doctor's note. [EM: Did you already have a doctor's...?] I had everything ready, yeah. [EM: How did you know how to...?] That? I think I found out through... I talked to somebody about it. I think that a lot of times you just go and talk to people who are sitting there. [EM: At an AIDS service organization?] Yeah. Not counsellors but some people who were seeing them. [EM: At a drop-in centre?] Yeah. [EM: They just told you what kind of forms to get or...] Yeah. But I actually did it--I called the social services for Family Benefits. I called them myself. [EM: So the worker came in and you gave her the forms and she said that it would be three to four months?] She said it COULD be. And also with my Unemployment [Insurance], I was eligible for, it was so minuscule--the amount that I was eligible--I was to collect that. I had to consume that until it was finished. And then they would... I found it to be very confusing because I had to go on Unemployment... They were giving me something. I forgot what it was. I think it was \$99 a week and then the rest the Family Benefits would send it. [EM: Oh I see.] So it was very confusing.

This account is important in a number of ways. First, it sheds light upon the kind of work that PHAs do to "hook up" to social services. To access FBA, the PHA quoted above had to get through to the welfare office and deal with his welfare worker. He also spoke with friends about their experiences of going on welfare, and had his doctor complete the necessary forms. These activities, along with others such as collecting documents, having a home visit from a worker, visiting government offices, filling out forms, having a welfare worker do a "layman's medical," spending hours on the phone, speaking to a social worker at a hospital, getting advice from a counsellor at an AIDS service organization and carrying documents from office to office are representative of the detailed work that PHAs do to access social services.

The account also shows how difficult "hooking up" can be. While the PHA quoted above eventually got onto FBA, he found the process, as he says, "very confusing." Part of what made it so confusing was having to coordinate the eligibility requirements of three government programs that appear to be

autonomous, but actually function interdependently--General Welfare Assistance, Unemployment Insurance and Family Benefits Assistance. PHAs often have to deal with more than a single social service bureaucracy at a time. For the PHA quoted above, accessing FBA was further complicated by trying to find a place to live. Ordinarily it is the PHA who has to attend to this work of coordinating "hooking up" to different social services simultaneously.

The Lesbian and Gay Community as a Storehouse of Knowledge about "Hooking Up"

The above account also suggests how the work of "hooking up" depends on access to knowledge about how social services work. The PHA in the example above had difficulties because of the bureaucratic complexity of "hooking up" and because he was not well. At the same time, he already had some supports in place. For example, he had his own HIV primary-care physician who could attest to the state of his health. He was also connected with an AIDS service organization and with other PHAs who were knowledgeable about how to access social services.

Time and again our conversations with PHAs revealed the importance of this type of networking and information sharing for "hooking up." For example, one gay man we interviewed spoke about how accessing social services was aided by informal knowledge gained from friends:

EM: ...Did you get on to FBA on your own?

INT: Yeah. The manager here [supportive housing for PHAs], I don't think she did--she was really pretty busy at that time, so I did a lot of that on my own. And also, a lot of friends that are on FBA, like gay, would tell me "Well, this is what you do." So it was almost like by the grapevine that got me through a lot of the initial phases of trying to get settled.

Another gay PHA we spoke with told us about how he "hooked up" to housing after moving to Toronto from a smaller town. His account shows how certain almost taken-for-granted features of the lesbian and gay community work to facilitate the "hooking up" process for those who are connected with it. This man moved to a very large city that he was unfamiliar with. However, by virtue of his sexual orientation and also his class background he was able to access a community of knowledge through which he "hooked up" to the services he needed:

INT: ...Well, I went through a gay newspaper first, to find out what kind of gay or HIV associations there were available. And then, I picked up the Pink Pages, that little directory that has all the organizations. So I just went through it and I thought, well these people should be able to help me. And so that's who I went to first. Through them I found out about, well, I found out about [a worker at an AIDS service organization] and he said I was too well to get into a hospice because they have 24-hour care. So they said [a supportive housing facility for PHAs] would probably be my best bet.... And the [AIDS service organizations] here have helped me so much.... But, I did all this through

looking through pamphlets and things that are available to any gay person. You can pick them up in the bar, you can pick them up anywhere on the street.

The two examples above show how for gay men, the lesbian and gay community acts as a storehouse of knowledge and personal experiences with accessing social services such as welfare, FBA and housing. This informal, community-based knowledge was a source of support for many of the gay PHAs we spoke with. Through their lovers, friends, acquaintances and connections with AIDS service organizations, these PHAs were able to develop networks of support and information about how to go about the work of accessing social services.

Of course not all the gay PHAs we interviewed were able to access or develop these kinds of personal and community networks. Some never had many friends, while others were too ill to create or maintain friendships. Still others were isolated because many of their friends were now dead. As we examined the informal networking that goes on in the lesbian and gay community more closely, we also found that it was organized around relations of gender, class and race. Most of the people involved in these networks are men. In addition, mainstream community-based organizations of the lesbian and gay community are dominated by white, English-speaking, middle-class, mostly college-educated gay men. Less visible are lesbians, gay men of colour or those gay men who work in low-paying, non-unionized, service sector jobs. As well, there are gay PHAs who are only marginally connected to the dominant community. We have in mind older men, those living outside the downtown core, deaf PHAs, PHAs who do not speak English and PHAs who are sex-trade workers, street youth or homeless. Also, we found gay PHAs who were visa students, immigrants and refugees and who were rarely connected to the downtown lesbian and gay community. None of these groups have the ease of access to social services that well-connected gay men have.

In Toronto, community-based organizations for lesbians and gay men of colour exist at the margins of the larger, dominant gay community. Nonetheless, they provide an important place for their members to network, share experiences and make friends. Some of these groups have more recently developed AIDS service organizations. While most of these organizations are mandated to provide AIDS education, others also provide support to PHAs. A Native PHA we spoke with described how his community organization facilitated informal sharing of knowledge about HIV and AIDS:

EM: So, at one point did you sort of connect up with the group here?

INT: When they first got it together, three years ago. Well it used to be called Gays and Lesbians of the First Nations. [EM: Right, so have you been involved since the beginning?] Yeah... [EM: And have you sort of met other HIV+ people through here?] Yeah. The friends that I know, the ones that are HIV+, we talk about... It can be one on one, or maybe there's three of us. It was not a planned get-together, you know. If we happen to go visit a friend and the conversation comes up, then we just talk--how we deal with it [HIV/AIDS]. How not to deal with it. All this medication--whether to take it or not. We just have really good

conversations, and we--that's probably how much it is just, you know, talk about being HIV with friends.

Families as a Resource in "Hooking Up" to Social Services

Families were another important source of information and support for the PHAs we interviewed. There was nothing stereotypical about the families of the PHAs we talked with. On the contrary, there was a great deal of variation in how families responded, both immediately and over time. For example, some gay PHAs had support from their families, despite the stigma attached to both AIDS and homosexuality:

EM: So are you getting financial assistance from your stepfather and mother?

INT: Well, yes, they've been helping me out this month and said they would until the FBA thing is... [GS: Oh, I see, you haven't got FBA yet?] No. And... [GS: How long have you been waiting for it?] I just applied, the 20th of January. They said they couldn't guarantee when I'd get it. So yeah, my parents are helping me out. Because with the rent I'm paying at [supportive housing] is \$99 a month. My welfare is altogether \$360 [per month] which I can't exist on that.

Overall, however, families were more important for the heterosexual PHAs we interviewed than for gay PHAs. Of course, some heterosexual PHAs were able to access AIDS service organizations and there were others who did not have families to turn to. For example, a street youth we interviewed was virtually disowned by his Dutch Reform family when he told them he was HIV+. For those who did have families, however, they were an important source of information and support in "hooking up" to social services. This support often took the form of money, food or a temporary place to live. For example, we interviewed a heterosexual PHA of colour whose only form of institutional support related to AIDS was the hospital he visited. His main source of assistance was his sister who not only gave him a place to live, but also managed his application to welfare. Overall, of course, middle-class PHAs received more support from their families than did PHAs from poorer backgrounds. Usually this was simply because poorer families had fewer resources to draw on:

INT: My brother helped me once.... my other sister helped me once.... but my sister.... she doesn't live with her husband. She's supporting one child, a teenage daughter. It's difficult, she has a child and she's getting \$8.50 an hour. She's working at a daycare. Now if I ask for more money from them I feel sort of a burden to them.

Stigma as Social Location

Part of the difficulty the heterosexual man discussed above had accessing social services stemmed from the stigma with which he experienced living with HIV. In some respects, his situation was not unlike that of an HIV+ woman we interviewed. She was extremely reticent to tell her friends and

acquaintances that she was HIV+ and took great pains to keep up what she called her "double life." After some years she was able to connect with AIDS service organizations. Even so, she lived in extreme isolation. Her main source of information for accessing income assistance was her family. As she explained to us how she applied for General Welfare Assistance:

"I have a cousin who works with the government and stuff. She knows and she passed the information on to my parents, and you know, that's how it got through."

Other PHAs we interviewed lived under similar conditions of stigma. These individuals were primarily heterosexual men and women, hemophiliacs, and members of ethnocultural and racial communities. Through an interpreter, we interviewed a Portuguese heterosexual man living with HIV:

INT: When I first found out that I had it [HIV] I just stayed at home and just drank water, constantly crying and staying in bed.... Now I can't sleep at night because I'm always thinking about it. I still eat okay but I just can't sleep and it bothers me the whole day, the whole night... I'm constantly thinking about it.... I know there's no cure but if I could just get something to maintain myself and even get me a little heavier. That way I could even go to a coffee shop... because I'm embarrassed to go to a coffee shop... where I can get out of the house and then I would be feeling better about myself. But this way, I'm scared to get out of the house, I'm embarrassed to get out of the house, I'm thinking everybody knows that I have this and I'm deteriorating, because I'm skinny, it's driving me crazy.

Like others living under conditions of extreme stigma, this PHA's life was severely complicated by the pain and anxiety promoted by the stigma of HIV/AIDS. He was extremely afraid of being publicly known as HIV+ and of being assumed to be gay. As such, he led a life of profound social isolation. None of his friends or family members knew he was HIV+ and he withdrew from the Portuguese community. He was also completely cut off from AIDS service organizations and other PHAs. He and others who lacked access to the networks of knowledge and assistance offered by these sites had severe problems accessing the services they needed. For some PHAs, matters were made even worse when the stigma of HIV/AIDS was compounded by other forms of discrimination:

INT: I've always had to face hardship. There's always been something. When I was in Jamaica, I was gay, so I had society against me there. When I came to Canada I was black, so I had a problem there, and I was gay, too. Oh, brother, it's a no-win situation, you had no choice but to count on yourself, basically. I mean there was nothing else. Friends were few and far between when I first arrived here.... And you know, if I go in Jamaica I'm ostracized and, you know, my black friends here are not too sure. Gay, kinky, you know.

Social Locations and the Varied Work of "Hooking Up"

Our research revealed many other ways in which the social locations of PHAs shaped their experiences of accessing income assistance and housing. For example, we interviewed drug users who told us about the difficulties they faced in "hooking up." In the first instance, they spoke about how they were unable to take on the work of accessing social services in earnest until they could control or stop their drug use. This was complicated by a shortage of drug rehabilitation facilities and by approaches to treatment such as the 12-step model and forced disclosure of HIV status or sexual orientation, which discouraged their use of these facilities. The drug users we interviewed also spoke to us about the barriers they faced accessing housing. The most problematic of these were application procedures at provincial housing and some supportive housing facilities which identified individuals who were drug users or who had drug use histories as 'unfit tenants.' This often required them to find workers in AIDS service organizations or other organizations who would advocate on their behalf or provide documentation and other assurances that they would make 'suitable tenants.' We interviewed one woman living with HIV who had been a drug user, who spoke about her experiences accessing provincially-subsidized housing this way:

INT: I applied for housing in October and [my worker] promised me "Don't worry everything's gonna be taken care of." That was a week, then it was four weeks, then another week and it just got to the point where I was gettin' so stressed out 'cause she kept promising me and promising me. And it was a dead-end street.... They gave me the run around like you wouldn't believe. I'm very upset with them because they told me that I'd be in housing. Because I was on the street--I had no fixed address. I was in a hotel, right? Because of what they put me through--kept telling me a week and that--I was clean... I was 145 pounds. I was clean... I wasn't using. They caused me, because of all the stress and that, they caused me to go out and use again. And then the pattern started and then I became wired again and then I got up to a gram a day which is \$400 a day... They just got me to the point where I said "AAH!" And I went out and used and I got wired again. And that went down to nothing. I was sick and pathetic. It was just pathetic, right? And I was thoroughly fed up with housing, you know? Tell me it's going to be six months. Don't tell me it's going to be a month and then ... You know? [GS: Yes, be truthful about it.] 'Cause that's my life out there. You know what I mean?

In another context, we interviewed a Native PHA who told us how a two-spirited friend did not tell his welfare worker that he was HIV+, out of fear of being discriminated against. As a result, there was a delay in getting him "hooked up" to FBA and the slightly higher income this program provides. This is but one example of how a history of discrimination on the basis of race comes to shape the work of "hooking up."

We also interviewed HIV+ women who told us how their work in the family, caring for HIV+ partners and children, delayed their own efforts to address their needs and access the services they required. There were also street youth we spoke with who needed to be accompanied by youth workers in order to

keep appointments with, and be treated seriously by, doctors and government workers. There were people who did not speak English, for whom the work of "hooking up" was complicated by the lack of interpretation services. There were also homeless people, for whom "hooking up," including the taken-for-granted work of maintaining forms and personal identification, was rendered extremely difficult by the circumstances of their daily lives:

INT: Living on the street with HIV is not, not nice. Its--there are agencies you can "hook up" with, yes. But if you're homeless, it's even harder.... I don't have a phone number, don't have a steady environment where you know, my life is steady instead of scattered all over the place. And the street is not the best environment. I don't have, there's nothing there. If I had a house and a good place to live maybe it would be different.

These examples could continue. What is important is how they demonstrate what is actually involved for PHAs in accessing social services. "Hooking up" involves human effort that extends far beyond what is suggested by official accounts of applying for social services. In addition, the shaping of that work by social relations creates different barriers of access for different PHAs.

Accessing Home Care

The later phase of "hooking up," which focuses primarily on accessing home care, can also involve a lot of work for PHAs. Since PHAs are ill when they access home care, this work is doubly difficult for them. Most PHAs we spoke with found "hooking up" to home care to be extremely complicated. As with access to other social services, their experiences of "hooking up" to home care varied with their social location.

The Work of Accessing Home Care

An important part of accessing home care involves participating in assessments. This work goes beyond the initial matter of qualifying for home care to include evaluations of health status that are conducted on an ongoing basis. Obtaining medical equipment and other materials that are required as the conditions of a PHA's illness change is part of what makes home care so complex. It is also an important feature of the ongoing nature of access to this service.

The complexity of home care also arises out of coordinating the work that goes on in the home with the work of hospital clinics, doctors' offices, insurance companies and the efforts of the hospital or district home care coordinator. The work that goes on in the home is, itself, difficult enough to manage. PHAs must deal with frequent changes in home care staff--the visiting homemakers and nurses. New staff and volunteer care-givers have to be continually re-oriented to the home and the PHA's needs. For example, the housekeeping personnel need to know what to do and how to do it. They need to know where the cleaning supplies are kept, and how and where to do the laundry. People who put great store in personal privacy sometimes find these arrangements difficult. Other people, such as partners, can also be affected by these arrangements:

INT: And with John, because I didn't just know what the progress of the disease would be, all of a sudden I had someone who's fully functional and within 12 hours he had absolutely no balance, no mobility, totally incontinent. I, you know, I'm not in great shape myself, and uh, and I needed the help. But home care had backed off because he, he was functional.... Then all of a sudden he needed all kinds of care and of course it takes a little while to get a care team mobilized. And uh, it was just a nightmare around here, you know. One day there would be no one and the next day there'd be nine people. And everybody who comes in has to be briefed on where everything is and it's just, just too crazy. And everyone shows up to assess you at once.... I know it's necessary too, that's the problem with bureaucracy, but... I mean people, people out here assessing and... I was really unclear.

Home Care and Class

As in the case of access to income assistance and housing, we found class relations to be extremely important in shaping PHAs' experiences of home care. The following account illustrates some of the complexities of these relations. It describes the problems a gay couple we interviewed, one of whom was on home care, had getting heparin paid for. Heparin is an anti-coagulant that is used to clean Port-a-Caths and other intravenous devices for the treatment of various diseases. The ratios in the following account, such as "1 to 100" or "1 to 10,000," have to do with dilutions of heparin. A dilution of "1 to 100" is too strong for cleaning a Port-a-Cath, so the Ontario Drug Benefit Plan makes no provision for paying for it. The medical day unit referred to is a clinic where hospital out-patients go for medical care during the day. The problem this couple had centred on how the heparin was to be paid for.

INT1: Yeah, well, we have a good relationship right now with home care, at least in this district. And it seems to be getting easier. But the latest thing was--you have to have heparin for the Port-a-Cath. [GS: Right.] Medical day unit put a script in for 1 to 100 units. Well, if it was 1 to 1,000 or 1 to 10,000, it would have been covered under the home care drug benefits card, but not the 1 to 100. So we phoned our own pharmacy that we get along with. I thought [our hospital] was fouling up again.... They phoned [another hospital] and they said, "No," because they've never had anybody go through them for heparin or saline or anything. Everybody seems to be getting it at the hospital. So, but they did some checking for us. They said, "No, its got to be 1 to 1,000 or 1 to 10,000. Otherwise you pay and Blue Cross pays you back." Which we don't mind in one sense, but once the Blue Cross runs out or whatever, then we're back to "What can we do?" So we went to the medical day unit and they said it's got to be covered because they've been working with home care at doing more of the takeover, away from hospitals. So, yes, it is new to home care. But who was to tell you. We have a [home care nurse] in here twice a week. They're not being told to tell the patients when and if you need this service. "Here are the new things that are being added in our jurisdiction." So we

discovered, through the medical day unit, that how you get the coverage for 1 to 100 units is to get another form. [INT2: But they never told us about the form.] So finally we got it but that's the point. It's too frustrating to do deal with.

Both of the gay men in this interview were professionals. The man doing most of the talking had worked as a nurse in a large city hospital. The language he uses ("script," "medical day unit," home care "district" and "jurisdiction") along with his description of the way he and his partner went about networking, point to how this work was organized within a set of professional, middle-class relations; in this case, organized independently of the lesbian and gay community.

The account documents the frustration they felt trying to get medical supplies paid for. The case eventually involved two hospitals, the provincial Home Care Program, a pharmacy, Blue Cross Insurance and a nursing registry. It took place at a time when, apparently, arrangements between the hospital and the Home Care Program were being reorganized. Again, these men faced the all too typical problem of not knowing how things work. For example, they did not know about the special form they needed. They also needed specialized knowledge about how payment for medical supplies was to be handled. Again, they produced the knowledge they needed by informally networking with people they knew. They started by talking to their pharmacist. And other people took it from there. Eventually, they had a solution to their problem.

Access to a professional network like this was out of reach for many of the PHAs we talked with. This scenario would have played out very differently in the case of street youth, homeless people, people who have been in prison, some drug users and most of the really poor people we talked with in the course of our research. None of these PHAs would have had the language to establish these relations. The situation, of course, would be more complicated for individuals who do not speak English or where there are ethnic or racial differences. We do not want to suggest that how these two men went about getting the heparin paid for was somehow wrong. What we want to do is to show how their class background helped them to organize this work.

Our research indicated that class relations shaped PHAs' experiences of home care in other important ways. For example, the Ontario Home Care Program does not provide sufficient hours of care in the home for PHAs who are extremely ill. In our interviews, we found that only middle-class PHAs who were able to supplement the provisions of the Home Care Program with private nursing were able to die comfortably in their homes. Those without access to private nursing had to rely on friends or family members to fill in the gap. We found that in addition to class, relations of sexual orientation shaped whether PHAs had this type of support. Gay, middle-class PHAs who were well-connected with AIDS service organizations and the downtown lesbian and gay community had an easier time organizing care teams to look after them than did other PHAs. Many of the heterosexual PHAs we talked with and others isolated by the stigma of HIV/AIDS simply did not have the friendship networks to draw upon to form a care team. Street youth, homeless PHAs, some drug users and PHAs with unstable housing also faced difficulties putting together a care team because of fragile and shifting personal support networks.

Summary

This section of the report focuses on the work PHAs do to "hook up" to social services. An important theme of the section is that what is actually involved for PHAs in accessing social services extends far beyond official accounts of applying for social services. Using PHAs' own accounts, this section demonstrates how the process of "hooking up" works differently for PHAs who are socially located in different ways. For example, PHAs who are drug users face problems accessing housing that others do not. Similarly, PHAs living under conditions of extreme stigma face much longer delays in accessing the services they need than do other PHAs. This highly social and varied nature of the "hooking up" process is accounted for by class relations, relations of sexual orientation, the stigma of HIV/AIDS, the health status of PHAs, access to sources of knowledge and support such as the lesbian and gay community, friendship networks and family members and experiences such as leaving work and finding out about one's HIV+ status.

The description of the "hooking up" process offered in this section of the report focuses on how barriers of access are rooted in the social location of PHAs. The next section of the report expands on this analysis of the "hooking up" process. It describes the problems PHAs face in accessing social services from a slightly different perspective. It focuses on three specific social contexts where problems in "hooking up" arise.

III. Making the Connections: A Strategy for Action

This section of the report examines barriers in "hooking up" to social services that arise in three social contexts. First, we describe how the extended social relations that shape the "hooking up" process can produce problems for PHAs who are accessing social services. These relations include the stigma of HIV/AIDS, 'case management' and advocacy, and knowledge about social services. Next, we describe problems in the organization of social services that create difficulties of access for PHAs. We specifically examine income assistance programs, housing and home care. Lastly, we turn to other institutional sites that are important for "hooking up" to social services. We describe how "hooking up" problems arise out of the way HIV clinics, prisons and drug treatment centres are set up and run.

This section takes the form of a strategy of action for addressing the many barriers which create problems for PHAs and others involved in the work of "hooking up". The strategy for action deals with each of the three social contexts described above. Within each, goals are identified and accompanied by contextualizing text. This is followed by suggested forms of action for levels of government in general, government agencies, AIDS service organizations and other organizations important for the "hooking up" process.

In designing the strategy for action, we have taken into account the financial exigencies currently faced by all levels of government. Some recommendations, if implemented, will involve new expenditures. However, it is also the case that many recommendations can be used to reshape and fine-tune services that are already funded.

As a whole, the strategy for action serves as a framework for responding to the difficulties and inequities that PHAs face in "hooking up" to social services. While it is based in research on the organization of "hooking up" within a large urban centre, many of its suggestions pertain to other areas of the country. PHAs, AIDS activists and others concerned with the conditions under which PHAs are able to live their daily lives should find in it a useful guide to action.

The Social Relations of "Hooking Up"

The most powerful organizers of the "hooking up" process are the broad social relations of stigma, 'case management' and advocacy, and knowledge. These relations produce enormous barriers to "hooking up" which cut across particular social services. A concerted effort to transform these relations is needed. Without it, changes in access to individual social services will have a limited impact.

1. The Stigma of HIV/AIDS Must End

EM: I was wondering whether the stigma of HIV has been a problem--how that has been a problem in your life or not. You said that you didn't want to let certain welfare workers know about being HIV+ and...

INT: Yeah, 'cause I don't feel comfortable with telling I have it. You know, when I just found out, I was going around saying "Well, guess what?" "I have HIV?" And then my friend goes to me, "You shouldn't be telling everybody, you know." And I thought, "Oh, okay." So I just didn't tell nobody at all, you know. [EM: How long did that last, that period where you didn't tell anybody?] I didn't tell anybody for a long time. I still don't tell anybody, you know what I mean? I'm just now getting used to telling people, like I'm not talking about personal people, but like if I go to a hospital or some stuff like that. I'm now getting used to that.... Whereas at one time, I was just so ashamed I couldn't do it. Cause like, the first thing they ask me is where I get it. [GS and EM: Yeah.] You know what I mean? [sarcastically] Oh yeah, I was using drugs and I was on the street, I was, what is that word, per... [EM: Promiscuous?] promiscuous." You know what I mean? Yeah, society don't look at these things, you know.

The comments of the woman living with HIV quoted above demonstrate how the stigma of HIV/AIDS is "carried" in talk about HIV transmission. This metaphor has a double use. On the one hand, it points to how the stigma of HIV/AIDS is actually established and reproduced in the language of risk groups, HIV transmission and so on. On the other hand, the comments of this particular PHA "carry" or "hold" the stigma of HIV/AIDS in that they tell us about how this stigma is socially organized.

An important part of the social organization of AIDS stigma is the work that epidemiologists and public health officials did, and continue to do, to prevent the transmission of AIDS. Historically, this work located AIDS, as an illness, within institutional relations that protect the general public from infectious diseases. It was work that involved explaining HIV, as well as establishing procedures for defining 'cases' and organizing surveillance. It was also work through which the stigmatization of AIDS was made possible and partly accomplished.

One way this occurred, was in how medical researchers, epidemiologists, and public health officials initially labelled AIDS a gay disease. They called it GRID--'Gay Related Immune Deficiency.' They further attributed its cause to a 'lifestyle' which they saw as comprised of 'promiscuous' sex and drug 'abuse.' The stigmatization of AIDS was further supported in the way they used the concept of risk groups to organize their response to HIV transmission. The notion of risk groups promoted the identification of certain groups of individuals as 'responsible' for the spread of infection. These included groups already oppressed by society, namely, homosexuals, drug users, prostitutes, hemophiliacs and Haitians.

An important part of how the stigma of AIDS was and is socially organized, then, is through institutional work that ties AIDS to the problem of transmission and, through this, to particular categories of people. In the first instance, this work was accomplished by epidemiologists and public health officials. However, their work also set in motion an extended course of action through which these associations were repeatedly upheld. A crucial part of this course of action is the media's work of reporting on AIDS. To produce stories on epidemiological and scientific research, as well as other aspects of AIDS, the media used a language that associated AIDS with death, constructed AIDS as a 'gay plague,' and defined PHAs as 'AIDS victims.' This coverage simultaneously shaped how people think about AIDS and reinforced its stigmatization.

But the media is not the only relevant site in this course of action. The stigmatization of AIDS involves more than institutional work that shapes how we think about AIDS. It also includes the actual work of responding to AIDS in various institutional sites. The activities and practices of a wide range of individuals whose work brings them into relation with AIDS form this course of action. These individuals include doctors, researchers, public health nurses, social service workers, policy makers, community workers and others. In certain ways, their work follows from the early epidemiological and public health work noted above. It is shaped by this work and sustains its stigmatizing efforts.

One can think, for example, of how the conception of AIDS as a public health problem and a disease of particular groups of people structured how government officials went about setting up the funding requirements for many AIDS service organizations. These funding arrangements, in turn, shaped how community workers set up these organizations' activities. The stigma of HIV/AIDS and the conception of AIDS as a disease of 'others' also shaped the response of health care practitioners to AIDS. These work practices, as well as others not mentioned here, are social processes through which the stigma of AIDS is accomplished, reinforced or carried. They form a complex of professional and organizational activity into which PHAs must enter in order to access services.

This way of understanding stigma differs from others by emphasizing its social character. Typically, stigma is associated with shame, fear or other psychological experiences which emerge from being labelled or set apart. While these mental states are an important part of the experience of stigma, we want to move beyond them in our approach. Our concern is to emphasize how PHAs actively make their lives in relation to conditions of stigma. How do PHAs live under the stigma of HIV/AIDS? How does stigma shape certain forms of interaction among people and organizations? How does it enter into the process whereby PHAs access social services?

The stigma of HIV/AIDS emerged as a particularly important issue in our research as we began interviewing PHAs who were not gay. Our conversations with them showed the dramatic ways that the stigma of HIV/AIDS shapes how PHAs "hook up" to social services. These conversations also helped us to see the ways that the lesbian and gay community manages the stigma of HIV/AIDS. They also revealed to us how PHAs' individual experiences of stigma relate to the ways they are connected to this community.

Toronto's downtown lesbian and gay community has a history of over 10 years of struggle and response to HIV/AIDS. Over this period, numerous AIDS service organizations have played a critical role in shaping a sex-positive and

life-affirming approach to AIDS in the lesbian and gay community. This way of experiencing and understanding HIV/AIDS enters into daily life within the downtown lesbian and gay community in many ways: in poster images at gay bars, in brochures about AIDS and safer sex, in newspaper articles in the lesbian and gay press and in conversations among PHAs and other members of the community. This works to establish a context for daily life in which the stigma of HIV/AIDS is reduced; in which HIV/AIDS is no longer unusual or 'deviant,' but regular and almost commonplace.

All of this does not mean that gay PHAs do not experience stigma. Nor does it mean that those PHAs who are not gay necessarily do. It simply points to how people who connect with the downtown lesbian and gay community are able to access resources and forms of knowledge that help to destigmatize HIV/AIDS.

Making this connection is no simple or direct process for PHAs. Instead, it works for them in complicated and different ways. For example, many gay street youth we interviewed were only marginally connected with the downtown lesbian and gay community because their daily lives did not "fit" or match up with its middle class character. In another context, two of the HIV+ heterosexual women we spoke with had always had many gay friends. Connecting with AIDS service organizations of the lesbian and gay community and tapping into networks of gay men was not as difficult for them as for other heterosexual PHAs we interviewed. The latter often had difficulty accessing AIDS service organizations, which frequently represented their sole point of contact with the gay community. Some felt uncomfortable with what one person referred to as the "gay centred atmosphere" of these organizations. Others were more actively excluded from them. Some did not seek out AIDS service organizations of the lesbian and gay community because they were homophobic. For others, the stigma of AIDS itself prevented them from accessing these organizations of the lesbian and gay community.

However it happens, PHAs who do not connect with the downtown lesbian and gay community are left to face the full force of the stigma of HIV/AIDS. Often, they come to lead daily lives of extreme social isolation that severely restricts their ability to "hook up" to social services. This is a serious and pervasive problem, experienced by many of the PHAs we spoke with. For example, a number of street youth we interviewed would not use AIDS service organizations. In part, this owed to possible ridicule or street gossip about their HIV status if they were to be seen entering or leaving them. Stigma was also a problem for homeless people. For example, a homeless man we interviewed spoke of how he had to constantly reinvent stories to explain his weight loss to his friends. Discussion about HIV/AIDS was not part of his daily life. He was unable to tell his friends he was HIV+ or seek support from other homeless people because he feared he might be beaten up.

In another context, the Native people we spoke with talked about how the stigma of HIV/AIDS often operated to ostracize Natives living with HIV/AIDS from the reserves where they grew up. In some instances stigma also prevented them from telling welfare workers they were HIV+. Here, the fear of being known as HIV+ overlapped with centuries of state intervention in the lives of Native peoples to create a mistrust of welfare workers and the social service system in general.

The stigma of HIV/AIDS also created problems for certain gay men. For example, an AIDS counsellor spoke of gay clients who left work when ill without accessing accumulated sick leave because they feared being publicly known as gay or HIV+. Other gay men we spoke with had to contend with the problem of stigma in their work lives. Known, or thought to be gay by their employers, they were forced to apply to programs of income assistance unexpectedly and without any preparation, after being fired from their jobs for missing work due to "unexplained" illness.

The stigma of HIV/AIDS had an especially powerful shaping influence on the lives of the women and members of ethnocultural communities we interviewed. Not only would they not access AIDS service organizations, but many led lives of extreme secrecy around their HIV status, often not telling friends or family members:

EM: Is it hard for you, that no one in your family knows you're HIV+?

INT: See, I don't know how they would take it. [GS: Yeah.] You know. Like, either they take it well or you know, push me out the family. You know, don't want to talk to me. She got AIDS, you know. It's hard but I think one day I'll sit down to them, you know, to the whole family and... but I don't know how they take it yet. And I'm the baby. [EM: So do you have brothers and sisters?] Yeah. [EM: And none of them know.] None. Only my cousin knows, the only one who knows. And my aunt who live in Toronto, the only two people know. And my aunt and my cousin won't tell nobody. You know like, like, the family knows my cousin got it, but they don't think I got it. [GS: Well, how do they treat her.] Far. [EM: Really.] Yeah, they don't want nothing to do with her. And like, anything going on they don't invite her to anything. [EM: No.] [GS: Oh.] And that hurt me. [GS and EM: Yes.]

Whether experienced by hemophiliacs, street youth, Native peoples, heterosexual men and women, members of ethnocultural and racial communities, people who do not speak English, drug users, prisoners or others not connected with the lesbian and gay community, the stigma of HIV/AIDS can result in profound social isolation. Under these conditions, the work of "hooking up" is made extremely problematic. It is often done alone, with little assistance and under great emotional stress. Those living under conditions of extreme stigma, particularly women and members of ethnocultural communities, often have no access to other PHAs and the informal, but valuable knowledge about "how to get things done" that circulates within PHA networks. Their fear of being publicly known as HIV+ often prevents them from connecting with AIDS service organizations and benefiting from the ways these organizations help manage and coordinate the "hooking up" process. Often, their only organizational connection is the hospital HIV clinic they attend every few months. In the worst situations, they are completely cut off from any life-affirming activities to do with HIV/AIDS.

Because of the extreme impact of stigma on the daily lives of PHAs and the barriers it creates for their ability to "hook up" to social services, it is recommended that:

- 1.1 The federal government, in association with the Canadian AIDS Society, its member organizations and the Canadian Hemophilia Society should begin immediately, the design and implementation of an all-out campaign to eradicate the stigma of HIV/AIDS that will:
 - a) Be funded by all levels of government.
 - b) Make the connections between the stigma of HIV/AIDS and the stigma of other diseases and disabilities.
 - c) Draw upon ethnocultural and other AIDS service organizations' expertise in prevention education to design effective, multi-media strategies for the specific purpose of combating the stigma of HIV/AIDS.
 - d) Be targeted to a wide range of constituencies including: health care providers, particularly emergency room staff and non-HIV primary-care physicians; home-makers working in home care services; ethnocultural communities; people of colour; deaf people; drug users; homeless people; prisoners; street youth; hemophiliacs; heterosexual men and women; sex trade workers; Native peoples; the lesbian and gay community; and others.
 - e) Include content that is appropriate to the specific target group being addressed.
 - f) Take various forms including print information, video, posters, workshops, and training programs.
 - g) Be conducted in various languages.
- 1.2 Public health authorities at all levels of government should be mandated to conduct campaigns against the stigma of HIV/AIDS and other diseases and disabilities.
- 1.3 The Ontario government should address HIV-related discrimination in the workplace by:
 - a) Fast-tracking Human Rights cases dealing with AIDS.
 - b) Promoting greater awareness of the Canadian AIDS Society's AIDS in the Workplace program.
 - c) Ensuring that people with HIV/AIDS are aware and make use of the protection against discrimination provided by the Ontario Human Rights Code.

2. 'Case Managers' and Advocates Should be Available to All PHAs in Order to Facilitate their Access to Social Services

How PHAs access social services is profoundly affected by the work community-based agencies do to facilitate the "hooking up" process. This work involves interfacing between the lives and needs of PHAs on the one hand, and the rules, procedures and work processes of social service agencies, on the other. It has three distinct forms: 'case management,' individual advocacy and institutional advocacy.

The main site of 'case management' is the direct relationship between an HIV+ 'client' and a 'case manager.' It typically begins with some form of assessment of the 'client's' living conditions and the degree of his or her need for agency assistance in "hooking up" to social services. The assessment establishes standard organizational courses of action which range from explaining "how the system works" to more rigorous efforts at coordinating and managing the "hooking up" process. The latter are designed to move the 'client' into a situation in which he or she is receiving maximum financial assistance and living in adequate housing. The type of work involved might include assisting the 'client' to obtain a health card or to make an application for a social insurance number, financial counselling to reduce debt loads, connecting the 'client' with an HIV primary care physician, liaising with other agencies or managing the application procedures for income assistance programs and government subsidized housing.

Emerging out of the work of 'case management' is individual advocacy. We use this term to refer to forms of work in which 'case managers' or other AIDS workers enter into direct contact with service providers on behalf of their 'clients.' Advocacy is typically carried out in anticipation of a stalled process of "hooking up" or in response to barriers which delay a 'client's' access to services. Examples include repeated phone calls to a welfare worker to speed up the processing of a PHA's file or writing letters to a housing agency on behalf of an HIV+ street youth, to improve his chances of being housed.

When individual advocacy of this type is repeated time and again, signalling some form of systemic problem, a third form of facilitating work may be embarked upon--institutional advocacy. Institutional advocacy is typically removed from the particularities of a single 'client's' 'case' and, instead, is directed at making changes in the regulations, policies and procedures of social service agencies. An example is the work Toronto's HIV and Mental Health Group has done advocating for changes in the procedures used to establish eligibility for home care and home-making. Of all the forms of facilitating work, institutional advocacy is the furthest removed from the daily face-to-face work of helping an individual client access social services.

The work of 'case management' and advocacy that workers in AIDS service organizations (ASOs) do is made possible by knowledge about how social services work and by connections with workers inside social service bureaucracies that PHAs do not have. These connections can take numerous forms such as private telephone numbers that allow ASO workers to call directly into government offices or the exchange of information and viewpoints regarding a PHA's 'case.'

We refer to these connections as 'quasi-professional' relations. What we mean by 'quasi-professional' is the way staff in AIDS service organizations, on the one hand, are not authorized to provide government services to PHAs, yet, on the other hand, play an important role in facilitating the delivery of these services. Also, workers in AIDS service organizations do not have the professional standing of social workers or nurses who work in HIV clinics and other health service agencies. Lacking this standing, they can not enter or invoke professional relations when they connect with social service workers. Instead, they are required to operate in a grey administrative area between 'clients' and government officials.

Part of the work of 'case management' and advocacy, then, involves producing and maintaining good, 'quasi-professional' working relations with government housing and income assistance officials. One way this is accomplished is to work at being treated as a 'professional.' There are various strategies to accomplish this, including helping ease the workload of an overworked welfare worker by ensuring that the proper documentation and identification are in order for a PHA's case. Another way, as told to us by a worker in an AIDS service organization, is to 'schmooze' with front-line social service workers:

EM: I was just going to ask you about that. What happens when the contacts you have in the different [government] offices move?

INT: Well we're always developing new ones--always. Every time I meet a worker, you know--this is the woman from office Q who I haven't dealt with before. I copy down her number and make quick notes to myself either about how she responded to questions; whether she prefers an "all business" attitude or whether she likes to chat a little bit. Crazy stuff. [EM: You have those files?] Yes. [EM: And prior to calling you go through your files?] Sure I do. I look and see if I have the information. It makes a difference. I can promise you a hundred times over, it's paid for itself in terms of... I don't know, an example: The other day someone happened to mention that this woman at [a housing office] was a very "60's"--she was kind of trapped in the "60's." And I phoned her up and one of the terms I always use is groovy, anyway. And she was saying something and I said "Groovy." And she went, "Ah, groovy; I haven't heard groovy for..." and then it clicked in my mind who I was talking to. And so I went into this whole thing--we were talking about Birkenstocks and I said that I loved those cotton skirts they used to have. And she said "I happen to be WEARING one of them." And I'm thinking to myself, oh boy. But I'm not saying that to her. She had my client housing THAT afternoon. Which was three months since the date of application. And it would not have happened, I can promise you...

This kind of success in establishing 'quasi-professional' relations with the government social service bureaucracy is not without its problems. The most serious pitfall is cooptation. As AIDS service organizations establish relations with social service workers they come to operate as surrogate government offices. In particular, they can be drawn into participating in the organization of

class relations through which some 'clients' receive social services and others not:

INT: ...I'm not going to set up a client for failure. If I get a client in here that I don't believe is capable of living on his own, or I see has drug problems or alcohol problems, I'm not going to refer him to [provincially-subsidized housing]. I will refer them to supportive housing. I will not support their application for [subsidized housing]. And the [housing authority] appreciates that A LOT. Because as you know, they've had a lot of problems in that area. And subsequently when they DO get referrals from us, they usually move heaven and earth to get them in as fast as possible.... You know we're very lucky here at the agency. I think that we really deal with the top of the line. Most of our clients have at least a moderate education and have been living... have no support, but have been living fairly well, mostly in the gay ghetto and have always had nice apartments and nice jobs and groups of supportive friends. That's changing now.

As the AIDS worker quoted above remarks, many PHAs in Toronto are middle-class gay men who, very often, make ideal clients for social service agencies. However, as AIDS demographics in Toronto change to include more drug users, street people and sex trade workers, AIDS service organizations will have 'less appealing clients.' Facilitating their access to income assistance programs and other social services will be more difficult.

The two quotes above suggest, from the perspective of AIDS service organization workers, how 'case management' and advocacy can ease the process of accessing social services. For the most part, these forms of agency work smooth out what, for PHAs, can be an extremely confusing and bumpy ride of accessing social services. They can result in huge differences in the services that PHAs access and the subsequent conditions of their daily lives. Here is one account, produced this time, from the location of PHAs:

INT: My case is fairly interesting in that I went to [an AIDS service organization] and I was sort of hooked into their financial counselling there and it's very good. He's so well-connected okay... I got an appointment to see their counsellor there. [GS: This is before you quit work?] Oh yeah, way before. And he says "Don't worry about a thing, I'll walk you through the whole thing." And uh, he goes, "You'll never make less than like eight something, nine hundred dollars a month. Never. Even when you go on General [welfare] and you're waiting for your FBA we'll subsidize you. We'll subsidize your FBA." And uh, he got me housing over here [downtown]. Everything is brand new in there and it's... I tell you, you just can't get in there. Anyway so I was lucky enough like he knew I needed housing and he knew that, and he does it all. Like he's well-connected. He picks up the phone and he's talking to the boss at Metro Housing and he's saying I've got these patients and I want them in some housing and they respond really well to it. And when I had my worker come to see me from the Family Benefits, I was in a rooming house then and she was a woman and they don't send female workers to rooming houses. But thanks to his connections, she

came right over and it was like, you know, there was no hiding anything that I could have. You know what I mean? She goes, "If you need clothing or if you need, what do you need? Do you have blankets? Do you have pots and pans?" You know. "Do you need a moving allowance?" It was all, all there for me, they were really good to me. Really compassionate you know, it's like you could see, like they were concerned and they knew this wasn't just some sort of, like a welfare scam type of thing to get money out of them because I went through [an AIDS service organization] and he talked to like the supervisor there and it goes really smooth if he does it for you.

In Toronto, there is only one AIDS service organization (ASO) that practices 'case management' as described above; that is, 'case management' that involves the ongoing coordination of "hooking up" to General Welfare Assistance (welfare), Family Benefits Assistance (FBA) and government-subsidized housing. Other organizations including those that serve street youth, HIV clinics, AIDS service organizations serving Native peoples, ethnocultural and racial communities, and some doctors offices carry out discrete and more piecemeal forms of 'case management' work. They do this work alongside other forms of support they provide for PHAs, whether that be counselling or medical services. It is not organized into an independent and overall service of 'case management.' Often it takes the form of providing information about social services or doing preparatory work for applications to those services, after which 'clients' are referred to the aforementioned ASO for the ongoing work of managing the "hooking up" process.

Because of its relationship to 'case management,' most advocacy around welfare, Family Benefits Assistance, and government housing is also done by the ASO noted above. While other AIDS service organizations advocate on behalf of their 'clients' in these areas, most of their advocacy work focuses on other areas of service such as hospitals and hostels. At the same time, organizations that serve 'difficult clients,' such as street youth or drug users do considerable advocacy with AIDS service organizations, particularly supportive housing facilities, to try to ensure their 'clients' appropriate access.

With the exception of the AIDS service organization noted above, it is rare for 'case management' or advocacy to be offered to PHAs as a program of support, in the way counselling services are, for example. Advocacy, in particular, often rests on the initiative of individual workers who are willing to put in extra time and effort beyond their regular work responsibilities. Staff receive little if any training in how to do advocacy work. There are few records kept. Insider's knowledge of how social services operate and contacts made with social services workers are often lost with staff turnover. Most importantly, ASOs have not been provided the resources to transform the ad hoc nature of this work, or to extend 'case management' to other services areas such as home care. All of this can produce uneven advocacy and 'case management' for PHAs, both within and across the organizations that serve them.

Most 'case management' and social service advocacy for PHAs occurs within AIDS service organizations of the gay and lesbian community. This is entirely appropriate given that most PHAs are gay. At the same time, however, it creates problems for PHAs who are not part of the lesbian and gay community or who do not connect up with it. They include hemophiliacs, women, street youth,

drug users, people of colour, Native peoples, members of ethnocultural and racial communities and others. Most, but not all, of these individuals are heterosexual.

Many do not access AIDS service organizations of the lesbian and gay community by virtue of the stigma of HIV/AIDS, or because they are homophobic. But those that do try often feel that "they do not belong," that the organizations are "not for them," in much the same way that gay men would feel using heterosexual organizations. In the end, many are left without organizational resources to assist them in "hooking up." In some cases, they do not "hook up" at all.

Because of the vital importance of 'case management' and advocacy for "hooking up" to social services, it is recommended that:

- 2.1 Through the AIDS Bureau, the provincial government should make funds available to establish a coordinated system of 'case management' and advocacy services for PHAs involving:
 - a) Increased funding to transform the ad hoc organization of advocacy and 'case management' services in AIDS service organizations of the lesbian and gay community into a program of sustained and viable support for PHAs.
 - This transformation should include distinct allocations of time, staff and financial resources to the work of advocacy and 'case management'; appropriate forms of training and related support; the inclusion of advocacy and 'case management' responsibilities in job descriptions, with appropriate levels of worker specialization; and the extension of advocacy and 'case management' to other government services, particularly home care.
 - b) The establishment of a parallel system of independent community-based advocacy and 'case management' services for PHAs who do not use AIDS service organizations of the lesbian and gay community, including members of ethnic and racial communities, Native peoples, women, families, drug users, street youth, homeless people, prisoners, prostitutes and others.
 - A central strategy of outreach to these individuals conducted by the advocacy/'case management' service should be liaising with social workers in HIV clinics, organizations serving homeless people, street youth and prostitutes, prisons, Hemophilia Ontario and AIDS organizations serving Native peoples, people of colour and ethnocultural communities.
 - c) Wherever possible, a system for delivering advocacy services that is organizationally linked to the daily, front-line work of meeting the needs of PHAs.

- d) The hiring of one or more government HIV/AIDS advocates in the AIDS Bureau of the Ontario Ministry of Health, with responsibility for liaising with community-based HIV/AIDS advocates and 'case managers' in order to complement and support their individual advocacy and to coordinate meetings and other mechanisms to further their efforts at institutional advocacy.

- 2.2 The Canadian AIDS Society should make advocacy and 'case management' for PHAs a priority by undertaking a coordinating role in facilitating skills development in advocacy and 'case management' among its member organizations.

3. The Base of Knowledge About Social Services Among PHAs, People who Work in Social Services, Health Services, Prisons and Community-based Organizations Should be Improved

Knowledge about social services dramatically shapes how PHAs "hook up." This knowledge does not "fall from the sky," but is produced and exchanged as part of the work done by PHAs and others involved in "hooking up" to social services. This work of learning about social services is extremely difficult. It often involves piecing together partial and incomplete information gathered from various individuals. The process is time consuming. People often give confusing and contradictory information and there is very little that is written down. Worst of all, very few people actually know how social services work. These knowledge problems greatly complicate the "hooking up" process. They are a common experience for PHAs, but also for workers in community-based organizations and health services and, to a lesser extent, social service workers themselves.

PHAs come to the work of "hooking up" with varying types of knowledge about social services and different resources for finding out how they work. Some have the advantage of having used social services in the past. Others have worked in large-scale organizations and are familiar with bureaucratic procedures, which help orient them to the world of social services and to "ask the right questions." Some are well-connected with PHAs or the lesbian and gay community, which are important sources of knowledge about "hooking up." Others, who are more socially isolated, are left with very few opportunities for gaining knowledge about social services.

As PHAs come to address life problems such as loss of income or housing that require them to "hook up" to a social service, they enter into new episodes of learning about "what to do," "what's available," "how to get it" and "who can help." In general, finding out about how to "hook up" is done in a context of uncertainty. Many do not know or anticipate the problems that they will face in the future. As such, they face difficulties in planning out the work of "hooking up" in advance.

Worse still, social services themselves are not organized to be easily understood by the people who use them. Many PHAs we interviewed spoke of their confusion about which services actually existed. Many experienced difficulty finding out about the entitlements and special provisions of particular services. Still others were uncertain about what services they qualified for:

GS: So are you on welfare then?

INT: I'm on FBA. [GS: You're on FBA? How did you get on FBA?] I got on FBA through my worker. I only been on it what, two months now. [EM: What worker? Sorry.] Uh, welfare. [EM: Oh, your welfare worker.] Yeah. [EM: So when you applied for welfare your worker made an application for FBA too?] No, it was a friend of mine that was at the Don [Jail] that had been on FBA. He was telling me that I had a disability, that I can... I thought you had to have like a family--Family Benefits. That's what I thought Family Benefits meant. He goes "No, no, no." I said "I have to have a kid or something." And he goes "No," he goes "Just something medically wrong with you." Then I said "Oh." Then at that time he goes "Get yourself 'hooked up' with a doctor." So like before I didn't have a doctor, but now I do.

The above quote suggests some of the ways that "not knowing" can produce problems for "hooking up." It also points to a particular kind of learning. By talking with his friend, the PHA quoted above, developed an understanding of how social services work. He learned about the difference between General Welfare Assistance and FBA; that the eligibility for the latter is established through disability; that HIV/AIDS is considered a disability; and that doctors are needed in order to access certain services. This kind of knowledge about how the social service system is put together is particularly valuable to PHAs. At the same time, it is knowledge many lack as they embark upon the process of "hooking up."

In addition to knowing about how social services work, there is a second form of knowledge that greatly facilitates the "hooking up" process. This is knowledge about how to organize and coordinate the "hooking up" process itself. It involves knowing how to put together a course of action that effectively moves one through the social service system and that responds to the changes in life circumstances that necessitate that movement. One PHA we interviewed spoke about it this way:

INT: I wish there was some handbook that says, okay, you're HIV+, you do this, that and the other thing. Don't worry about the rest, okay, do this, that and the other. You go here, you go there and you go to the next place. I wish somebody had just had a checklist of things I could do.

The most important sites of this knowledge about coordinating and managing the "hooking up" process are AIDS service organizations of the lesbian and gay community that provide 'case management' services. These organizations are invaluable sources of information about which service to apply for, when and how. Members of ethnocultural communities, people of colour, drug users, street youth, hemophiliacs, heterosexual men and women, Native peoples and others who, because of stigma or other reasons, do not access AIDS service organizations of the lesbian and gay community, are severely disadvantaged with respect to knowing how to "hook up" to social services.

The knowledge that AIDS service organizations have about how to "hook up" to social services was not produced without difficulties. There are, for example, no training programs, liaison officers or other formal mechanisms

whereby social service agencies provide information about their services to ASOs. Most of what is known about "hooking up" within AIDS service organizations is acquired in an ad hoc manner by individual workers who establish personal connections with social service workers. These connections take a great deal of time to develop and are extremely tenuous, often ending with staff turnover.

With limited organizational and financial resources, ASOs have difficulty maintaining, let alone expanding on what they know about how to "hook up" to social services. In fact, most of this knowledge is restricted to one or two AIDS service organizations of the lesbian and gay community. Within these organizations, very little of the knowledge is documented. Few records are kept and there are no training manuals. AIDS service organizations of the lesbian and gay community have done remarkably well under these circumstances. At times, however, the consequences of the organizational problems which they face in developing knowledge about social services are felt directly by PHAs:

INT: I haven't had a lot of connection with them [AIDS service organizations]. Not directly. But when I did go, I couldn't get, couldn't seem to pin down a benefits counsellor. One [AIDS service organization] sent me through a telephone round to [another] because I wanted to apply for my Canada Pension and see a benefits counsellor. First of all, she didn't know anything. You know, she, I don't know, she may have just been new at the job but don't meet clients until you... [GS: No.] And it's partly the federal bureaucracy. There's no contact number. She didn't have any numbers to call. And what do you do? Do you call all those numbers in the blue pages? I don't know. It was a really frustrating experience and I asked her about the death benefit, which is available for everyone. Which I hadn't known but my mother told me about. I thought I would ask about it. She had never heard of it...

Lack of knowledge about how social services work is not limited to PHAs and AIDS service organizations. In some cases, it extends to actual social service workers. A recurring example in our research was lack of knowledge about home care. One of our concerns was to understand how home care users access additional hours of nursing care under home care's complex care program. The PHAs, physicians, hospital nurses and social workers we interviewed did not know. But the confusion also extended to the home care workers we interviewed--a nurse, hospital intake worker, community intake workers and district coordinator--all of whom gave different accounts of what complex care was.

Lack of knowledge about the provisions and organization of a social service on the part of those who provide it can have serious consequences for its users. In some instances, as in the one told to us by a welfare worker below, it means that users do not receive what they are entitled to:

INT: Sometimes people do reveal their HIV status--and I've come across a case like this in our office--to a worker and the worker has no knowledge of the nature of how that illness is treated. We had a case like that in our office, where the client, who was set up, his case was set up in an outlying office and transferred

into our office, the worker was aware that the guy was HIV+, but she wasn't aware that it was a referrable issue, to FBA. So the guy was kept on an employable case load. [GS: So that's just like worker ignorance.] Exactly. And lack of worker training. Whether it's lack of worker training, I think the worker was sympathetic because when she transferred the case over, the worker that got it in our office, she called over which is really unusual for a worker to call over and ask to speak to the new worker. And she called over and she says "I don't really know what should be done with this case. We should be, you know, doing something with this guy. I don't know whether we should have him on an employable caseload." But she never went through the trouble of doing the referral work to get him off the employable caseload.

Knowledge about social services dramatically shapes the "hooking up" process for PHAs. At the same time, it is not adequately distributed among the various organizational sites of "hooking up." Nor does it move smoothly among and between PHAs, workers in AIDS service organizations and other community-based organizations, health care workers and social service workers. In order to remedy these problems the following strategy aimed at three target groups is recommended:

3.1 For PHAs:

- a) Information about social services, particularly income assistance programs and assisted housing should be included as a standard part of post-test counselling procedures.
- b) Information about social service access and delivery should be integrated into the activities of AIDS service organizations, particularly their counselling services, volunteer training programs and support groups activities.
- c) Manuals dealing with how to "hook up" to income assistance programs, provincial housing systems and home care should be produced. They should be written from the perspective of PHAs, in multiple formats and languages and should stress the importance of planning to go on social assistance.
- d) AIDS service organizations should advertise, in a regular and detailed manner, the full range of services they provide to PHAs, including those relevant to the work of "hooking up" to social services.
- e) Support groups for PHAs who do not have access to informal PHA knowledge networks should be established and properly funded.

3.2 For workers in AIDS service organizations and other community-based agencies:

- a) The provincial government should establish in-service

training programs regarding the delivery and access of income assistance programs, housing, and home care.

- These programs should be designed in consultation with workers in AIDS service organizations. They should also include a feedback component through which government service providers can learn about and take action on the "hooking up" issues that are most relevant to PHAs.
- b) The AIDS Bureau of the Ontario Ministry of Health should fund the production of a practical manual on eligibility requirements, application procedures, entitlements and related issues for provincial income assistance programs, housing and home care.
 - This manual should be distributed to AIDS service organizations, HIV primary care physicians' offices, HIV clinics, anonymous test sites and other organizations providing services to PHAs and should be updated with new information as required.

3.3 For social service workers:

- a) The provincial government should develop and conduct programs of in-service training for intake workers and other staff of income assistance, housing and home care so that they will have consistent and competent knowledge of all aspects of entitlements, eligibility, etc. in relation to HIV/AIDS.

Social Service Agencies

PHAs face numerous barriers in accessing particular social services. Some of these arise out of the broad social relations which shape the overall process of "hooking up." Others stem from more specific problems in how the services are organized. This section focuses on the latter. It highlights the difficulties produced for PHAs when the organization of their daily lives runs counter to the way social services are set up. An important focal point through which this disjuncture is "detected" and managed organizationally is the practices which establish eligibility for social services.

4. Ease of Access to Adequate Levels of Income Assistance for all PHAs Should be Established

INT: My [AIDS worker] set up an appointment with welfare. I had talked to her on Wednesday and she called from her office and they gave me a home visit the next day at my place. That's how quick it happened for me. I was also fortunate that the worker that came did the application for Family Benefits at the same time. But I know I lucked out. I mean it doesn't happen very often. Because I have friends who apply for welfare in the city

and it takes them sometimes three days to get through on the telephone. [GS: These were people with HIV infection?] Yes. [GS: Did they go through an AIDS service organization?] They didn't know about it. You see, I just, it's not that I'm that clever, but I just used some common sense and said, "Look, these organizations should be able to work with me." And trying to do it on your own, I know, is just disastrous. I have tried to call, you know, at other times. Well actually when I first decided I'd do this, I tried to call the office. I tried for four hours and couldn't get through the switchboard. It was constantly busy and then they'd put you on hold and you'd get disconnected, call back again, and it gets very frustrating for somebody who's just not on an even keel emotionally or intellectually because of this disease. [GS: Yes.] It gets extremely frustrating so you pull your hair out. And then, you may have to wait up to two weeks to have a home visit too. And on top of everything else, if you're out of money and not able to work, it can be extremely depressing.

The PHA quoted above describes his experience of "hooking up" to Family Benefits Assistance as lucky and unusual. But the ease with which he accessed this service had to do with more than mere chance. For example, it depended on the existence of 'case management' services at an AIDS service organization (ASO). It was also made possible by his own social location and knowledge, which made it easier for him to make use of this ASO than was the case for his friends. His smooth "hook up" to Family Benefits Assistance, would also not have taken place unless certain conditions and procedures required of the application process were met. For example, all of his identification had to have been in order, he had to have been connected up with a doctor and the medical and other forms needed to have been properly completed.

His "trouble-free" experience also depended on the establishment and practice of certain procedures within welfare offices. Over time, these procedures have become almost routine in the downtown Toronto offices which see large numbers of PHAs. They rest upon the categorization of PHA applications as 'permanently unemployable,' after which they can be transferred to Family Benefits Assistance--the long-term income assistance program. Under these conditions, the application to FBA is begun at the point of application to General Welfare Assistance and the file is often given a rush or urgent status to speed its transfer between the two systems. In the best of cases, a PHA can begin receiving Family Benefits Assistance three months after he or she applies for welfare.

Quick and unproblematic access to FBA then, occurs only under certain conditions. It is something that is accomplished and made possible when the work of individuals at various sites of the "hooking up" process is well coordinated. Unfortunately, things do not always happen this way. It is in his recognition of other, more problematic experiences of accessing FBA that the PHA quoted above is quite correct in describing himself as lucky.

Numerous obstacles can interfere with "hooking up" to FBA. For example, the stigma of HIV/AIDS can make it very difficult for PHAs not connected with the lesbian and gay community to access AIDS service organizations and benefit from their 'case management' services. The problem of stigma can also prevent some PHAs from disclosing their HIV status when

applying for welfare:

INT: ...Oh, when I seen my [welfare] worker it was like, when I seen my worker it was like, [my friend] said "Tell them that you want to be on FBA and ask for this form that I got." Because the worker I had, it was like, "I don't think you can be on FBA." Like he said that I didn't, he didn't think I needed it. [GS: That you didn't qualify or that...?] Yeah, exactly. Basically that's what he was saying. I was like, "Why?" He goes "Well, you can work." Cause it was like, cause it was a while that I got on it. [GS: Right.] [EM: Did he know you were HIV+?] Not at first and then I told him. Then it was like, "Of course" he goes, "Well you have to get a doctor's note for me to verify this." So I get the doctor's note, but then after it was like, I asked him, its only two months I got on it, I was waiting 8 months. [EM: You had to wait eight months to get on FBA?] I waited basically eight months before like, before it even went over... [EM: So, when you applied for welfare, did they know you were HIV+ then or not?] Not at first, no. Cause I didn't want to tell welfare, government. I'm thinking, I don't want the government--so then after a time I told my [welfare] worker. When he said get it verified, I didn't have, I didn't have a doctor and I went out to [a clinic] and talked to my friend. He goes, "Go get a doctor." He told me this, and I said "I can't get a doctor." Then I came here [a street youth agency] and asked the workers here.

In addition to the operation of stigma, the above quote shows how knowledge problems can create delays in accessing Family Benefits Assistance. As was the case for the person quoted above, some PHAs do not know that they qualify for FBA. For example, we interviewed two HIV+ men who had applied for refugee status who were unaware that they were entitled to receive FBA. Others did not know that they could receive clothing allowances and other forms of support that had been available under the Special Assistance Program.³ Still others were unaware that they could receive cheques immediately as part of 'emergency assistance.'

The esoteric nature of much of this knowledge stems from the way programs of income assistance are set up and run. For example, many government workers, themselves, do not know what is available. Those that do, often do not fully explain these entitlements to PHAs and others applying for income assistance. In other instances, PHAs may encounter welfare workers who do not know about or choose not to follow procedures which hasten the transfer of applications to Family Benefits Assistance. This can be particularly true for those PHAs who apply at offices outside the downtown Toronto area. These features of the organization of income assistance produce a system with a highly discretionary character. In many respects, PHAs' experiences of accessing income assistance can depend on what an individual welfare worker knows or chooses to do:

³ General Welfare's Special Assistance Program was set up to provide services such as walking aids, wheelchairs, dental services, and coverage of transportation costs for medical reasons. Recent cutbacks in funding have eliminated many of the services available through this program.

INT: Listen. If it wasn't for my welfare worker, I wouldn't be getting the benefits so quick. I wouldn't have gotten those cheques. I wouldn't have gotten anything--it's because she's actively involved--she's an activist I think. [GS: Yes she is.] The only reason I was treated like that... otherwise I would sit in that welfare office for six to eight hours and they would have sluffed me off and told me to come back. It was just because of my worker, is the only reason I got anything. [EM: Was it a coincidence that you just "hooked up" with her?] It was a FLUKE that she ended up with me. And she's helped me in every possible way. Otherwise, like I've gone there before and they sluffed me off--"Sorry we can't help you". Da, da, de, da. They never told me about any facilities available for people like me. You know... AIDS! They stood back kind of like this, right. [GS: Really?] Oh, yeah. He took three steps back, right. He said, "Well I really can't help you," you know. And... [GS: When was this?] This was in October. [GS: And you were applying for welfare?] For an emergency cheque. And they made me wait there from the morning, 8:00 in the morning until it was almost ready to close. And then... [GS: Really. And then they didn't give it to you?] No they didn't give it to me. So I called up my doctor and got a letter from him and I brought that down there. And that's when I ran into my worker. And she said... she was freaking. She said, "You're entitled to everything we have available here--you're entitled to an emergency cheque every month until you're on Family Benefits." She said, "You should have been on Family Benefits a long time ago." So she got... like I said, there's not many like her around. So I can imagine the people that had to go through what I had to go through, you know. It's a lot of stress. And when some people are sick, they can't sit in those offices for hours and hours.

How application forms are completed and managed can be a further source of difficulty for "hooking up" to income assistance. Long delays ensue when forms are filled out incorrectly. Sometimes this happens when PHAs are required to complete them alone without the assistance or guidance of 'case managers.' But this is not the only way problems with application forms arise. For example, we spoke with one PHA who had to wait months before getting Family Benefits Assistance because of a protracted conflict between his doctor and FBA worker over the "proper" filling out of his medical form. His situation was further complicated when his file went missing at the FBA office. These sorts of problems create more than delays. In order to be resolved, they often require ongoing communication with a welfare worker. As the PHA quoted at the beginning of this section noted, this can be extremely difficult.

"Hooking up" to income assistance can also be made difficult when PHAs apply under conditions of extreme illness. In addition to the problems described above, others, such as lack of proper identification or not having a stable address can further interfere with accessing FBA. What results are long delays in the process whereby applications are transferred from General Welfare Assistance to Family Benefits Assistance. For some PHAs we interviewed, this meant living on welfare rates for six to eight months before accessing FBA. Under these conditions, many fall behind in rent and lose a place to live. Even under higher FBA provisions, many PHAs have difficulty making ends meet. Funding cutbacks

which have eliminated many services formerly available through the Special Assistance Program have only made matters worse. In the end, the health of PHAs suffers as they find it hard to maintain healthy diets, use nutritional supplements and other therapies not covered under their drug cards, or find clean, safe accommodation.

In order to alleviate the procedural and organizational barriers to accessing income assistance and to facilitate access to adequate levels of income support for PHAs, it is recommended that:

- 4.1 The two-tiered character of income assistance programs in Ontario should be eliminated.
- 4.2 On-site intake for income assistance should be established at HIV clinics and AIDS service organizations and applicants should be processed regardless of the district to which they might normally report.
- 4.3 Relevant application forms should be kept on-site at physician's offices, HIV clinics and AIDS service organizations.
- 4.4 Drug cards should be made available to PHAs and others living with catastrophic illnesses who do not have private health insurance, so that they are not forced into the social service system in order to access drug treatments they cannot afford.
- 4.5 The provincial government should support current provisions for supplementing income from Family Benefits Assistance by establishing an employment program for PHAs. This program should provide part-time jobs with AIDS service organizations, or other employers, for PHAs who are able and want to supplement their income.
- 4.6 For PHAs, the medical determination of disability should not be restricted to an AIDS diagnosis. Significant numbers of people become seriously ill from HIV infection with, for example, fatigue and are unable to work.
- 4.7 Government workers should be trained in HIV/AIDS and in working with PHAs.

5. All PHAs Should have Access to Appropriate Housing

The housing conditions under which PHAs live dramatically shape the character of their daily lives. Housing establishes a foundation for daily living. It forms the immediate social and physical context within which PHAs come to organize their lives. The PHAs we interviewed lived in a range of housing situations. Some found housing in contexts that helped them maintain their physical and emotional health and access community-based and other support services. Others were less fortunate, living for extended periods of time in inadequate housing from which it was difficult simply to keep "body and soul together." The social locations of PHAs partly contributed to the housing difficulties they experienced. However, these difficulties also emerged as a

consequence of how housing was organized. For example, admission to housing was established through procedures which produced certain groups of PHAs as 'unsuitable tenants,' or 'hard to house,' and as such, ineligible.

The importance of housing for organizing daily life, maintaining health and facilitating "hooking up" was made clear in our research by PHAs who spoke of how their lives changed when they entered improved housing situations. For example, one woman living with AIDS told us how her life became better when she was accepted into a downtown co-op that was located closer to her physician and the community-based services she was using. Prior to acceptance at the co-op she had been sharing a bachelor apartment with her mother and brother, where she slept on the floor.

Another PHA we interviewed spoke about renting space in a privately owned townhouse. Over the six months he lived there, the rent increased by two hundred dollars. When additional tenants moved in, the character of the house changed. Parties were held constantly, there was a lot of violence and drug use and he feared for his safety. He was only able to "get his life going" after moving into his own apartment. Here, he developed a close relationship with his neighbours who became important sources of emotional and practical support.

In a final example, an HIV+ youth we interviewed spoke of his circumstances as radically changed after moving into supportive housing. Previously, he led what he referred to as the life of a "gypsy." He was continuously on the move and lived alternately on the street, in hotels, rooming houses, hostels or with friends or lovers. He described supportive housing as a place which provided him stability and assistance in "dealing with HIV seriously." As he described it, he no longer had to worry about being on the street, about being too cold at night or waking up sick and alone. With the help of workers at the house, he was able to bring his drug and alcohol use under control and to "hook up" to a range of community-based support services.

While the PHAs noted above were able to make changes in their housing, a number of others we spoke with were less fortunate. Their social locations were such that they lived for long periods of time in inadequate housing and had few options for changing their living situations. For some, unsatisfactory housing was not a new problem, but one they experienced well before their HIV infection. In many instances, it went along with unstable or poorly paid employment. The social locations of others involved a cycle of drug use, crime and continual movement in and out of correctional facilities. Under these conditions, PHAs were unable to maintain stable homes. Overzealous policing and limited access to drug treatment centres and supportive housing perpetuated this cycle and hampered their efforts to change their lives.

Other PHAs were socially located in ways that made it difficult for them to connect with gay AIDS service organizations or the downtown lesbian and gay community in general. As such, knowledge about housing options that circulates in these sites was unavailable to them. They also were unable to use 'case management' services which facilitate "hooking up" to government-subsidized and supportive housing. Under these circumstances, many could not find improved housing. Others had to wait long periods of time for better housing, in some cases over a year.

The housing problems experienced by PHAs also stem from difficulties in the organization of social services. For example, many PHAs we interviewed were pushed into inadequate housing situations after they stopped working. The transition from work to income assistance often involved drastic and stressful changes in life circumstances. Faced with greatly reduced incomes and little time to adjust, many could not maintain their homes or find clean, safe alternatives.

The organization of housing also produces problems for PHAs who need a place to live. Provincially subsidized housing and supportive housing are both set up in ways that exclude certain groups of PHAs from being housed.

In Ontario, access to provincially subsidized housing is organized through a set of three interrelated processes: the determination of eligibility, procedures for deciding whether applicants will make 'good tenants' and the accumulation of points on a points system. Individuals who are 16 years of age or over and who are Canadian citizens, landed immigrants or refugee claimants are eligible for provincially subsidized housing. Applicants are selected for housing vacancies from a waiting list, on the basis of points they accumulate on a point-rating system. Points are scored for income, current rent, current housing conditions and other factors.

Intervening between these two processes are procedures for determining whether applicants will make 'good residents.' It is in these latter procedures that the local housing authority acts in ways most similar to any other landlord. Deciding whether applicants will make 'acceptable tenants' is a process rooted in landlord-tenant relations. It is also the procedural site of the exclusions faced by PHAs who wish to "hook up" to provincially subsidized housing.

The most important criteria used for deciding whether applicants will make 'good tenants' is their ability to 'cope on their own' or 'live independently.' These latter judgments are, in part, formulated on the basis of information provided by applicants, or included in their housing applications and accompanying medical forms. Evidence of drug use, sporadic tenancies, having no fixed address, or a history of psychiatric care can all enter into the production of an applicant as suspect. Suspect applications are met with a course of action that can include reviews, appeals and rejections. During this process, applicants considered unable to 'cope on their own' are obligated to produce evidence to the contrary. This is possible only for PHAs who are well-connected with a range of agencies that can provide letters of support or other interventions that help establish their suitability as tenants:

EM: You said before that things are stressful in your place.

INT: Yeah, we don't have enough space. And most of the space--I can't get [provincially subsidized] housing because I owe them money. But I was talking to somebody at a women's drop-in centre, and what they're going to do is give me an application. I'm filling it in but I think I have to wait 'till my counsellor comes back because I need a support letter from him. I need a support letter from a whole bunch of people. Then they're going to put it in and they're going to see if maybe the government will give me a place and then let me pay them so much a month that I owe them. And more than likely they're

going to turn me down. But if they turn me down, I'm going to fight it. [GS: But it's the drop-in centre that's helping you with that?] Yeah. I really can't blame [the AIDS service organization] really, because they did give me a form to fill out, but I never went back because at the time I was still fighting my addiction thing. You know, like now I'm more stable in my clean time. But at that time I wasn't, so I never went back with it.

The housing predicament faced by the woman quoted above was not uncommon among the PHAs we interviewed. Accessing provincially subsidized housing can be extremely difficult for PHAs who are street youth, homeless, ill, or who have crime, drug use or psychiatric histories. In some instances, these PHAs genuinely require forms of assistance not provided by subsidized housing. ASOs have responded to this problem by referring these PHAs to supportive housing. However, PHAs who live on the street, who are drug users, or who are otherwise considered 'hard to house,' face difficulties accessing supportive housing as well.

In Toronto, there are six supportive housing facilities which exclusively accommodate PHAs. Most are houses in downtown residential neighbourhoods that have been converted from private residences. They generally accommodate four or five PHAs and the rents depend on the income of residents. The support provided takes the form of counselling, often with an emphasis on life-skills and self-help. There is also some diversity in the forms of support offered by the various houses. For example, one of the homes focuses on accommodating people living with AIDS who are significantly ill and unable to live on their own. Others have developed programs of counselling and support around drug use. In addition to supportive housing there are two independent living facilities for PHAs in Toronto. One offers rooming house style accommodation; the other is a house with shared living arrangements. Both are designed to provide minimal support services to residents.

Shared living is an important part of how supportive housing works. It also produces serious organizational problems particular to this form of housing. The requirement of shared living shapes access to individual houses, as well as much of what goes on in them, including the work of staff. Supportive housing is by necessity a social environment. The PHAs who live there share space, typically kitchens, living rooms and bathrooms. They also share each other's lives. They talk with one another, share meals, negotiate the use of house facilities and, in general, live together in ways that people who live in any house do. At the same time, their situation differs from other cooperative settings in that they have not chosen to live together. Many are referred to supportive housing because they have no place to live. Often, they have experienced difficult and harsh conditions as part of reorganizing their lives in relation to HIV. These circumstances can all make living in supportive housing stressful. An important organizing principle of a house then, is ensuring that people get along or, as one housing worker we interviewed put it, 'keeping the house together.'

This is partly accomplished by staff who do the work of smoothing over relations between residents, preventing disruptions and so on. However, it is also established by procedures which shape entry into the house. Admission to supportive housing is often organized in such a way that new applicants must 'fit in' with existing residents. Entry can involve a lengthy process of interviews with staff, board members, and residents which screens out applicants deemed to be

'inappropriate.' While this preserves certain forms of continuity within the house, it can also work to exclude people who are 'different,' or seen to be 'difficult.'

These latter designations are produced in relation to the social character of a house and problems in staffing. Most of the residents of supportive housing for PHAs are gay. They share a commonality of experience from which can emerge a certain camaraderie or house culture which helps to 'keep the house together.' From this starting point, people who are not gay or who have other identities, experiences or social backgrounds become 'different.' Their inclusion in a house raises the organizational problem of integrating people from different social backgrounds into a communal environment. This problem is aggravated by staffing. Few supportive houses have on-site workers around the clock and most have limited staff support. This makes it difficult to provide assistance to those who do not have experience living cooperatively or who require ongoing support to control drug use or deal with other 'special circumstances.' We interviewed a worker from an AIDS service organization who told us about the problems these individuals can face accessing supportive housing:

GS: What happens to people who are HIV+ who are drug users. Where do they go?

INT: Well they go into [supportive housing]. But there's no answer to any of that.... I think it's going to be a huge problem especially since all of them [supportive housing] started out the same--that they would be taking the hard-to-house. After dealing with the hard-to-house for a while, now they want people with clean histories. Because they can't take on the problems any more.... They take clients that can cope for themselves. Who have treatable dependencies.... So I mean IV [intravenous] drug users and kids with these kinds of very unique problems are going to be more and more disenfranchised and isolated as we go along.

Shared living and limited staffing also produce illness as an organizational problem. For example, many of the PHAs we spoke with preferred not to live with residents who were sick, finding it stressful and a constant reminder of HIV disease progression. Most supportive houses also lack the resources to respond to the needs of PHAs who are ill or become ill during their residence, particularly those with dementia.

In general, housing for PHAs is set up according to criteria of successively reduced ability to 'live independently.' But the nature of HIV infection is not predictable or stable with respect to these criteria. While houses are designed to accommodate PHAs who fit particular criteria of autonomy, they are not set up to provide greater support as a PHA's need for care increases. This produces a housing system in which PHAs must continually find new places to live as the conditions of their illness change. In some cases, the problem is further aggravated by the funding requirements of housing projects which limit the forms of support they can provide.

These various organizational problems often mean that supportive housing is a restricted option, available primarily to PHAs who are white, gay, male and relatively healthy upon application. As organizational problems, they are joined by others, discussed above, relating to the social locations of PHAs

and the organization of housing and social services, to force many PHAs into housing that is unsafe, unclean and unhealthy.

For some of the PHAs we spoke with, this meant staying in cramped, dirty rooming houses without cooking facilities. Others were forced to live in hostels where residents were openly homophobic. Under these circumstances, most were afraid to be open about their HIV+ status. They were also burdened by regulations requiring residents to leave the hostel during the day. Others experienced housing problems when they were taken advantage of by unscrupulous roommates or landlords in the private housing market. At times, some PHAs we interviewed had no recourse but to live in bath houses or on the street, even during periods of illness.

In order that all PHAs may live in housing that helps them maintain physical and emotional health and access the support services they need, the following changes in the organization of housing are recommended:

- 5.1 The provincial government should establish an emergency housing fund for PHAs who are making the transition to social assistance. The fund should provide temporary financial support in order to prevent disruptions and losses of income that cause PHAs to lose their homes. It should be designed to provide PHAs sufficient time to find alternative, affordable housing.
- 5.2 The provincial government should establish a program of portable rent subsidies for PHAs in order to increase their housing options and to help them maintain adequate levels of housing.
- 5.3 Emergency interim housing should be established for PHAs including street youth, homeless people and drug users who have no recourse but to stay at hostels, bath houses, crack houses or on the street when in need of housing in critical situations.
- 5.4 Hostels should be made safer places for PHAs by:
 - a) Establishing and enforcing procedures for dealing with residents who harass HIV+ and gay residents.
 - b) Permitting PHAs and other residents who are ill to stay in hostels during the day.
 - c) Improving mechanisms for maintaining confidentiality with respect to the HIV status of residents.
 - d) Providing regular HIV/AIDS training to hostel staff that includes information about "hooking up" to social services, health services and AIDS service organizations.
- 5.5 More research investigating the organization of supportive housing for PHAs should be conducted. This research should examine how supportive housing works. Its purpose should be to develop models of housing that respond to the varied needs of

PHAs. It should address issues such as cooperative living, procedures for admitting prospective residents, how funding shapes and limits the provision of support in supportive housing, staffing, how houses are managed, how architectural design influences the social environment of a house, how a house responds to illness, how people with different social backgrounds get along, etc.

- 5.6 The provincial government should fund the establishment of HIV/AIDS supportive housing for Native peoples; women, particularly those with children; street youth and PHAs who are ill, particularly those with dementia.

6. The Wishes of All PHAs Who Want to Die at Home Should be Met

Our research revealed home care to be the most complex and troubling of all social services for PHAs. The difficulties PHAs experienced "hooking up" to home care had many sources. For example, since access to home care is triggered by a decline in health, PHAs were at their most frail when "hooking up" to this service. Their problems with home care services also stemmed from how these services were organized in relation to the social locations of PHAs. As we mapped out the work of "hooking up" to home care, our attention was directed to a number of concerns in this regard. These included: the cost of health care; how hospitals work, especially the procedures for discharging patients; how support networks including lovers, family and friends and for some gay men, the lesbian and gay community provide help with "hooking up" to home care; how both the housing a PHA has and his or her income affect the "hooking up" process; and lastly, the actual organization of the Home Care Program, particularly how eligibility for homemaking services works, the nature of assessments, the delivery of complex care and the difficulty of knowing how home care works. Two features that weave their way through these various issues are the wish on the part of many PHAs to die at home and the way class and sexual orientation provide the organizational context of "hooking up" to home care.

In the present era of government fiscal restraint, efforts at managing health care costs create problems for patients needing home care services. Inadequate funding forces managers of the Home Care Program to at least try to hold the line on expenditures. Under a fiscal regime such as this, the regulation of entitlement and eligibility and the work of assessing patient needs work as standard mechanisms for "rationalizing" service delivery and holding down costs.

The use of these administrative devices can create "hooking up" problems for PHAs. For example, they are often the source of institutionalized discrimination. We are thinking specifically of systemic discrimination against disenfranchised people. These include: the working poor, homeless people, street youth, drug users, Native peoples, immigrants and refugees and people who do not speak English. These people are often seen as 'difficult' or 'hard cases' by 'case managers' and government workers.

We are not suggesting that the various managers within the home care system purposely discriminate against these people. We found no evidence of

that. However, we did find that class differences permeated the work of home care assessment, advocacy and access. Disenfranchised PHAs who had someone prepared to advocate on their behalf fared much better in accessing home care than those who had to go it alone. An AIDS activist and PHA gave us the following account of getting home care, which he terms palliative care, for a friend of his:

INT: Same is true with my friend Serge, who died quite recently. He died about five weeks ago. He was told in November [that they could do nothing more for him].... [His doctor] told him to go on palliative care. He didn't even know what palliative care was.... [His doctor] said, go on palliative care. But he's obviously in no condition to do any of that arranging for himself.... He's lying there at home unable to do anything for himself, and he's supposed to find palliative care by himself.... I, once I got back on my feet again, I made some calls and then they did...

This account provides, in part, the organizational context of one PHA getting "hooked up" to home care. A major problem for him was that he did not know how to go about getting home care and was too sick to make the arrangements himself. He did not receive the necessary support to access home care from his physician and had to rely on a friend to help negotiate its bureaucratic complexity. How these difficulties come to organize his life and the choices open to him is an important part of his social location. His situation differs substantially from how a middle-class PHA and his partner went about arranging to get heparin paid for under the home care drug benefit plan (see p. 20-21).

Efforts to reduce hospital costs also affect PHAs' experiences of accessing home care. A nurse at an HIV hospital ward explained to us that, at times, PHAs find themselves caught between the rationalizing practises of hospitals and the Home Care Program. On the one hand, hospitals endeavour to quickly discharge patients; on the other hand, the Home Care Program more stringently assesses eligibility for its services. In another context, it was historically the case that seriously ill patients, who were home alone, were transferred to hospital. Today, however, home care agencies have relaxed these procedures, resulting in consenting ill PHAs being left alone at home. Also, hospitals usually expect PHAs with no hope of recovery to go home to die. These policies work to get people out of hospital. However, they create serious problems by transferring the burden of caring for PHAs to lovers, friends and family members. One person we talked with told us about bringing his partner home from the hospital:

INT: Well, even actually before we get to home care, one of the things that has been problematic for me is the... how... I mean home care begins when you get out of the hospital. For me, at least at [my hospital] and I'm not sure if this would be any different anywhere else, how they deal with people in terms of introducing the home to home care. There's,... like there's no real preparation. It's, it's just very, very abrupt, pardon me, I'm on morphine... [GS: Oh, that's alright.]... looking for words... [GS: Take your time.] Well, Brian's example. They sent for me and [the doctor].... He had tried everything within his power and so [Brian] was sent home, there was no preparation, there was no....

They just told us, you know, essentially that you can take him home to die. I asked, since I was going to be looking after the care-giving work, what I should expect. He's certainly not the first person with toxo[plasmosis]. And uh, [they said] take it a day at a time. If I had known then what I know now about toxo, if someone had just sat me down. I was having a lot of problems finding printed material about it. [GS: You mean, what would be the course of the disease?] Yeah, you know, it does act like a series of strokes, those kind of things. My own assessment of the care, and what I needed to prepare for would have been so much more informed and I could have anticipated some of the nightmare. I could have understood more at the time.

While this quote reveals the problems produced by certain hospital discharge practices, it also shows how the success of home care relies on the unpaid support of lovers, family members, community volunteers and friends. At best, the Home Care Program covers only a portion of a PHA's care. This is a particular problem for PHAs who require around-the-clock attention. Middle-class PHAs with long-term disability insurance can afford care in addition to that paid for by the province. In fact, these individuals were the only people we found who can die comfortably at home. The rest of the PHAs we interviewed had to rely on their own support networks. They depended on friends, lovers, family members and AIDS service organizations to provide attendant care. This involves food preparation, help with eating, changing diapers and dressings, giving medications, help with going to the toilet, making beds, help with intravenous infusions and so forth. This is the invisible, unpaid work of home care.

In our interviews with PHAs, we found that many had difficulty creating and maintaining the kinds of support networks required for assistance with home care. For example, a number of PHAs we talked with had recently moved to Toronto in order to have better access to medical treatments. While this seemed like a good idea early on in their infection, in the end, moving to Toronto often left them without the personal support networks they needed when they became seriously ill.

Class relations were also important to PHAs' personal support networks. Homeless people, for example, or former drug users who left their friends to go "clean" because they were HIV+, or street youth who were left behind by their sex-trade friends once their health began to decline, often had little in the way of personal support. These people were targeted for supportive housing. However, these agencies often brought together individuals with little in common except for their HIV infection. We are not saying that poor people do not have friends or friendship networks. Rather, what we want to point out is how these networks, often for reasons related to income and housing, are more fragile than those of middle-class individuals.

Class relations also shaped the types of assistance that families could offer PHAs in need of support in the home. Usually, middle-class families gave more support than poorer or more marginalized families. Often, this was simply because they had more resources. Families that could, often provided a place to live, while others gave financial support or took over the care of the children of PHAs. Of course, some PHAs we interviewed were estranged from their families, often because of homophobia, AIDSphobia or the stigma of drug use,

along with any number of usual reasons. As we have discussed earlier, some of these PHAs found it virtually impossible to tell their family or friends about their HIV status.

In addition to class relations, networks of support for PHAs were also organized according to sexual orientation. There are important differences between the resources gay PHAs bring to managing home care compared with their heterosexual counterparts. Heterosexuals generally have to depend on their families for home care support. In comparison, gay PHAs often get support from lovers, friends and families as well as from the infrastructure of AIDS service organizations of the lesbian and gay community. Care teams doing palliative care are an important part of this support.

Friends, lovers and others who come to care for PHAs in the home often do so at a great cost. Managing home care for someone who is critically ill, and very often dying, is not easy. Part of the problem stems from the complexity that arises in coordinating the work of many people and the supplies and equipment that PHAs need. Often, there are turnovers in staff or supplies run out. This means that PHAs or their care-givers must continually orient new home care personnel to their homes, with all the lost privacy that this necessitates.

A further problem in the organization of home care is the way access to homemaking is linked to eligibility for professional home care services under the Home Care Program. Homemaking includes housekeeping and practical assistance with daily living, often referred to as attendant care. Professional home care services include those provided by nurses, occupational therapists, social workers, nutritionists and speech therapists. Often, what PHAs need most is some form of homemaking. For instance, they may be frail or have extended bouts of fatigue. In these situations, they would not need nursing, but would require assistance with housekeeping. However, at the time our research was conducted, such assistance would not be available to them through the Home Care Program. Under its regulations, only those requiring a professional service are eligible for homemaking. This provides an example of how the medical model's organization of eligibility for the Home Care Program runs up against the needs of PHAs.

Problems with home care assessment extend to the procedures used to evaluate the health status of PHAs. Time and again, we heard how evaluation procedures failed to take into account the rapidly fluctuating nature of PHAs' health. A Native health worker we interviewed described for us her experience of securing an adequate level of care for a Native PHA:

INT: Okay, then it was a question of trying to find him housing because he was just kind of up in the air. He really didn't--he hadn't been able to work for a while because he was sick. And he didn't have a place to stay. And so he managed to find.... he ended up in a house with HIV--special needs--people with HIV.... So he was able to... [GS: Was this especially for Native people?] No, no. So he was able to get a room in that place. Then we had to create a support system around him because he didn't want to die in hospital. And he didn't really want to go to [an AIDS hospice]. He REALLY wanted to die at home. And home to him was where he had gotten his room. So what we had to do was to create a whole team that were able to take care of him

at home. Then we had to try and find ways of getting health care--more professional health care--like home care for him. And it was a REAL struggle and it was a REAL nightmare. Because Home Care would come in and they'd come in on a day he was feeling great and looking good and they'd say, "No we judge that he doesn't need more than one day of home care." And then maybe the next day, he'd have a bad day and he'd wake up and he wouldn't be that lucid and it was really difficult. And then we'd have to start that whole process over again. I don't know HOW many times we had to go through that whole process of evaluation and working with the coordinator. And she was saying, "Well my nurse said that he looked fine and all I can go on is her evaluation and her assessment." So it was constantly going through--working through the system.

This account shows how the assessment of a person's eligibility for home care is on-going in a way it is not with, for example, income assistance. This means that advocacy around home care also has to be on-going. The PHA whose situation is discussed in the above quote was fortunate to have an advocate working on his behalf. During our study, we discovered that community-based agencies do less systematic advocacy work for PHAs around home care than around other social services. So, unlike income assistance programs and subsidized or supportive housing, PHAs are more or less left to their own devices when negotiating home care.

The above account also demonstrates the importance of housing for accessing home care. Organizing a care team and managing ongoing access to home care was only possible for the PHA discussed above once he had secured stable housing. For some PHAs, having a home to die in can be extremely problematic. We have in mind the homeless PHAs living in hostels we interviewed, the Native woman we heard about who died in a women's shelter and a street youth who lived at various gay steam baths until he became acutely ill. He was then admitted to hospital where he died shortly thereafter. For this person, and for many others like him, a hospital often becomes the last in a series of homes of last resort.

A final organizational problem faced by PHAs and their care-givers concerns knowledge about how home care works. Part of the difficulty stems from the complex nature of home care. For example, the Home Care Program offers various types of services as well as a range of medical devices and equipment, it provides different levels of care and there are many types of staff, it has a unique terminology of categories, a range of assessment and evaluation procedures and a multi-level bureaucracy. PHAs and their care-givers can often be overwhelmed by this complexity. Matters are made worse by the tendency for home care staff to offer minimal explanation of how the service works, the dearth of written information and the minimal home care 'case management' available at the community level.

It is also true that many care-givers do not know what to expect once they have "hooked up" a PHA to home care. They are often unaware of the full extent of work involved in caring for a PHA at home or how to go about doing it. This can make caring for a person at home very stressful. Indeed, we heard of one woman who had a nervous breakdown as the result of caring for her brother. One man we talked with, who acceded to his partner's request to die at home,

lost his job because of the demands made at home on his time and energies.

Problems in knowing how home care works extend beyond PHAs and their care-givers to include community workers, social workers and doctors. For example, we found that many of the professionals we interviewed did not know that Metro Social Services provide homemaking without first having to be eligible for nursing care or another professional service. Similarly, as noted earlier, we found that most of the people we talked with could not tell us what complex care is. We got conflicting accounts from virtually every care-giver, lay and professional alike. "Hooking up" to complex care seemed to arise out of how entitlement and eligibility are interpreted, as well as how assessments are carried out. In our view, much of the confusion over complex care came from people not understanding how home care services are financed and organized.

In order to relieve the organizational problems faced by PHAs, their care-givers and others involved in managing ongoing access to home care for PHAs, it is recommended that:

6.1 Within government:

- a) Eligibility for homemaking services should not be contingent on a PHA's need for professional services.
- b) Assessment procedures for home care should be modified to take into account the fluctuating health status of PHAs. Assessment must be organized in ways that do not miss a decline in the health of PHAs.
- c) Home care intake procedures should be improved so that potential users are fully apprised of the services and levels of care to which they are entitled at the point of application. These procedures should include the provision of explanatory written material to all PHAs.
- d) Support for care-givers of PHAs should be facilitated by establishing:
 - A program of income support similar to maternity leave, paid for and administered by the Unemployment Insurance Program. This program should be restricted to the primary care-giver designated by the PHA.
 - A program of respite care for care-givers that includes support both in and out of the home.
- e) More funding should be provided to expand palliative care facilities for PHAs.
- f) More funding should be provided to establish long-term, chronic care facilities for PHAs (see recommendation 5.7).
- g) Pay scales be adopted that will attract a stable, better trained homemaking staff.

6.2 Within community-based organizations:

- a) Programs of practical assistance should be expanded so that advocacy and 'case management' services around home care are as developed and effective as those for other social services.
- b) A manual on accessing home care should be produced (see recommendation 3.1).

Other Institutional Sites of "Hooking Up"

Recommendations in this section are based on how HIV clinics, drug treatment centres and prisons are involved in the process of "hooking up" to social services. While these organizations have obvious differences, they are all sites where work that mediates PHAs' access to social services is carried out. We draw attention to problems in how these organizations work. Remedies are suggested to help transform them into better sites of facilitation for PHAs who are "hooking up" to social services.

7. HIV Clinics Should Become Better Sites of "Hooking Up" for PHAs

HIV clinics are important sites of "hooking up" for PHAs who do not access AIDS service organizations of the lesbian and gay community. For heterosexuals, particularly those from ethnocultural communities, HIV clinics are often the only AIDS-related organization with which they are connected. In most cases, the routes they follow in "hooking up" to HIV clinics are exceptionally difficult. Some have highly negative experiences with HIV antibody testing. Others are virtually abandoned by family doctors who have little knowledge of AIDS or who refuse to provide medical care. Few have access to forms of support and knowledge that can help make living with HIV/AIDS easier. Instead, they must make their way under conditions of extreme stigma that can produce unbearable stress and social isolation.

HIV clinics differ from other places where PHAs "hook up" in that they are sites of professional work. Most HIV clinics are staffed by teams of professionals that typically include tertiary care physicians, nurses, psychologists, social workers, psychiatrists and dietitians. Within the clinic setting, the work of "hooking up" clients to social services is done primarily by social workers. Their work, like that of others at the clinic, is shaped by professional relations. The most important way this takes place is in the constitution of social work as therapy. 'Case management,' in this context, has less to do with coordinating or organizing the process of "hooking up" PHAs to social services and more to do with managing their emotional and psychological states. This can involve a range of procedures such as examining 'psychological histories,' assessing 'coping styles' or evaluating 'personality characteristics,' which are used to categorize certain PHAs as potentially 'dysfunctional' or 'unable to cope.'

While social workers at HIV clinics do some routine facilitation of "hooking up" for their clients, for the most part, they rely on an AIDS service

organization to provide this form of 'case management.' As one clinic social worker we interviewed told us:

INT: I make a fair amount of use of [an AIDS service organization] and their benefits counsellors because I think they do a very fine job. They're very good advocates for people and they have all these sort of inside numbers at the welfare office. I have a few of them but I don't have the contacts that they do... So actually for more difficult cases, or cases where I've had some problems with just your standard referral to social assistance, I quite often refer people there. And they'll help people out that have been having problems. I also sometimes refer people there for help with housing because I'm... they sometimes know about co-ops and things that I really don't know about.

"Hooking up" clinic 'clients' to social services through referral to the AIDS service organization noted above creates problems for PHAs who are unable to access ASOs of the gay and lesbian community. As noted earlier, many in this situation are heterosexuals who belong to ethnocultural communities. In many instances, they do not speak English. While clinic staff work hard to provide translation, they are limited in their efforts by the absence of well-trained on-site interpreters. As such, translation is often uneven and organized at the last minute. It is usually provided by other hospital staff who speak the language in question, but who have no specialized knowledge of AIDS or its terminology. These basic communication problems only add to difficulties in "hooking up."

In order to improve access to social services for PHAs who use HIV clinics as a primary site for "hooking up," it is recommended that:

- 7.1 HIV clinic social workers should conduct detailed assessments of the social service needs of their 'clients' as part of their intake procedures and ongoing evaluations. Moreover, their job descriptions should be modified to reflect the importance of the work of "hooking up" PHAs to the social services they need.
- 7.2 PHAs from ethnocultural communities and other HIV clinic 'clients' for whom access to AIDS service organizations of the lesbian and gay community is problematic should be referred to a parallel system of 'case management' and advocacy (see recommendation 2.1).
- 7.3 HIV clinics should make professional interpretation services available to all PHAs who need them. Interpreters should be trained to advocate on behalf of clinic 'clients.'

8. The Conditions Under which PHAs Living in Prisons "Hook Up" to Social Services Should be Improved

Most of the PHAs we interviewed who had lived in prison were men and women convicted of drug and prostitution offenses. Some had stayed at city jails, others at provincial prisons. Many of the people we spoke with experienced a cycle of repeated brief stays; others were in prison for longer periods. Some

were ill and using treatment for their HIV infection, others were not. While their experiences varied with these conditions, most encountered overwhelming problems with their daily lives while in jail and "hooking up" to social services was difficult upon their release.

For many of the people we interviewed, prisons were unsafe and dangerous. The basic conditions of prison life often represented an extra burden for PHAs. One man we interviewed spoke about the stress and health risk involved in living in cramped prison conditions:

INT: ...when you're HIV+ too and you go to jail there's so much tension. And you know, you're always--are people going to find out? And there's fights all the time, you're crowded, I mean there's three people in one cell designed for one. You know, there's one on the floor with a mattress, and two in a bunk. You have to share everything, and there's like, it's so overcrowded. Like these ranges were built for ten people. There's thirty people living in them, you know what I mean? There's only two picnic tables and one washroom during the day. You're locked out of your cells from seven in the morning until ten at night, with nothing but just cement to sit on. You have an area, a closed area with a lot people, so you're, we're open to whatever's going through there. Whatever kind of sickness, you know, colds and all this stuff. And your nerves are shot.

An important source of the tension and "shot nerves" experienced by the PHA quoted above, was his concern over the consequences of his HIV+ status being known within the prison. This is a dilemma faced by all PHAs who know they are HIV-infected upon entering prison. The decision to reveal one's HIV status is often tied with the question of whether to request medical treatment for HIV infection. Those who do not reveal their status are left without access to treatment, but can be spared HIV-related mistreatment and abuse from prison workers and fellow inmates. Those who choose to reveal that they are HIV+ in order to receive medical care may be provided access to basic forms of treatment. At the same time, they are left to face the consequences of a prison system in which knowledge of an inmate's HIV+ status is regularly exchanged between and among health care workers, guards, and inmates.

Disclosure of HIV status, however, does not guarantee access to appropriate medical care for PHAs in prison. For example, we interviewed one man whose HIV+ status was known to prison officials and who had been receiving methadone for his heroin addiction prior to his incarceration. Against his own wishes and despite the efforts of his primary care physician to guarantee access to treatment, he was forcibly removed from methadone while in prison. He subsequently experienced severe withdrawal symptoms including excruciating pain, dramatic weight loss, seizures and anxiety attacks, inability to sleep and blackened eyes. At another point during his stay in prison, this same man, known within the prison to be living with immune-compromising HIV infection, was locked in solitary confinement for over a week.

The problems that PHAs experience in prison are made all that more difficult by the lack of knowledge about AIDS that is characteristic of prison settings. Not only does this contribute to the abuse of HIV+ inmates, but it has serious consequences for "hooking up." PHAs living in prisons do not have the

same opportunities to learn about how to live with HIV infection as PHAs on the "outside." Depending on their social location, the latter are able to connect with other PHAs and AIDS service organizations, which are important sources of support and knowledge about living with HIV and "hooking up" to social services.

PHAs in prison rarely have these types of opportunities. Instead, they often live under conditions of extreme stigma and in contexts where prison staff are rarely equipped to provide either emotional support or practical assistance with "hooking up" to the resources they require upon release. Once they leave prison, many face the additional burden of active discrimination from social services or run up against services which are not organized to meet their needs. This is particularly true in the case of housing.

Even those PHAs who become connected with AIDS service organizations or other community-based organizations prior to entering prison have difficulty maintaining regular contact with them over time. An important part of the problem is a cycle of repeated incarceration that disrupts their relationships with AIDS workers and sets back the latter's efforts to "hook up" their 'clients' to social services. As one worker told us:

INT: Jail by far is the worst hindrance to us because so many of our clients go to jail for prostitution charges. It's such a waste of time to send them to jail for prostitution charges. I just don't think that they should be sent to jail anyway for prostitution. But the justice system just isn't understanding--especially for someone that's HIV+ that we deal with--that when you're working on all these issues and you're trying to get them housing and you're trying to get them drug treatment and you're trying to work on the issues, if they send them to jail for four months, that all goes out the window. We just have to start all over again at the beginning. And we have clients that go through that cycle every eight or nine months. I mean we do this thing; then they go to jail; and then they come back; and we do it again; and then they go to jail; and then we do it again; and then they go to jail. And that's the pattern.

The repeated cycle of work noted above involves not only accessing drug treatment and housing, but programs of income assistance as well. Upon entering prison, PHAs and others receiving income assistance are typically cut off and, in order to regain access, must reapply after they leave. This creates needless work and delays in receipt of assistance for PHAs who, upon release, may already be facing illness, financial hardship, unstable housing and other problems.

These disruptions in income assistance can be further complicated by jurisdictional disputes. For example, we interviewed one PHA whose application for Family Benefits Assistance was initially not processed because he was living in a bail house. FBA officials viewed him as a ward of the Ministry of Correctional Services and, as such, did not wish to provide him assistance. Only with extended advocacy on the part of his physician and others did he receive an FBA comfort allowance and a drug card, which he required in order to access the treatments he needed.

In order to improve the conditions under which PHAs living in prisons "hook up" to social services, it is recommended that:

- 8.1 Procedures should be established so that PHAs receiving Family Benefits Assistance prior to entering prison or other correctional facilities are entitled to maintain their comfort allowance and access drugs covered under FBA.
- 8.2 In view of the importance of doctors for "hooking up" to social services, all HIV+ prisoners should receive medical care from HIV knowledgeable physicians and, that whenever possible, those who had HIV primary care physicians prior to entering prison should continue to have their medical care directed by this physician.
- 8.3 Prison staff as well as physicians and other health care workers associated with prisons should receive training about HIV/AIDS.
- 8.4 Appropriate discharge planning should be established in prisons and, in the case of PHAs, should include assistance with accessing income assistance, housing, proper medical care and, where required, home care.
- 8.5 Sentencing procedures such as compassionate relief from prison should be extended to PHAs convicted of minor offenses. Without this change, months of work with counsellors around drug use, health maintenance, access to housing and income assistance will continue to go to waste.

9. The Availability and Flexibility of Drug Treatment Programs for PHAs Should be Improved

INT: Okay, well I'm HIV positive... let me see. I'm HIV positive, I wasn't on welfare until I found out about this, right. Actually I found out in 1988 but I was a heroin addict and I continued to use the heroin. And I was in denial. I didn't want to admit that I had a problem and that I had HIV, so I just continued to use the heroin... I was dealing, stealing and doing a numerous amount of things, the only thing I wasn't doing was prostituting myself for money to buy the heroin... but I was just doing the thefts to support my habit, it was sick, it's a sickness and you'll do anything to get the heroin. Really it's pathetic what you become, you become a monster, right... And like I went all over the city looking for help, all over the place and I got turned away by everybody. And that's why I was just devastated, I couldn't get help and I wanted help. [EM: Can you tell us more about those places you went to?] First of all I went to a doctor in Parkdale... And I went to a place on Bloor street. I forget what the name of the place was and it was a thing I got out of the newspaper: treatment and addictions. Those places are just a gaff. They were just like "Sorry we can't help you, you're a heroin addict, we can't do anything for you..." And I went to a drug treatment centre. They told me there's a waiting list I'd have to go on... I

need help now! [GS: Yes.] Ya' know eight months down the road I'm gonna be in jail or I'm gonna be dead and I'm also going to be stealing thirty thousand dollars worth of stuff a week to support my habit.

The experiences of the woman quoted above were shared, in different ways, by many of the drug users we spoke with in our research. Most had used heroin, cocaine or crack and, at the time of our interview, had either stopped using or had brought their drug use under control. During periods when they were using, the context of their daily lives was such that the work of "hooking up" and looking after their health was extremely difficult to do.

Like the woman quoted above, many of the PHAs who used drugs, that we spoke with, were forced into crime in order to pay for them. This often meant spending endless hours stealing, hustling, dealing or doing anything that might bring enough money to pay for the drugs they needed. In many instances this led to a repeated and, at times, desperate cycle of getting money, getting drugs and getting high.

Engaging in crime also left these PHAs vulnerable to arrest. This often resulted in repeated prison terms during which any income assistance they might have accessed was terminated. Others lost their homes during their sentences, which only contributed to the kinds of shifts and disruptions in housing that they experienced.

For many, being high on drugs also meant that they did not have to "deal with being HIV-infected." As one woman living with HIV we interviewed noted:

INT: When you have an addiction and your addiction is active, you know, you might know things that you should be doing but you just don't want to do them. You know what I mean. If I'm using, when I'm using I don't want to spend time at [an AIDS service organization] or somewhere else, when I could be at home using. [EM: Yeah.] You know. It's the truth. I'm not proud of it, but that's the way it is.

PHAs' ability to attend to their health was also made difficult when using. While many felt "wonderful" when they were regularly high, these were also times when they might go for days without sleeping or eating. As such, many became ill or lost weight. The organization of access to medical care on the basis of scheduled appointments also meant that the care of a physician was not available to most. This problem also extended to social services, where additional organizational difficulties discussed earlier further complicated their ability to "hook up."

Many of the circumstances which made "hooking up" and attending to health difficult for the drug users we interviewed, changed when they stopped using or brought their drug use under control. For one PHA we spoke with, this involved connecting with an HIV primary care physician's office which offered methadone treatment. This office was staffed part time by a public health nurse who provided counselling and assistance in accessing social services to PHAs and other 'clients.' The office became an important base of support in the PHA's life. After connecting with it, the context of her daily life changed dramatically. She gained weight, began treatment for her HIV infection and her health

improved. She no longer spent most of her time trying to make money to buy heroin. She was given access to counselling and assistance in "hooking up" to AIDS service organizations. She also received support in connecting to social services and advocacy with legal problems she was experiencing.

All of this is not meant to present drug rehabilitation as a panacea for the problems faced by PHAs who are drug users. We are not suggesting that drug rehabilitation always works or that PHAs do not have negative experiences with it. Nor are we proposing that PHAs should be forced off drugs; nor that they are unable to access social services while they are using. What we do mean to emphasize is that the work of living with HIV and accessing social services is made easier when PHAs stop using or are able to control their drug use. For these individuals, access to drug rehabilitation has important consequences for the "hooking up" process.

The PHAs we interviewed experienced numerous problems accessing drug treatment programs. The dearth of such programs meant that many simply had no access or had to wait for months before they could enter. These delays often came at times when people were in desperate situations and needed immediate help.

Those who did participate in drug treatment programs often found themselves at odds with the therapeutic models used. For example, street youth often experienced difficulties with programs based on complete abstinence. This requirement did not correspond to the forms of availability and use of drugs typical of their work and broader social locations. Abstinence often set up unrealistic expectations and a cycle of failure and re-enrolment.

Other PHAs spoke about the problems they experienced in support groups that were included in drug treatment programs. As part of the therapeutic approach to these groups, participants are required to disclose intimate aspects of their lives. For many PHAs this was not possible without revealing their HIV status. At the same time, the support groups rarely had other HIV+ participants. Worse still, facilitators often had little knowledge of HIV issues and, as such, could not provide emotional support or structure group discussion in ways that responded to the needs of HIV+ participants. One PHA we interviewed spoke about the experience of being at a drug treatment centre this way:

INT: It was sort of, there were really, there were days that were rough because I know one of the guys there, he was freaking out when he found out that my friend [also at the centre] had it [HIV]. And he's going "Oh my God I'm in the same place." I got really angry and I started screaming at him saying "What the fuck!" "You think you're going to catch it from walking in the same hallway?" And then I go to my friend, "Wait, watch this, wait till I tell him I have it too!" But then, the way that worked out, the counsellor came and he took the guy. He had to leave cause he was creating a lot of problems, whatever. He was going out screaming at the counsellors "I'm going to the hospital," cause he didn't think he should be in the same place as people that had AIDS. And it's hard when you're sitting there and people don't know you have it and you hear all this negative stuff, you know, because they really don't know. [GS: So they'd be talking about it, you mean?] Yeah. Yeah. My friend got so fed up with all

that, that he went out and brought out all kinds pamphlets and stacked them up and he put all kinds of posters around.

In order to remedy the problems PHAs experience with drug treatment programs and to improve access to such programs so that the conditions under which they "hook up" to social services are improved, the following are recommended:

- 9.1 The provincial government should establish more alcohol and drug treatment facilities.
- 9.2 Within existing and newly created alcohol and drug treatment facilities, programs should be established which respond to the varied needs of PHAs. This should involve:
 - a) Using therapeutic models that do not force disclosure of HIV status or sexual orientation;
 - b) Introducing therapeutic models based on harm reduction rather than abstinence;
 - c) Establishing programs that are specific to, or take into account, the social location and identities of participants living with HIV/AIDS, including those who are Native, gay, women, people of colour, street youth, etc.;
 - d) Establishing programs that provide long-term support.
- 9.3 More methadone programs should be established in primary care doctors' offices and community health clinics. These programs should involve alternative treatment modalities.

IV. Closing Summary

This report examines how PHAs "hook up" to social services. Its purpose is to provide knowledge that can be used to improve how PHAs access the social services they need. The most important feature of the knowledge offered in the report is its grounding in the actual experiences of PHAs.

The report shows that contrary to the "official view" of "hooking up," accessing social services is a highly complex and social process. Investigating "hooking up" as a social process draws attention to the human effort and activity that go into accessing social services. In the context of AIDS, this approach emphasizes how "hooking up" is done by PHAs and by others in community-based organizations, health services, and government offices.

An important goal of the report is to make visible the work that PHAs do to "hook up" to social services. More specifically, the report shows how this work varies with the social locations of PHAs. PHAs follow different courses of action to "hook up" and face different barriers in accessing social services depending on their class, race, ethnocultural background, age, gender and sexual orientation.

The report identifies three main contexts in which barriers to "hooking up" arise for PHAs. The most powerful barriers originate in social relations that cut across the delivery of particular social services. These include the stigma of HIV/AIDS; access to community-based 'case management' and advocacy; and knowledge of how social services work. Without transformations in these relations, changes in access to individual social services will have a limited impact.

PHAs also face barriers of access to particular social services, namely programs of income assistance, housing and home care. The report highlights the problems produced for some PHAs whose daily lives run counter to or do not "fit" with the way social services are set up and run. An important focal point through which this disjuncture is "detected" and managed organizationally is the practices which establish eligibility for social services.

Lastly, problems in the organization of other institutional sites important for "hooking up" to social services also produce difficulties for PHAs. The report examines how HIV clinics, drug treatment centres and prisons are involved in the process through which PHAs "hook up" to social services. While these organizations have obvious differences, they are all sites of work that mediate PHAs' access to social services.

The report offers a strategy for action which deals separately with each of the three main social contexts where "hooking up" problems arise for PHAs. Goals are identified for each area along with suggested forms of action for levels of government in general, government agencies and AIDS service organizations.

As a whole, the strategy for action serves as a framework for responding to the difficulties and inequities that PHAs face in "hooking up" to social services. While it is based in research on the organization of "hooking up" within a large urban centre, many of its suggestions pertain to other areas of the country. PHAs, AIDS activists and others concerned with the conditions under which PHAs are able to live their daily lives should find in it a useful guide to action.