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LIVING WITH AIDS/HIV:

A PROVINCIAL STRATEGY

Brief to the Minister of Health

January 24, 1991

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EXECUTIVE SUMMARY AND RECOMMENDATIONS

AIDS Action Now! is a Toronto-based activist group that fights for equal access to high-quality treatment and care for People Living with AIDS/HIV. This policy paper outlines the key obstacles that stand in the way of health care and support that empower PLWA/HIVs:

- the high cost of drugs, unavailable services in so many parts of the province and other barriers to equal access to vital treatment, care and support;
- overpressured, inconsistent and inadequate standards of medical treatment and care;
- fragmented and inadequate community-based health and social services;
- the poverty, racism, sexism, and housing and other problems that make it so difficult for many PLWA/HIVs to take care of their health; and
- fundamental to all these issues, the lack of a coordinated and comprehensive provincial strategy on HIV.

The challenge of forging an equitable and progressive AIDS/HIV policy is not being met in Ontario; not because the resources are not available, but because of failures of strategy, policy and vision. We identify the policies and programs that can overcome these failures and call for significant changes in the scope and provision of treatment and care for PLWA/HIVs.

Action Plan

Some of the recommendations we make throughout this paper require immediate action. We have demanded that:

- All EDRP and HPB approved drugs be provided to all PLWA/HIVs free of charge under Ministry of Health programs.
- The ODB formulary be restructured at once to expand the range of people eligible for assistance, to include all HIV drugs as they are approved, and to cover a wider range of non-pharmaceutical treatments.
- The government ensure access to anonymous testing facilities across the province.

- The Minister appoint a new chief medical officer of health who will work with community groups to prevent HIV transmission and provide treatment to those who are infected.

- The government must commit itself to appointing people living with HIV and AIDS who are accountable to key service and activist groups to all boards and committees involved in AIDS and HIV policy. The government must immediately appoint more PLWA/HIVs to the Ontario AIDS Advisory Committee.

Others point to issues and problems that have to be addressed as soon as possible in consultation with the AIDS/HIV community. We have recommended that:

- Complementary and alternative therapies whose effectiveness has been demonstrated should be publicly funded.

- The Ministry of Health commit itself to ensuring that an adequate minimum spectrum of services and resources is available in every region of the province by January 1, 1992 and in every District Health Council by July 1, 1993.

- The government develop mechanisms to ensure the confidentiality of all HIV-related treatment and testing.

- The Minister of Health introduce the necessary legislative amendments so that reporting of the names of individuals who test HIV + to public health authorities is no longer mandatory.

- The Ministry of Health establish a working group to monitor and upgrade the education and training of health care professionals on HIV infection.

- The Ministry expand special funding for data collectors and other support services such as specially trained paraprofessionals and caseworkers to complement physicians with large HIV caseloads.

- The Ministry restructure doctors' compensation schedule for HIV patients to reflect the more intensive nature of HIV treatment.

- The Ministry of Health establish an HIV Standards of Care advisory and monitoring committee.

- The mandate of the HIV clinics be expanded to include the provision of experimental treatments.

- Extensive community consultation across the province must be a part of the HIV clinics policy and program review.

- The Ministry of Health increase funding for community-based HIV programs. In coordination with other ministries, levels of government and community groups, it should expand and coordinate services so that a comprehensive continuum of care is equitably available.

- In consultation with the HIV community and with such groups as the Ontario Advocacy Coalition, the government must ensure that advocates able to specialize in protecting the rights of PLWA/HIVs to health, social and community support programs are available to all who need them.

- The Ministry of Health fund pilot projects of community clinics that offer a comprehensive range of treatment, care and support services for PLWA/HIVs. The goal would be to concretely explore how the concept of a continuum of care could best work in practice.

- The government should move quickly to implement the SARC reform proposals.

Underlying all of these issues is the need to develop policy mechanisms that reflect the needs and interests of PLWA/HIVs. We recommend that:

- An AIDS/HIV Directorate should be established with the mandate, power and resources to coordinate the development of overall provincial policies for HIV, monitor all policy and programs and advise the government on directions for the future. The scope and resources of the OAAC could be broadened to become the community and technical advisory board to this Directorate.

- Policy coordinators and units should be established in each relevant Ministry. They must have the mandate and power to coordinate and direct Ministry policy and programs. This would mean that the authority of the existing AIDS coordinator in the Ministry of Health, for example, would need to be enhanced.

- Senior policy advisors in each Minister's office must be assigned responsibility for the development of HIV-related policy within the Ministry and for liaising with community groups.

- The Province fund an Action Conference of community activists, front-line providers and PLWA/HIVs in the spring.

- An Action Plan be developed out of this conference for

organizing and coordinating provincial policy and programs, to be released by September 1, 1991.

The goal of provincial strategy must be nothing less than ensuring that every PLWA/HIV has equal access to the full spectrum of needed services and the highest quality comprehensive care and treatment.

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Starting Points

What should the goals of public policy be in relation to the needs of PLWA/HIVs? A prior question is where do we draw this policy from? The most innovative, imaginative and effective programs have arisen out of the communities most affected by the crisis, especially the gay communities. The guiding principles of a compassionate and dignified public policy have been forged through the experience of hundreds of community groups and thousands of AIDS activists. These principles are:

- equal access to all needed services;
- comprehensive care and treatment for the full spectrum of PLWA/HIVs needs. This is best seen as a continuum of care that covers all PLWA/HIVs' changing and diverse needs and integrates health care counselling and services with other forms of social, accommodation, domestic, advocacy, psychological, emotional and legal support and services that PLWA/HIVs need in their daily lives;
- community involvement in the design, operation and evaluation of all services and programs; and
- above all else, respect for individual's decisions in planning their own health care. This means more than enhancing individual participation in their health care; it also means policy and programs dedicated to the empowerment of all PLWA/HIVs.

The key policy challenges facing the health care system follow from these principles -- how to ensure:

- rapid development and availability of drugs, treatments and therapies;
- consistent and high-quality standards of care and treatment that meet the full range of PLWA/HIVs needs;
- equal access to treatment and care regardless of how much money people have or where they live;
- that health needs are not contradicted by systemic barriers such as poverty and lack of housing, discrimination based on sexism, racism and homophobia, and lack of coordination between Ministries and governments.

These goals and challenges are not being met in Ontario; not because the resources are not available, but because of failures of strategy, policy and vision. In the following sections we identify the crucial barriers to people getting the care and treatment they need to live and outline policy directions and programs that will overcome them. Many of these barriers and demands were identified by PLWA/HIVs in a recent community forum AIDS Action Now! had in Toronto on provincial health and social policy and programs.

EQUAL ACCESS TO HIGH QUALITY TREATMENT

High Cost of Drugs

An increasing amount of research and accumulated experience has shown the potential of early clinical intervention. Beginning treatment early and aggressively, even before symptoms appear, can forestall the development of full-blown AIDS and alleviate associated symptoms and illnesses. The benefits of early intervention will likely continue to improve as a wider range of more effective drugs are developed.

A key principle of the health care system is universal and equitable access to the care and treatment people need. However, there is a significant danger that the benefits of accelerated care will not be equally available to all PLWA/HIVs because of the high cost of promising new drugs. Drugs are not normally covered under OHIP and not all PLWAs have supplementary health insurance plans through their employers. Even when they do, the costs can still be high: one person told our recent forum on provincial strategy that while his employment plan payed 90% of costs, his drugs cost some $2,000 per month.

The high cost of drugs and other treatments can have a devastating impact on many people. In effect, people are forced to make decisions about their health care on economic grounds; do they buy the drug they need to control their condition or do they buy the proper food that they need just as much? It is unethical that people must be faced with such dilemmas in a system whose formal goals are equity, universality and comprehensiveness.

The province moved quickly to include AZT under programs that provide treatments free of charge when it came onto the market. But it has not been so quick with fluconazole, which costs between $650-1,000 per month. PLWA/HIVs have had to pay these amounts individually; this has simply been beyond the resources of many who have had to turn to the PWA Foundation for financial support for the drug.

There is a pressing need for proactive policy here. It was known in advance when AZT and fluconazole would be approved. It is also well known that more and more drugs will be coming onto the market in the immediate future. It is equally well known that the high cost of crucial drugs, provided free to participants in experimental trials, will be a tremendous burden. The case of fluconazole is an emergency that should never have been allowed to develop; the more general problem of paying for vital drugs is a crisis that can be easily prevented.

Funding and approval decisions must not be made on a solely ad hoc basis. For a truly equitable and comprehensive health care system, crucial drugs to treat chronic and catastrophic conditions must be available free of charge. The only way to ensure equal access to life-saving treatments is for the government to ensure that all drugs for the catastrophic and chronic conditions faced by PLWA/HIVs are available free as soon as they become available. We recommend that:

1 **All EDRP and HPB approved drugs be provided to all PLWA/HIVs free of charge under Ministry of Health programs.**

One way that these drugs and other key treatments can be gotten into peoples' hands as soon as they become available is through the programs such as the HIV project at Sunnybrook Hospital. Other mechanisms for speedy and equitable distribution must be developed without delay.

We do not think people should have to rely on the Ontario Drugs Benefit program for the treatments they need; this in effect means that people have to become destitute before being eligible for this program. However, until the primary goal of full public funding is achieved, the Ontario Drugs Benefit program must be dramatically improved. The ODB approval process has two fundamental flaws. The time from a drug receiving its notice of compliance to being approved for the formulary is far too long. Secondly, the existing mechanism to fill this gap -- Section 8 exemptions -- are themselves needlessly slow and cumbersome. They take up an incredible amount of already overstretched primary care physicians' scarce time.

In addition, the ODB formulary simply has not been expanded quickly enough to include new drugs as they are approved and emergency and/or experimental release drugs. There are three key directions in which the ODB program for HIV must be restructured:

i) the range of people who are eligible for the program must be broadened -- it must not be restricted to only the most destitute.

ii) drugs have to be approved for the formulary far faster.

Ideally, a drug must be available under the ODB program as soon as it has received federal approval for distribution.

iii) the formulary has to be expanded to include non-allopathic treatments. For example, the nutritional supplement Ensure is used by many PLWA/HIVs, but is too expensive for those on low incomes. We do realize the general pressures to control over-medication and the escalating costs of drugs that have shaped the way in which the formulary has been restructured. But these particular concerns are not relevant for HIV-related conditions. This example again speaks to the need for condition-specific analysis of how to provide and fund treatment and care.

Getting promising drugs into the hands of the great majority of PLWA/HIVs who cannot afford to buy them must be the Ministry's highest immediate priority. We recommend that:

2 **The ODB formulary be restructured at once to expand the range of people eligible for assistance, to include all HIV drugs as they are approved, and to cover a wider range of non-pharmaceutical treatments.**

This of course, means that the approval process must be streamlined. We will come back to policy mechanisms that can guarantee more timely and responsive decisions, but one means should be an expanded mandate for the Ontario AIDS Advisory Committee.

Alternative and Complementary Therapies

A related barrier is the high cost of alternative and complementary therapies such as vitamins, Chinese medicine, massage and acupuncture. Large numbers of PLWA/HIVs use such treatments to good effect. This points to the need for a more flexible and comprehensive view of appropriate therapies and treatments. But these alternatives should not be available only to the affluent. As their effectiveness is demonstrated, they should become seen as part of the standard therapies that must be equitably available to all.

The Ministry must expand funding to include the wide range of appropriate and effective complementary and alternative treatments that PLWAs currently use and facilitate the evaluation of complementary and alternative therapies within the AIDS/HIV community. We recommend that:

3 **Complementary and alternative therapies whose effectiveness has been demonstrated should be publicly funded.**

Regional Inequities

We detail throughout this brief the range of services that must be available for PLWA/HIVs. Unfortunately, we simply do not know how available specialized expertise, resources and services are in the different regions of the province. We certainly do know that HIV primary care physicians, other relevant professionals, hospitals and other resources are heavily concentrated in downtown Toronto and that access in other areas is inadequate.

The key starting point is a census of available resources and an assessment of how well they meet PLWA/HIVs' needs. After there has been an enumeration of what minimum facilities and resources are required in the different regions of the province, a coherent plan for ensuring their availability must be developed. As always, this plan should be developed with PLWA/HIV and community participation. We recommend that:

4 **The Ministry of Health commit itself to ensuring that an adequate minimum spectrum of services and resources is available in every region of the province by January 1, 1992 and in every District Health Council by July 1, 1993.**

Minimum standards involve more than concrete services; access to information resources is vital as well. One mechanism may be to develop means of communication so that the resources of the treatment information exchanges in Toronto are available to PLWA/HIVs and their health care providers throughout the province.

Fear of Discrimination

A further key obstacle lies in the politics of AIDS. In the context of pervasive heterosexism at the best of times, considerably heightened by AIDSphobia and the equation of AIDS and gay, PLWAs and the HIV positive are extremely vulnerable to harassment and discrimination. The stigma of AIDS is so great and the spectre of discrimination is so daunting, that fear of being publicly identified as having AIDS or being HIV+ can prevent many from coming forward for the information, counselling and treatment that can save their lives and help prevent passing on infection. Policy and program development must recognize that fear of discrimination is an important obstacle to individual access to health care and to overall public health preventive campaigns.

Anonymous Testing

Anonymous testing, where the person testing is the only one who can provide the link to her/his test result, is a significant component of a public health policy that recognizes the health

care needs and priorities of people living with HIV and AIDS. We recommend that:

5 **The government ensure access to anonymous testing facilities across the province.**

As long-time advocates of anonymous testing, we would recommend certain conditions which must be in place for an anonymous testing program to be truly effective. These conditions include that anonymous testing be:

- provided with high quality pre-and post-test counselling in which informed choice is an essential component;
- widely available and equally accessible across Ontario;
- free of charge and not require the use of an identifying OHIP number for testing and counselling services.

While common guidelines and protocols for counselling and testing should help to ensure high quality services across the province, they must also be flexible enough to meet the specific needs of particular communities.

The best way to provide these services is in community-based organizations or facilities. The first step is to ensure that all existing STD, public health, reproductive health and other clinics provide anonymous testing and comprehensive counselling. The longer term goal should be to create a network of community-based clinics across the province that can be points of easy access for individuals to receive the information they need to get into the health care system.

To this end, we would also recommend that you draw upon the experience and expertise of Hassle Free Clinic staff, who have been providing these services for the past 5 years. You may know that a variety of health care professionals from across the province, and indeed from outside Ontario, have been consulting Hassle Free on how to establish and operate anonymous testing and counselling. It could be useful for the Ministry to formally retain them to act as consultants and trainers to other providers and facilities in implementation.

Protecting Confidentiality

Concerns about confidentiality have been well illustrated by the much publicized recent cases of people being tested for HIV antibodies without their knowledge and consent. Testing for the HIV antibody must always be voluntary and must be provided in such a way as to ensure fully informed choice and consent. Extensive pre-test counselling should be a necessary part of the testing procedure.

In general, the HIV antibody test has been the main focus of debate regarding confidentiality and reporting. However, there are other HIV/AIDS related tests such as the p24 antigen, CD4 and beta 2 microglobulin used in monitoring the immune system and response to treatment. These tests should also be governed by the same principles of confidentiality and fully informed consent.

There was considerable concern within the HIV community when it became known that the Ministry of Health intended to use the p24 antigen test to identify HIV+ people. The fact that this was occurring at the same time as increasing anonymous antibody testing was limiting the Ministry's ability to identify the HIV + was not lost on front-line providers and AIDS activists. This type of development must not be allowed to happen. There must be sound confidentiality protection for all treatment-related testing.

A wide range of tests are now an integral part of the treatment of PLWA/HIVs. This has a key consequence for confidentiality: in effect, particular drugs and tests and particular programs and centres identify people as HIV +. And, of course, OHIP is used for all of this, which ties these procedures to particular individuals. As the number of treatments for HIV continues to expand, the means of identifying PLWA/HIVs within the health system will also grow. Similarly, for those on private insurance plans, claiming for particular drugs such as AZT in effect identifies a person as HIV infected.

We recommend that:

6 **The government develop mechanisms to ensure the confidentiality of all HIV-related treatment and testing.**

In fact, the underlying basis of the fears that keep people away from the health care system can be addressed quite simply. HIV should not be a reportable condition. This will remove the concerns of surveillance and centralization shared by so many PLWA/HIVs. Those who are most at risk of infection and those who are afraid to have their names on government lists will come forward for testing and counselling sooner. The effectiveness of public health tactics of partner notification and contact tracing, where appropriate, will be greatly enhanced by PLWA/HIVs' increased confidence in the health care system. In practice at least, many public health authorities have come to recognize these benefits by no longer requiring physicians or clinics to report the names of those testing HIV +.

We recommend that:

7 **The Minister of Health introduce the necessary legislative**

amendments so that reporting of the names of individuals who test HIV + to public health authorities is no longer mandatory.

Once HIV is not reportable, the principles of confidentiality and fully informed consent can then simply apply to all HIV tests in the same way as any other medical procedure. Information can still be reported in non-identifying ways for epidemiological purposes.

Community Confidence

The government must do more than simply eliminate systemic and institutional discrimination, as crucial as this will be. It must also ensure public and community confidence in the overall health care system. Removing mandatory reporting of HIV + people will be a key contribution to this end. But, in fact the structure and processes of government policy making have themselves been a further important barrier. The experience and background of most key officials has been within the public health field, a perspective which emphasizes prevention of further infection as opposed to treatment and care for those already infected and ill. Nor has there been sufficient consultation with community groups on the priorities of Ministry of Health policy. The result has been dangerously little long-term policy planning on treatment and care issues within the Ministry. This has especially been the case for the growing number of women PLWA/HIVs.

The danger of inflexible and narrow views within the Ministry has been shown all too clearly by a number of wildly irresponsible statements from officials on quarantine, safer sex and anonymous testing. It is absolutely crucial that the public in general and those communities most affected by the AIDS crisis in particular have confidence in public health authorities. Unfortunately, this is not the case with the current Chief Medical Officer of Health for the province. We recommend that:

8 **The Minister appoint a new chief medical officer of health who will work with community groups to prevent HIV transmission and provide treatment to those who are infected.**

We have been pleased to see the useful policies proposed by the Ontario Human Rights Commission and the Information and Privacy Commissioner to protect confidentiality. These reports speak to the need for proactive government action to identify and then eliminate the roots of discrimination against HIV + people.

This government action against discrimination has to always take account of the specific situation and needs of women. For example, the reproductive rights of HIV + women, who could face pressure to have abortions or be sterilized, must be protected.

Social Barriers to Access to Health Care

In addition to the threat of discrimination, there are important communities and sectors of the population whose access to care is atrocious. First Nations' peoples have traditionally faced unequal access to health care in general; this is a particular crisis for the specialized care and support needed for PLWA/HIVs. The same can be said of the homeless, street youth and the very poor. The government should provide education, condoms, lubricant, dental dams and clean needles within provincial prisons and psychiatric institutions. HIV treatment improvements should include access to proven and experimental therapies, access to HIV physicians outside the institution, and training in HIV treatment for institution staff.

In all of these areas innovative policy is needed to provide care to those traditionally marginalized from the health care system. The Ministry should increase its support of community programs such as those of the Anishnawbwe health project. These examples also illustrate the complex non-medical barriers that exist to people getting the care they need. They illustrate a theme we will return to: the interdependence of public policy in relation to AIDS/HIV. The best medical care in the world will make little difference if people are too poor to afford proper nutrition or are homeless. And this highlights that the government response to HIV can never solely be a matter of health care policy.

STANDARDS OF CARE

While the previous discussion dealt with the issue of ensuring equitable access to needed care, this section explores what kind of treatment and care is needed to enhance PLWA/HIVs' health and quality of life. We identify a number of problems that must be overcome to provide consistently high-quality care and treatment.

Burn-out/Pressure on Primary Care Physicians

There are currently far too few doctors providing the great bulk of primary HIV care, and the pressure on those with large caseloads can be unbearable. At the same time, there are not enough physicians specializing in HIV work, especially outside of Toronto, and most doctors do not know enough about HIV illness.

All of this is much worse for women. Most physicians do not know how to diagnose HIV + women's particular conditions. There has not been enough research on the specific symptoms, progression of their illnesses and treatment for women living with AIDS/HIV. More generally, all care must reflect the diversity of women's specific needs and experience; this means providing services and

counselling in women's languages and cultures, and acknowledging lesbians in all programs.

Two directions are needed here: we must broaden the base of doctors who are able to provide basic care and increase the numbers who develop specialized expertise. The Ministry must take a proactive role in working with the professions to these ends.

Professional Education and Training

An important challenge is to improve the education of doctors and other health care providers about appropriate standards of care and accelerated care options. This involves both ongoing training and upgrading as well as initial medical education. In terms of the latter, what is covered in medical schools and residencies clearly varies a great deal. Toronto's Hassle Free Clinic staff have spoken to residency programs and medical students have done placements in the clinic. These examples are certainly promising; but they would appear to be fairly unusual. The Ministry could facilitate other schools and hospital programs taking advantage of resources in their area by providing lists of community providers and advocates and helping form contacts.

The best mechanism to identify gaps in existing medical education, problems in ongoing training and potential areas for development may be to establish some form of working group of community representatives, professional associations, the medical and other schools and the Ministry. As always this group must have significant PLWA/HIV representation. We recommend that:

9 The Ministry establish a working group to monitor and upgrade the education and training of health care professionals on HIV infection.

Innovative ways of encouraging physicians and other health care workers to take up HIV care must also be found. One possibility is to develop preceptorship programs in which those just moving into the field work closely with experienced HIV doctors. This can involve both an initial period of 'hands-on' training in the experienced doctor's practice and some form of ongoing 'buddy' system in which the beginning doctor can continue to call on the more experienced for advice and expertise. In this latter way, the tremendous experience amassed by current primary care physicians can be used as a resource to develop new doctors. In terms of the first issue of direct training, we understand that some form of preceptorship program is being considered to increase the availability of abortion services in the province. Adequate compensation schedules would need to be developed for both the experienced and training physicians.

Support for Primary Care Physicians

The huge volume of HIV-related paperwork, such as filling out the lengthy forms to get drugs for people under the ODB program, takes physicians away from providing primary care. We certainly think many programs' administrative requirements are excessive and ill-planned, and need to be dramatically streamlined. We stressed, for example, the urgent need to speed up the availability of drugs under the ODB program. But more immediate action is also needed and we recommend that:

10 **The Ministry expand special funding for data collectors and other support services such as specially trained paraprofessionals and caseworkers to complement physicians with large HIV caseloads.**

Problems also result when physicians are the primary base of case management. Doctors spend an inordinate amount of time in effect acting as social workers: addressing the non-medical but vital emotional and psychological sides of their patients' lives, providing referrals to social and other agencies, and acting as advocates for their patients in their dealings with the wide range of institutions they come into contact with. All of these facets of support for PLWA/HIVs are crucial and they do have to be integrated. But we will argue below that there are more effective means of case management than using physician's scarce time in this way.

The changes we have recommended do amount to a significant restructuring of physician training and support. They reflect the more intensive nature of HIV treatment and care. However, a relatively simple immediate change can also make an important difference. We recommend that:

11 **The Ministry restructure doctors' compensation schedule for HIV patients to reflect the more intensive nature of HIV treatment.**

Hospital Care

The discussion so far has focused on physicians; a second challenge is to ensure high and consistent standards of care in hospitals across the province. Community activists and front-line providers constantly hear horror stories of inappropriate, inadequate and inconsistent care in hospitals. For example, PLWA/HIVs at our recent community forum told of having to go into emergencies on the weekend or late at night. They found that HIV specialists simply were not available in emergency departments and that many other hospital physicians had very limited knowledge of HIV conditions and treatments. Several participants also spoke to the need for on-site advocates in hospitals. This is not to say that hospitals never provide excellent care and it does not question the commitment of professionals working in the

hospitals. But there are certainly problems which need to be identified and acted on.

A further glaring gap is the lack of services for psychological adjustment to HIV illness. Only psychiatrists and not psychologists, therapists and other mental health practitioners are covered under OHIP. This in effect categorizes PLWA/HIVs seeking assistance as mentally ill. Moreover, the history of the psychiatric profession in relation to the medicalization of sexual orientation and homophobia hardly inspires confidence. There is also little understanding and treatment for dementia, and this condition is not a criteria for hospital admission. This has resulted in people suffering from dementia being referred to hostels or being cared for by untrained friends when in crisis.

For all of these reasons we think that the Ministry must take a proactive role in ensuring consistently high-quality care and in working closely with the medical professions and institutions to this end. We recommend that:

12 The Ministry establish an HIV Standards of Care advisory and monitoring committee.

Once again, this body must include people living with HIV and primary care physicians and other practitioners with direct HIV experience.

One mechanism to ensure consistent standards may be to enhance the role of the hospital HIV clinics to include a monitoring and evaluation function. Pilot projects which examine available care in certain areas and identify optimum standards could be funded. A more immediate measure may be to call inquests into HIV-related deaths from conditions generally seen to be preventable with available treatments, or where treatment was confused or inconsistent. The goal would be to identify systemic problems.

<u>HIV Clinics</u>

Another problem identified with the existing system lies in the complex medical division of labour: services PLWA/HIVs need are generally scattered among different institutions and disciplines, all of whose protocols and standards vary. Overcoming this fragmented and uncoordinated nature of HIV service delivery is a key challenge.

The goal must be to move towards providing a continuum of care which provides a comprehensive range of services, both from all the disciplines and professions within medicine and from social, legal and other support or advocacy services as well. Not only does this reflect the multifaceted nature of HIV illness but also the way in which the nature of the illnesses and conditions

associated with AIDS shape the way in which care can/should be provided. While AIDS has increasingly come to be defined as a chronic manageable condition, its progression and precise combination of conditions is unpredictable. There can be long periods of good health, followed rapidly by serious medical crisis, and many reversals and recoveries in an individuals' history. This means that people's needs for medical and other support will vary a great deal over the course of their illness and the full spectrum of services and settings must be available when needed and they must be provided in a coordinated and integrated manner.

Providing more integrated and comprehensive care was the rationale for the creation of clinics in hospitals in Toronto and other Ontario cities. The services they provide vary, but they all include counselling and related services as well as primary care. We support the rationale behind these clinics and we think they have an important part to play in enhancing continuity, coordinating programs and providers, and providing specialized care. But many PLWA/HIVs have had problems with the clinics and there are important questions as to the scope of their current role and how well they have been meeting PLWA/HIVs' needs.

Problems/Questions with the HIV Clinics

It would appear that the clinics do not provide a point of coordination with other units of the hospitals and physicians in the community. For example, the potential advantages of centralizing patient records in the clinics is clear. But we have heard many instances of PLWA/HIVs having to needlessly undergo particular tests again because results have not been shared, even within the same hospital.

Have the clinic programs been developed in ways that are complementary to the role of primary care physicians? Is there a consistent and effective range of care, including non-medical services, available in the clinics? What role do they play in individual case management? More generally, what types of liaison are best with other providers to facilitate overall planning? It would seem that the clinics have not developed well-planned and well-coordinated referral networks to community agencies and programs. If this is not a function for the clinics -- which it does not seem to be -- then what institutions exist to facilitate common local and regional planning?

Has research become a higher priority than treatment for the clinics? Are research projects coordinated among the clinics to prevent duplication?

Source of Innovation?

Some clinics are providing vital services, such as Compound Q and

Peptide T, for which official standards and protocols have not yet been established. This type of innovation and flexibility should be encouraged. However, significant institutional barriers stand in the way: doctors are not insured, and are vulnerable within their licensing requirements and hospital regulations when they work outside of established protocols. These barriers could be removed if the mandate and authority of the HIV clinics was expanded to include experimental treatments.

The clinics could become the key means of encouraging the development of new and promising treatments and ensuring that PLWA/HIVs have access to the broadest range of experimental treatments. Many PLWA/HIVs have been taking a range of experimental treatments. We believe that is their right; but whatever we and officials believe, people are going to continue taking the new therapies regardless. Recognizing this, the clinics could allow PLWA/HIVs access to the treatments they want in a safe well-monitored setting with the intensive care facilities of the hospital readily available in emergencies. This is a far better way of providing access to treatments than formal trials: not everyone meets eligibility criteria, many do not want to take the risk of being in the control arm that receives placebos and there simply are not enough trials for all those interested. At the same time, the records yielded by monitoring PLWA/HIVs' progress could be an invaluable research resource and could greatly help to elaborate protocols and standards for the new treatments.

In these ways the clinics could play a crucial role both in developing and in ensuring equitable access to experimental treatments. The infrastructure already in place in the existing HIV clinics. All that is needed is to expand their mandate and role. Such an innovation could make Ontario the leading jurisdiction in North America in the concrete development of new treatments. We recommend that:

13 The mandate of the HIV clinics be expanded to include the provision of experimental treatments.

Policy Review

We understand that the mandate and future placement of HIV clinics are being reviewed within the Ministry. We support such an evaluation, but are concerned that there has been no community input. We recommend that:

14 Extensive community consultation across the province must be a part of the HIV clinics policy and program review.

We also understand that the question of locating an HIV clinic at Wellesley Hospital has arisen. We would see that such a location

has important potential. However, the Ministry should take the opportunity of establishing a new facility to explore a more comprehensive model. Specifically, the new clinic should:

- emphasize community involvement and accountability from the start. There should be immediate public meetings and consultations on the clinic's direction and mix of programs and services. There should be a community board to set clinic policy and direction.

- offer a broader range of services: including social work, referrals, emotional support services, advocacy, etc. The goal should be to move towards putting a continuum of care into practice. Of course, this must be done in a well-planned way so as not to duplicate existing community services.

- organize individual case management. The clinic could be the base from which people are linked up with community services.

- be the base for innovative pilot projects. For example, the clinic should monitor and research experimental and alternative therapies that PLWA/HIVs are taking.

CONTINUUM OF CARE

We have stressed the need to ensure consistent standards and high quality in current medical treatment and care. But we also need to examine the scope of available care to ensure that it meets the full range of PLWA/HIVs' needs. One problem is people ending up in intensive care or hospitals inappropriately, because no other alternatives are available. For example, people have been hospitalized in order to get the drugs they need when they could not afford to buy them. Or people who need only a moderate level of assistance with daily medical and domestic needs stay in hospitals because they cannot manage for themselves or because home-based programs will not administer specific medications such as ganciclovir.

<u>Community-based Care and Support Programs</u>

A wide range of health and other service have been developed or adapted to provide care directly to PLWA/HIVs in their own homes and communities. For example, over 1,500 people have been admitted to the province's home health care program over the last five years. It can provide:

- Visiting nurses or other practitioners to change IVs, administer medication, monitor conditions and provide other

care;

- Physiotherapy, occupational therapy, speech therapy, nutrition counselling and respiratory therapy;

- Drugs, oxygen, medical supplies and equipment for home use and laboratory services.

Many PLWA/HIVs also need domestic assistance. This has led to a variety of programs that provide:

- Cooking, cleaning and other homemaking assistance is provided to people having difficulty managing for themselves;

- 'Buddy' systems offer practical assistance, emotional support and ongoing contact;

- Social work, financial and legal advice, housing, therapy and counselling, referrals, and overall advocacy with the many agencies and offices with which PLWA/HIVs come into contact.

These community-based programs are designed to facilitate people living as independently as possible in their own homes. The overall goal should be to create a continuum of services covering the full spectrum of peoples' needs that is equally accessible to all. We recommend that:

15 **The Ministry of Health increase funding for community-based HIV programs. In coordination with other ministries, levels of government and community groups, it should expand and coordinate services so that a comprehensive continuum of care is equitably available.**

A number of barriers currently limit this goal. While a wide range of services are available, they have developed in an ad hoc and uncoordinated manner. Some of these programs are provided by community groups (such as the PWA Foundation and the AIDS Committee of Toronto) and some by various ministries or other levels of government. Services can be fragmented and there are many gaps. While there can be wide range of programs available in Toronto, this is certainly less the case in smaller communities.

Even where programs do exist, many PLWA/HIVs do not know of them or how to get access to them. A significant problem is simply finding one's way through what can be a bewildering maze of programs and eligibility criteria. This speaks to the potential of some form of advocacy program. We support the concept of advocates outlined in the SARC Report and recent government commitments to implement advocacy. The best mechanism may be to

have advocates who specialize in the support and care needs of PLWA/HIVs. They must operate independently of municipal and provincial programs and all service providers. We recommend that:

16 **In consultation with the HIV community and with such groups as the Ontario Advocacy Coalition, the government must ensure that advocates able to specialize in protecting the rights of PLWA/HIVs to health, social and community support programs are available to all who need them.**

This also illustrates the pressing need for overall policy coordination. A useful starting point for interministerial cooperation could be the joint strategies on long-term care and home care programs developed by Health and Community and Social Services. We are pleased with their overall direction but disappointed that the specific needs of PLWA/HIVs were not considered. Representatives of the HIV community must be included in ongoing consultations. We support the emphasis on service integration and coordination through the proposed service access organizations. But the SAO's role seems confined to traditional case management; we would prefer an approach which seeks to empower the individual to plan and control their own care needs wherever possible. The SAOs also seem to have little power in relation to actual program development and service planning.

More generally, there is a clear need for coherent and proactive provincial strategy here. Funding for community-based support and care must be increased. This can best be seen as a key investment in preventing or forestalling the far more expensive reliance on hospitals and intensive treatment. But to avoid the pervasive fragmentation, duplication and lack of coordination of existing programs, this expansion must be well-planned.

Community Clinics

A key challenge is to develop coordinated and integrated policy that can bring together two directions that have proven so essential to PLWA/HIVs: the concept of a continuum of care and community-based provision. One model that could do this is community clinics that both provide a wide range of health and other support services on-site and at the same time are the hub or base from which services to PLWAs in their homes and neighbourhoods are organized and coordinated. This model of free-standing community clinics is much broader than the current hospital clinics.

Health and social services that are generally scattered could be centralized in one accessible location. Clinics could provide both treatment and a range of psychological and emotional support services: individual counselling and therapy, support groups, and

social and recreational activities. Day care for people who need medical and other assistance throughout the day, respite care for regular caregivers, and meals in a dining area could also be available.

The clinics could be information and referral points to other health services and facilities in the area. Clinic staff could be responsible for coordinating all of the diverse services provided to an individual and working closely with the individual in planning their care and needs. A further great practical advantage would be that all of an individual's records, of both treatment received at the clinic and elsewhere, and any follow-up or services provided at home, would be centralized. In these ways the clinics could be the key central location out of which comprehensive case management is organized.

At best, a network of such clinics should be established, based upon existing resources such as sexually transmitted disease and other clinics and well-established community groups, and in turn linked to hospitals, service agencies, hospices, nursing homes and other relevant programs and facilities. The development of such clinics would have to be carefully planned, with the maximum community participation, to build on the strengths of existing grassroots programs and groups. These clinics would need to be community-initiated and controlled, and while publicly funded, they must be independent of the Ministry. We recommend that:

17 The Ministry of Health fund pilot projects of community clinics that offer a comprehensive range of treatment, care and support services for PLWA/HIVs. The goal would be to concretely explore how the concept of a continuum of care could best work in practice.

THE SOCIAL CONTEXT FOR HIV POLICY

HIV infection is never purely a medical issue, either in individual's lives or at the level of public policy. For example, people can lose their housing, either through discrimination by landlords or because they can no longer afford the same accommodation if they lose their jobs. There are also homeless and street people whose daily lives are difficult enough, but who cannot survive HIV illnesses.

Housing Issues

An important short-term response has been to bump PLWA/HIVs up the priority list for public or subsidized housing. Many local authorities and cooperatives have done this and secure and affordable housing has made an immense difference to those accommodated. But these local actions have not met the need for

housing for the great majority of PLWA/HIVs whose incomes have dropped. This, of course, is part of the much wider crisis of affordable housing. The government must act to dramatically increase the availability of non-profit housing, including subsidized units for people living with HIV/AIDS.

Subsidized housing can be appropriate for those able to take care of their own needs. However, many PLWA/HIVs need accommodation that can provide some level of assistance. As with community-based health and other support programs, alternative residential settings can enhance individual autonomy and be a far more efficient allocation of resources than institutionalization. A range of accommodation is needed:

- Emergency shelters or transitional housing. Treatment of PLWA/HIVs in some shelters has been horrendous.

- On a longer-term basis, two types of settings have proven valuable here and in other jurisdictions. The first, in effect supervised homes, apartment buildings or complexes, has resident managers and/or some domestic assistance and medical supervision. In the second, more specialized residential facilities can provide accommodation, meals, and some level of personal care and supervision, but without significant medical care on site.

- The potential of adapting nursing homes should also be explored. They can provide relatively full medical care, but without the capital and human investment of hospitals. They can fill various needs: as transitional sites for people recovering from a particular bout of illness, long-term alternatives to hospitalization, 24-hour supervision for those with dementia, etc.

- Hospices are traditionally seen to be homelike and comfortable settings for palliative care. They can offer more personalized and intensive care than hospitals in ways that enhance individual autonomy. While they have all the specialized care needed for effective pain relief and comfort, hospices do not generally practice aggressive treatment. Again, this frees up the facilities of hospitals for acute treatment. Hospices' role has become much more flexible in response to AIDS; people can move in and out of the hospice as their condition improves.

The challenge of developing this full spectrum of accommodation and residential care illustrates the complexity of public policy on AIDS/HIV. Funding and regulation of these settings outlined above would come from at least three different Ministries and there would be many areas of shared or uncertain responsibility. For example, programs funded by both Health and COMSOC could provide home support services to PLWA/HIVs living in

accommodation funded by Housing. Are these Ministries jointly planning their services, let alone coordinating with municipalities? It would appear not.

Social Assistance

The problems mentioned most frequently by PLWA/HIVs at AIDS Action Now!'s recent forum on health, social and other provincial services had to do with inadequate levels and inflexible operation of social assistance. The most telling theme of this community meeting was the belief held by many that their friends on Family Benefits Assistance die faster. If this is so, it is a dramatic indictment of the assistance system.

Others spoke of the frustrations of being prevented from working because of rigid eligibility criteria; people who could work, but cannot afford to be cut off welfare and lose the drug coverage under the ODB program. There is the perennial problem of not being able to keep much of what is earned while on assistance. More specifically, as opposed to employment income, disability payments under CPP are taken off FBA dollar for dollar. Disability income should be treated the same as employment income. We made a series of recommendations on how to improve the flexibility and responsiveness of the social assistance system to PLWA/HIVs in the discussion notes for a recent meeting with the Minister of Community and Social Services.

The underlying problem, of course, is poverty. Drastically reduced and inadequate levels of income face many PLWA/HIVs, and greatly complicate maintaining their health. PLWA/HIVs, as well as so many others, would benefit greatly by implementation of the SARC Report proposals for welfare reform. We therefore join with many other community groups in recommending that:

18 The government should move quickly to implement the SARC reform proposals.

These interrelated problems have a very concrete impact on peoples' lives and prospects; for example, homelessness and poverty can prevent access to care and treatment, thus worsening symptoms and prognosis. The challenges posed by HIV and the solutions needed do not neatly conform to existing Ministerial and governmental lines of responsibility and jurisdiction. This brings us back to a central point: the pressing need for a comprehensive overall provincial strategy which can coordinate all facets of the different Ministries and agencies and most effectively bring to bear the necessary public resources.

THE NEED FOR AN OVERALL PROVINCIAL STRATEGY

One of the most important barriers to coordination and planning has been the lack of a coherent overall provincial strategy. As a result, policy and programs have developed in an ad hoc and fragmented way, without adequate coordination between different Ministries and areas. There has also been virtually no overall long-term planning. All of this has contributed to the gaps in available health care services, inconsistent standards of care, fragmented and poorly coordinated programs, and barriers to equal access that we have been emphasizing. A comprehensive provincial health care strategy on AIDS/HIV is all the more important because we know that increasing numbers of people are going to be needing care and treatment in the years to come.

Policy Process

Addressing these problems requires a thorough restructuring of the policy process. We recommend two interrelated developments:

19 **An AIDS/HIV Directorate should be established with the mandate, power and resources to coordinate the development of overall provincial policies for HIV, monitor all policy and programs and advise the government on directions for the future.**

20 **Policy coordinators and units should be established in each relevant Ministry. They must have the mandate and power to coordinate and direct Ministry policy and programs. This would mean that the authority of the existing AIDS coordinator in the Ministry of Health, for example, would need to be enhanced.**

The AIDS/HIV Directorate we propose would be designed to implement policy and streamline the administrative process. It could, for example, play a key role in speeding up the approval process for condition-specific ODB drug coverage. It could also be responsible for overall coordination, background research, and policy analysis. The Directorate would be the base for the working committees we have called for on standards of care and on medical training and education. It would be the hub out of which interministerial policy and program coordination takes place and in which the policy coordinators from the different ministries meet. The Directorate would play the lead role in the vital government-wide coordination that we emphasize.

This new Directorate, and other policy and program changes argued for here, would involve an expanded role for the Ontario AIDS Advisory Committee. The scope and resources of OAAC could be broadened to become the community board that guides the work of the AIDS/HIV Directorate. It would be the key government forum

for community input and policy discussion, and would bring together all the organizations and communities involved in HIV work. OAAC would be the central link between the Minister of Health and the government, and the community. To carry out this expanded role, OAAC would need to meet more frequently and have its own staff resources. And, of course, it would need greater PLWA/HIV representation.

While the final administrative arrangements will be the subject of ongoing consultation, the Directorate and OAAC would need to be far more than simply branches or bureaus within the Ministry. Operating together they can integrate policy and administrative functions so that policy is developed in a comprehensive and coordinated fashion and so that decisions are made quickly and effectively. The best structure may be to have the Directorate and OAAC report directly to the Minister of Health. They will together provide the vital link between PLWA/HIVs, HIV community groups, providers and the government. They will be the means whereby the Ministry and the government can play the proactive role they must.

While a central goal of both the Directorate and the enhanced OAAC must be to coordinate and initiate policy for the government as a whole, we would still see them to be based in the Ministry of Health. It is the largest service provider to PLWA/HIVs and is bound to be the lead ministry in joint efforts. Most importantly, these initiatives need a powerful Minister behind them to have the necessary leverage within the government as a whole.

The question of power leads us to our last point on the policy process. Ultimate responsibility still rests with the government and the key decisions are always going to be political. To help ensure that Ministers are able to take up their responsibilities and commitments, we recommend that:

21 **Senior policy advisors in each Minister's office must be assigned responsibility for the development of HIV-related policy within the Ministry and for liaising with community groups.**

The Minister of Health should appoint a special policy advisor in her office whose sole responsibility is HIV policy and programs. Appointing a person with front-line or activist experience would be the clearest possible signal to the community that the government is determined to address the crisis from the point of view of PLWA/HIVs.

Community Participation

The goal of these various changes is not to increase the power of Ministry bureaucracies, but to ensure that the needs of PLWA/HIVs

are the driving force of provincial policy and programs. The primary way to guarantee this principle is by requiring that the various working committees called for here and all other public consultation and advisory bodies on AIDS/HIV must have significant PLWA/HIV community representation. We recommend that:

22 **The government must commit itself to appointing people living with HIV and AIDS who are accountable to key service and activist groups to all boards and committees involved in AIDS and HIV policy. The government must immediately appoint more PLWA/HIVs to the Ontario AIDS Advisory Committee.**

To pull all of this together the province must develop a coherent long-term policy vision. In developing such a strategy, Ontario must avoid the federal experience of long delays, resulting in the end in an ineffectual and empty strategy. The way to do this is by ensuring that the policy is solidly based in the experience and initiatives of the communities most affected by the AIDS crisis and the needs and interests of PLWA/HIVs. We see several means of developing this strategy over the near future. First of all, we recommend that:

23 **The Province fund an Action Conference of community activists, front-line providers and PLWA/HIVs in the spring.**

The goal of this conference would be to identify existing barriers to equal access to needed care and support, elaborate the types of programs and services needed to enhance PLWA/HIVs' health and autonomy, and sketch out in broad outline a provincial strategy. We recommend that:

24 **An Action Plan be developed out of this conference for organizing and coordinating provincial policy and programs, to be released by September 1, 1991.**