

**Proceedings of AIDS Action Now! Retreat:
September 28-29, 1991
Wards Retreat**

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AAN! Retreat Sept. 91 Agenda

Friday

Arrival, snacks and informal chatter

21:30

Introduction to Wards Retreat (Full Group)

Saturday

10:00

Review and Evaluation of the year in the context of Policy Options 1991 (Full Group)

12:00

Playtime

13:00

Lunch

14:30

brainstorming and prioritization of goals and campaigns for next year (Small Groups)

16:00

Playtime

19:00

Supper

20:30

Reprots from small groups, consensus on goals and priorities (Full Group)

21:30

Playtime

Sunday

10:00

Full Group discussion on how we work together

11:00

Focus/Working groups, action plans

12:00

Playtime

13:00

Lunch

14:30

Reports from focus groups (Full Group)

16:00

Playtime

17:00

Departure

Introduction:

The third annual retreat of AIDS Action Now! was held at the wards retreat on September 28th and 29th, 1991. Focus was mainly on the politics of treatments and clinical trials, human rights and internal organization. The meeting was attended by about 25 individuals. It was deemed important to discuss our accomplishments and shortfalls right at the beginning as this would also determine the tone of the rest of the meeting and help prioritize actions for the next year. It was evident that considerable progress has been made in certain areas, whereas in certain others things have not moved much further. However, overall feeling was that a lot remains to be done. Generally speaking there was realistic confidence that a lot will be done in the year to come.

Accomplishments of the past year:

TISAH:

The demonstration at the beginning of April and lobbying efforts of AAN! and CAS together resulted in getting TISAH move out of U. of T. This was very crucial for TISAH (now ATIS) to survive as its death would have been guaranteed, had it stayed at U. of T.

Representation:

Led fight for reps at OAN.

AAN! played a major role in putting CNOPLWAHIV on its feet.

Met with the minister

Strong presence at pride day (IWD)

Pressed for human rights reform

HIV Clinic at ARCH

Alliances established - OAC, Disability, CST

Consultation amongst AIDS Groups

Incorporated Treatment into Prevention

Set provincial Agenda

Hightened awareness about women and AIDS - IWD Dec. 1st, 1990.

Demos

TISAH - 2

Dec 1

Provincial

OAN

ASAP

Gigantes meeting

Occupation

Consultation with Pharmaceuticals

Documents reflect organizational development - more sophisticated

Service deployment - needs assessment

Presence in law reform

Clinical trials work

New drugs on formulary

Smooth transition TIE --> CATIE

Prisons Committee restarted

Fire-fighters training

Pamphlets and brochures

Monthly meetings

New members

Establishment of services

Financially solvent, fundraising commitments half met?, fundraising profile

Shortfalls:

Outreach to people with HIV and People of Colour with HIV in particular seem to be poor.

Communication with CAS and CATIE poor

TISAH-->ATIS disappointment

Frustration with lobbying results

answering mail

communication between committees

phone tree

how user friendly are we?

new members

Shortage of human resources for oppurtunities

Difficultiese setting priorities

Skills development

Loosing members - Lull

Provincial effect vs Torontochauvenism

Treatments still unavailable, shifted focus, ie EDRP

Orientation system for new members

We are too comfortable as we have personal solutions to several problems associated with being HIV positive - this overlooks needs of a lot of PLWHIV

Physician support

Buddy system

Representation of groups on steering Committee doesn't work

Non-allopathic treatment funding

CRIT work

Need to expand 4.0 - Housing and homecare

Systemic discussion?

For determining priorities for the next year, members met in four groups and each group outlined what it had discussed to the group at large:

Group I:

1. Treatment Access:

In order to obtain treatments people with HIV first have to know that they exist, hence treatment information was considered as an integral part of treatment access. ATIS (AIDS Treatment Information Service) was hence considered an absolute priority. Community representatives on the Stakeholders Committee of ATIS could tell us more on where we are on the implementation of ATIS. Once this is known, clear strategies need to be developed for action on this dossier.

Educational campaigns on treatments and treatment issues:

Regular conferences, talks and panel discussions should be organized on a variety of issues. This would update our members about issues that govern our lives, identify problems in dealing with these issues and help develop strategies to deal with the problems thus identified.

Information on EDRP

Diffusion of information on the Emergency Drug Release Programme (EDRP) to people with HIV and their doctors is important, as this is supposed to be one of the mechanisms of accessing experimental treatments.

It was generally felt that EDRP was not designed to cope with an epidemic the magnitude of AIDS and HIV infection. However, since not very many people with HIV are aware of EDRP and most, if not all, doctors seem to be reluctant to take help of EDRP. If this programme was used to its full potential, it would be overwhelmed by demands for experimental treatments. Thus, though superficially it may appear to be an adequate programme to deal with the emergency, the reality about EDRP is quite different. It can never ever be an option to open arms of clinical trials in cases where trials of specific treatments exist in Canada..

Another issue about EDRP is the cost of treatments. Who pays for the experimental treatments? Release of these treatments is in the hands of Pharmaceutical companies. Some companies also defray the costs of treatments released through EDRP. However, even if experimental treatments were to be released liberally, unless some universal mechanism is in place it is going to be extremely difficult to access such treatments for their high costs.

Lobbying for the payment of experimental drugs with pharmaceutical companies and the government is thus a crucial issue.

Research Priorities

A document on research priorities is being prepared by the Canadian AIDS Society. (See point #4)

2. Social Assistance Reform Campaign
Coalitions - ARCH, Union of IW etc.
Rep to Moscovitz Committee on S. A. Review
Follow-up with COMSOC Minister regarding brief
Demos to raise profile

3. Human Rights/Discrimination Campaign
Meeting with Cheif Commissioner
Continued participation in long-term law reform
Determine priority of issues for test cases- Insurance, employment, services
Intervention and Demos regarding priority cases
Outreach re: Peoples rights
Coalition with other Communities

4. Research Priorities Campaign
Internal education and research
A document is being prepared by the CAS on research priorities. This document could be used by the community representatives on Expert Advisory Committee on HIV-therapies as well as NACAIDS working group on Research. If recommendations from this document will be accepted by the government, it will affect funding of research projects by the NHRDP and MRC. Lobbying and direct action with the pharmaceutical companies would, however, be difficult because they would not fund research projects according to our priorities.

Direct action strategy towards NHRDP
Research regarding companies and research on implementation of Bill C-22.

Group II

1. Treatment

EDRP - Potential users need to know how to access it, what it is etc.

ATIS - pressure government for it for it to become a reality

Promote other observational databases (like the one at CATIE - Medlog)

Pharmaceutical companies - Ensure that they provide compassionate arms etc.

Clinical trials

Special consideration for women in all of these.

2. Standards of care eg. push for home care, It would save government money, if patients learnt some treatment procedures at home - right to be treated at home - need to provide public with information on what they should expect if they are hospitalized with MAI, if markers reach certain stage etc.

3. Social services - Continue to push for full funding - free drugs on demand. Internally, everything we do must be made more accessible to large public. Media Committee needs to do more internal communications such as the preparations of fact sheets - cross appointments to every standing committee.

Group III

1. Member recruitment:

New members should feel that all committees are accessible

Call for new volunteers in writing

Volunteer pamphlet

More orientations

Orientation kits should always be available in the monthly meetings

Orientation kit should have the volunteer pamphlet, list of acronyms, committee contacts

Regular orientation meetings

Regular general meeting

Buddy system

Phone tree

Outreach to PLWHIV in the POC Communities

To look into an AAN! office space

2. Provincial Issues

Existing and new HIV Clinics

Long term

Standards of care

MOH takes a lead

OMA follow-up

We need to know more of MOH and OMA

Begin getting MOH and OMA a commitment that this is legit. within a year. Finding out what other standards of care exist in other provinces and other countries to use as a model.

3. TISAH back on track through CAS. Pressure on those who left it in Ottawa. It cant die.

Prison and AIDS

Briefs to CSC and provincial treatment and human rights violations

Group IV:

1.EDRP access: Campaign

2.Comprehensive drug funding

Coalition

Brief: Government

Pamphlet/Media

3. Standardds of care

Quality assurance

Demand conference

**4. Spectrum/Coordination of care
evaluation/planning of clinics**

5. Antidiscrimination

coalition

propaganda

6. Advocacy

coalition

institutional care

access to programmes and services

Overview of the priorities determined by the four working groups

Group I

Treatment access
Social assistance
Human rights
Research priorities

Group II

Treatment access
Standards of care
Social services

Group III

Outreach
Standards of care
ATIS

Group IV

EDRP
Drug Funding
Standards of care

How we work together?

Publicize how to contact AAN! phone etc., get AAN! materials

Follow up to new recruits

Targetted recruitment

Policy discussions

Cochairs overburdened

Discipline!

Media contacts - develop with more people

Coordinating Committee

Connections to other bodies such as the prison group, ARCH legal group

Orientation for all

Better written summary of the group available at all the meetings

Orientation meetings on a regular basis

Make buddy system work

More members needed with the M & R Committee

Merge M & R and Media committees

Articles in XTRA before meetings

Is the newsletter too slick? Can it become more tied inn with the group?

Communication

Office, mail etc.

Getting other groups to work

Need for more people

Asking Xtra etc to keep issues before community

Occupation of Office

Internal organization:

Priority Issues were

1. Membership and Recruitment

Only four individuals volunteered to be the active members of the Membership and Recruitment Committee. However, several individuals volunteered to be the resource people of the Committee. It is needless to say that all the other Committees will also try and recruit members on their own, as has been the case in the past.

What is needed in this arena?

Need targetted recruitment strategy

Need to make people feel part of the group and make them feel knowledgable in the orientation meetings

Need to keep specific tasks ready for new members, so that they do not feel useless and feel productive

Passive and active recruiting

Donation drive and financial involvement

Get membership to look for new members through personal contact

Contact specific community groups

what skills do we need to recruit people?

Volunteer recruitment campaign

Toronto Star

Coordination with ASO Volunteer Coordinators

Buddy system - Designated to greet new members

Need for a lot of hand holding and education during early period

Need to remind members to recruit

The general mandate and activities of the Committee were outlined considering the human resource this Committee has. What can four people do?

Phone tree

Orientation package

Organize buddies

Orientation meeting

General meetings (Monthly)

Flyer delivery

Liaison with and outreach to specific groups (People of colour, women, people with hemophilia, IVDUs etc.)

Annual General Meeting

Membership list

Newsletter

2. Policy Discussion

Identify issues as "Policy discussion" items

There is no mechanism, we can only react

Provincial committee discusses policy, as it should be

Round-table discussions

Worst-case scenario - an example of discussion that hasn't happened

Timely relevant discussion

Fact sheets, documents needed as background centralized info area

If you want info, go to specific committee

Involve other groups in discussion

AZT/ddl trial - no position to give to CRIT

No policy making to take place before presentation of fact sheets or subject to discipline proceedings before the D/C

Possibility of in-depth report from specific Committee on Steering Committee

Go to meetings, if you want info.