PRIORITIZING THE SCOPE OF HIV/AIDS ACTION:
An Applied Research Project

POLICY REPORT AND EXECUTIVE SUMMARY

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OUR OBJECTIVES

This Executive Summary is based on an 89-page Final Report to the Directorate General V of the Commission of the European Union. It is intended to reach a much wider audience, to be brief and concentrate on the most important aspects of the learning experience derived from this action oriented project. Unlike the Final Report, this Policy Report concentrates on general issues which benefit from but transcend individual and national experiences.

The starting point derived from a large scale comparative study sponsored by WHO which had produced detailed statistical evidence on the work of public and private non-profit organizations working with HIV/Aids. The follow up project was designed to use the previously accumulated survey data and convert it into a policy-action framework.

Unlike academic research which tends to finish with publications in specialized journals, our aim is (a least in the first place) to make the findings widely available through the network of people in the four countries who worked on our project and later through E-mail and the internet to reach a still wider audience.

OUR METHODS

To achieve this aim we assembled a group of ‘experts’, that is to say experienced professional workers in Voluntary Organizations engaged with HIV/Aids. They came from four European countries to work with the data through an Action Research method called Group Feed-back Analysis (GFA).

Group Feed-back Analysis emerged in the 1960's and has been successfully used to improve the quality of research as well as to achieve organizational learning. The method has

three aims: (i) to evaluate and agree on the validity of the data, (ii) to stimulate the motivation, experience and expertise of the participants to go beyond the presented data into greater depth of understanding of the phenomena under scrutiny, (iii) to reach informed judgements on policy and action relevant outcomes.

The process of achieving these objectives is to work through Dissonance Reduction. This is a technical term to describe problems presented in the form of conflicts and differences or lack of agreement (that is to say dissonances) with a view to achieve a degree of resolution Data collected on virtually any subject from any population shows variation. People's judgements and values differ and these differences are the raw material for GFA and Dissonance Reduction.[1]

We used this method through short workshop meeting between the researchers and groups of experts. There were four phases.

- Phase one was a meeting with each country team separately. The purpose was to explore the original data, the accumulated experience with HIV/Aids and any changes that had taken place since the original data was collected.
- Phase two was a meeting with the four country teams. The experience with the four separate country meeting had been summarized by the researchers and was fed back to the combined workshop for validation, comparison and further analysis. The main agreed problem areas were beginning to emerge.
- Phase three workshops were with each of the four country teams separately. Once again the material had been analyzed and summarized for feed-back. Nine Dissonances had emerged, though the degree of their importance varied by countries (see next section). The interim results of the project had been summarized for the European Union sponsor of the project and had been circulated to each member of the four teams.
- The final workshop again brought together the four country teams. The researchers' assessment was subjected to analysis, correction were made as appropriate and detailed consideration was given to each of the dissonances to achieve reduction where possible and a superior understanding of the essential nature of the problem when dissonance reduction is not feasible.[2]

[1] Further information on this method can be obtained on request.

[2] For the purpose of this Policy Summary this description of the method is minimal.

WHAT WE HAVE LEARNED: *THE DISSONANCES*

Dissonances describe major problems in handling HIV/Aids issues; that is to say the prevention of the disease or the amelioration of the conditions for those who have already contracted the disease. The dissonances are identified and analyzed from the discussion between the experts in the four workshops. The exact nature of the problem would vary, but often only slightly from country to country and the similarities and differences were analyzed in the workshops during phase 2 and 3. By the final meeting in phase 4, we achieved an acceptable consolidation on most of the issues.[3] By consolidation we mean either a *Reduction of the Dissonance* or *a Superior Understanding of the Essence of the Problem.*

One major learning experience shared between all four countries, though with different emphasis, was the extraordinary rapidity of change in circumstances and conditions from phase to phase during the two years of the project. This means that a project designed to stimulate organizational learning has to be longitudinal and would benefit from occasional follow up meetings using the same methodology.

DISSONANCE : RESTRUCTURING THE WELFARE STATE

During the second half of the 20th century, most European countries had developed an extensive policy of support for citizens who experienced a variety of problems from illness to unemployment; this is called the Welfare State. By the 1990s these policies had come under pressure from various quarters including free market economic theory, its application in the United States under President Ronald Reagan, and in the United Kingdom under Prime Minister Margaret Thatcher. More generally, a need was felt to respond to economic competitive pressures from the Far East, the need to meet a number of complex economic convergence targets to qualify for membership of the common European currency, the political desire to

[3] There were also interesting country differences. For these see Interim and Final Report.

reduce taxes to stimulate demand, and the consequent need to reduce the size and expenditure of government.

The timing and strength of these developments varied within the four countries in our sample and even changed during the two years of our project. So in one country during the phase one meeting the experts were quite confident that there was no question of the Welfare State being dismantled; they felt confident that current budget discussions were going well, and that necessary funding would be available. This position changed significantly by the phase two meeting nine months later.

There are other related pressures on the financial resources available to carry out the work of prevention and amelioration of HIV/Aids. Some of this overlaps with other Dissonances (see for instance Increased Life Expectancy and Under-represented Need Groups). Then there is the pressure on Central and Local Government from competing, allegedly more urgent, health priorities and from the popular perception that HIV/Aids is no longer an epidemic spreading rapidly through certain sections of the community and is therefore more or less under control. Given the pressures on the Welfare State, the conflicting claims on diminishing resources have to be countenanced and solutions sought.

Dissonance Reduction

The following three suggestions emerged from the discussions:

- Although the countries in our sample had little experience with fund raising, this way of making up for loss of Welfare State income will have to be explored and in some cases was already seen to have been successful. Income from contributions of pharmaceutical companies is one obvious source, but has to be handled carefully to avoid ethical problems. Other venues can be explored with the help of people (or professionals) with fund raising experience.
- An expansion of voluntary work, for instance through innovations based on the successful Buddy System was contemplated (see Dissonance: Innovation vs. Tradition).
- A third approach is through rationalization of activities, increased collaboration between organizations or even mergers (see Dissonance: Integration vs. Specialization). In at least one country, the government already formally encourages

such developments.

- Perhaps the most important insight was the agreement that anticipating the consequences of changes of the Welfare State had strategic advantages over accepting changes under pressure. There is still time to be proactive.

DISSONANCE : INCREASED LIFE EXPECTANCY

A new medication, antiretroviral combination therapy, (HAART) popularly known as the 'triple cocktail' has been used since about 1996 to combat HIV/Aids and has achieved substantial success in delaying the development of the disease for many people. During the first meeting the experts were much more optimistic about the treatment than later on when it had become clear that some groups of patients could not benefit from this treatment. The treatment is very difficult to administer and carry out successfully. Medication has to be taken at precisely defined intervals during the 24-hour cycle and often has unpleasant side effects. Not everybody has the ability and motivation to sustain this regimen over long periods of time without substantial help and encouragement. The consequences of not carrying out the treatment exactly as prescribed are dire both for the patient who develops an immunity to the treatment, and for the patient's sexual partner or partners who can also develop immunity to the 'triple cocktail'. In this way immunity to the new drug treatment can easily spread far and wide to the detriment of everybody.

The 'triple cocktail' is very expensive, about $20,000 per patient year. Since the treatment developed out of medical research and has to be prescribed by a medical practitioner it seemed logical to keep the administration in medical hands although not all doctors are trained in handling the complex medication. Furthermore, medical practitioners operate under substantial pressure and often have to ration the time available to each patient and they do not receive additional financial compensation for handling the antiretroviral combination therapy with the need for follow up, monitoring and control. Additionally, according to our experts, not all doctors who administer this treatment have the necessary patience and social skills. What, if

anything, can be offered to patients who, for a variety of reasons, cannot be treated with aniretroviral combination therapy effectively?

One way of dealing with this dilemma is to hand part of the drug administration back to non-medical people who regularly work with HIV/Aids patients and particularly to use qualified social workers available in hospitals and private surgeries to create the necessary motivational and supervisory condition to enable patients to persevere with the demanding and complex conditions to adhere successfully to HAART.

Increased Life Expectancy due to the new drug technology creates other problems. Patients who previously expected to die quite soon, left their employment and might have sold their home and other possessions. Now they are keen to re-establish themselves, obtain a job and a place to live. They need help to achieve their newly developed aims.

The Dissonance described by these conditions derives from what is called the *technological imperative,* that is to say an insistence that complex problems involving human beings can be satisfactorily solved by technology alone. There is extensive literature on the failure of technological imperative solutions.[4]

Dissonance Reduction

- Since HAART treatment is very expensive and the resources of the Welfare State are limited, the technocentric solution at first appears sensible. However, it makes assumptions that are highly unrealistic and can be shown to produce seriously negative results for a large number of patients who cannot or will not continue with the drug treatment. The consequences of failure will affect the patient as well as a wider circle of people, as explained above. Thus, secondary prevention becomes a crucial issue with HAART. It is, of course, accepted that a reliance on psycho-social help alone cannot deal with this problem. In addition, there is the problem for patients who successfully take the HAART but who have to re-establish themselves and need non-medical help to achieve a reasonable quality of life.

[4] The literature relating to this draws on the sociotechnical model. See for instance Heller, 1987 'The technological imperative and the quality of employment'. *New Technology, Work and Employment*, 2.19-26

- In the circumstances it is possible to envisage a socio-technical solution, by urging the funding bodies to allocate a sum of money for a patient/year which includes the cost of the technical treatment as well as provision for regular qualified psycho-social help. For instance, if a certain small percentage of the overall costs for HAART could be earmarked for a professional social worker, this might secure a more effective overall solution to a complex problem.

DISSONANCE : UNDER-REPRESENTED NEED GROUPS

From the time when HIV/Aids first became a health problem in the 1980s, the people affected by the disease and in need of help has changed drastically. Even in the two years of the project, our experts perceived the need to re-assess priorities.

When the epidemic first started it affected mainly homosexual men and a majority seemed to be professional well educated people accustomed to planning their lives and dealing effectively with bureaucracies. Later, small numbers of heterosexual men and women had become infected, but the majority were native to the country in which they lived. In more recent years, the experts became conscious of a major shift in the HIV/Aids population towards socially and economically disadvantaged groups who were less well educated and poor. Some were drug users, some were prostitutes and an increasing number were not native to the country in which they lived and did not speak its language adequately. Many were illegal immigrants.

The experience that had grown up in dealing with the earlier clients and the structures designed to help them, such as Buddies and self-help groups were not always thought to be appropriate or suitable to dealing with these culturally highly differentiated new need groups which lack priority on the political agenda.

Dissonance Reduction

The contrast between the needs of the early well represented and the under-represented disadvantaged need groups could not be eliminated but a significant amount of Organizational Learning was possible.

- There is a need for more systematic knowledge about the different under-represented groups, their needs and their cultural distinctiveness. For instance it is necessary to

learn about and be patient with characteristics that jar with the local culture, such as attitudes to time, punctuality and reliability in carrying out instructions.

- Cultural differences lead to different sex practices. Young people in one group which requires virginity in girls, will practice anal sex but lack the information about special anal condoms
- Community based organizations have been found useful in dealing with linguistic needs and culturally sensitive issues. Such an approach requires a re-allocation of existing resources
- In general, our experts felt that there was much to be gained in finding ways of empowering under-represented groups to discuss and chose ways and means of prevention and amelioration of the effects of the disease. Such empowerment can lead to the establishment of a special interest group like the International Organization of Turkish Homosexuals (IPOTH). It can also lead to adaptations of the Buddy system and Self-help groups that adjust to specific local customs and practices.
- The use of 'facilitators' has been successful in work with special need groups like prostitutes and transsexual workers. Facilitators have to be carefully selected and trained and usually come from the group in which they are expected to facilitate new ideas and practices. For instance, prostitutes have been trained to influence their colleagues to practice safe sex.

DISSONANCES : NETWORKING VERSUS AUTONOMY, LEADERSHIP, POWER AND EVALUATION

Modern organization theory and a considerable volume of literature are devoted to the analysis of networking to describe various forms of inter-organizational relationships. Networking is usually associated with positive outcomes.

Another part of organizational literature deals with leadership and the distribution of power in and between organizations. Autonomy or decentralization are structures or aspects of behaviour. As forms of behaviour they can be related to styles of leadership. From a structural perspective they can be treated as elements in the distribution of power. In either case. participative leadership and decentralized organizational structures are usually described in positive terms.

In our project both positive and negative aspects of Networking versus Autonomy and Leadership and Power became subjects of discussion and analysis in relation to the task structure of organizations working in the field of HIV/Aids.

At first there was a tendency to argue that there is no real problem with either of these issues and power is not always seen as a congenial topic. However, it emerged that one of the groups had a substantial problem with networking which they considered to be a potential threat to their established way of doing things. Others saw networking as presenting mutual benefits. From this contrasting position, the discussion opened up and established that Networking was not a uniform phenomenon it could for instance be formal or informal and its objectives could be pragmatic or idealistic.

People's perception of networks as being a help or hindrance depended on who started the move and what stated (and hidden) objectives were attributed to the initiators of such a structure.

Expectations about outcomes also differ; what is the purpose of networking: is it to exchange information, to carry out joint advocacy, to economize resources or to achieve consensus? Where does responsibility lie? Can policy be made through networks, can policy be implemented through networks? There are potentially positive or negative aspects in relation to each outcome. Even if the purpose is only an exchange of information, the person or group that has most information exerts a potentially powerful position; having and giving information may become competitive. Are other people in the network expected to use the information? If so, it means making changes. Not everybody wants to change. Yet the positive side is clear. Information is essential for successful execution of all tasks. Collaboration adds strength and duplication is wasteful.

Attempts to achieve consensus or instigate joint advocacy requires leadership and, at least in the first place, a degree of centralization. If such functions are handled by official agencies or government departments, the power structure is not easily challenged or reversed. On the other hand it would be churlish to deny that elected representatives and their accredited civil servants have the right to make critical decisions about funding and structure. A network may provide a forum for consultation and making suggestions and offer a degree of transparency that traditional non network organizations cannot provide.

It is widely agreed that it is right and proper to assess progress, that is to say successes as well as failures and - perhaps through networks - to obtain cross-organizational learning. This subject is often called Evaluation. In designing an Evaluation Scheme, the initiative can be taken by formal agencies (of the government for instance) or by the non- governmental voluntary bodies working in the field of Hiv/Aids. The kind of evaluation information requested by formal agencies is very different from that which voluntary bodies consider appropriate and helpful. Governments want to have 'facts', often in the form of statistics which are accepted as surrogates for 'facts'. Statistics are about numbers of people, hours worked, time spent, money used and so on; all broken down by specific categories.

The objective of Evaluation is to estimate 'value for money'. This kind of data is thought necessary for justifying the expenditure of taxpayers' money. The negative side of this form of Evaluation is that it takes up time(with the collection of data) that is of little utility for either prevention or treatment and can easily be falsified if the motivation to do so is strong.

There are a number of alternatives to the bureaucratic form of evaluation; much of it would be qualitative in the form of cases studies preferably under agreed headings. There could be assessments of facilitators or obstacles to prevention and treatment and round table discussion with client and helper groups and documented exchanges of experiences among voluntary agencies. Suitable quantitative data might also be helpful for instance about client preferences or priorities for activities and types of information. The quality of this type of Evaluation is likely to be high and, suitably presented, could be of value to government in assessing its own priorities and justification for giving financial support.

Dissonance Reduction

- Power is the critical dimension underpinning the two Dissonances (Networking versus Autonomy and Leadership and Power) as well as the Evaluation issue.
- Cutting through the various complexities outlined above, the following formulation was proposed and agreed: Firstly it was accepted that networking is important and desirable for progress, as long as the drive for consensus is kept in check. This formulation implies that the advantages of networking can be achieved without giving up essential aspects of ones own freedom of action. If these conditions are

accepted as the basis for a networking arrangement, mutual benefits rather than zero sum conditions would prevail.

- In relation to Leadership and Centralization versus Decentralization, a similar formulation could be worked out, that is to say, accepting leadership and a functional degree of centralization as long as within such a scheme an acceptable measure of semi-autonomy is achieved. The dissonance can be reduced or even eliminated by accepting that power does not have to be maximized either through networking or the exercise of leadership. At the same time autonomy (or decentralization) does not have to be maximized either. An optimum solution is to accept a degree of centralization (which can have functional advantages) with a measure of semi-autonomy (decentralization). Such an integrated solution has to be approached through dialogue and consensus. This is preferable to having it imposed by bodies with different values and inappropriate needs.
- Furthermore, it was accepted that Evaluation can have advantages but should be anticipated and designed by HIV/Aids organizations.

DISSONANCE: INNOVATION VERSUS TRADITION

Epidemiological, organizational, attitudinal and sociological conditions have changed more rapidly with HIV/Aids than most diseases. Change is endemic, nevertheless it is not always easily achieved, and innovation requires courage and ingenuity.

This Dissonance overlaps with several others, particularly Leadership and Power, the Restructuring of the Welfare State, Increased Life Expectancy, Under-represented Need groups and Ethics. However, Innovation versus Tradition will be treated here to draw attention to the need for constantly balancing the role of tradition and continuity with the need for innovation. Much has been achieved. Each country gave some examples of innovative development which demonstrated their ability for flexible thinking. For instance, as said earlier, a Peer Help System is used with selected and trained prostitutes who attempt to develop superior safety habits with their colleagues.

A need for innovation and ingenuity derives from the Restructuring of the Welfare State. Although the number of newly infected cases is diminishing, the substantially increased life expectancy of sufferers means that the total number of HIV/Aids patients in need of care is increasing. Hence new and larger resources are needed to cope. However, the government,

officials and the general public have been influenced by tendentious media coverage suggesting that the Aids situation is now more or less under control. Additionally, in many countries, the Welfare State is under attack from neo classical economists who urge a reduction in its size and a consequent reduction of the tax burden. Innovative approaches are needed to cope with these pressures. Fund-raising through voluntary organizations is not widely practiced in Continental countries and Aids has a narrower appeal with the general public than competitive causes.

Dissonance Reduction

As the impact of the disease has shifted from the relatively well educated and economically prosperous to less well educated and less well off groups including ethnic minorities and illegal immigrants, from gay men to heterosexual men and women, from a rapidly to a slowly progressing disease, from one where medical technology had a minor role to one were it has a dominant role - complex adjustments are inevitable.

- A particularly successful innovation built on the very traditional Buddy system which had achieved high status in the community as a result of careful selection and training. It started with (usually gay) helpers volunteering to carry out a variety of important jobs and to give sympathetic psychological support to homosexual Aids patients who were dying rapidly. The bonds between Buddy and patient became very strong. Then two things happened. As the result of the new drug treatment, homosexual Aids sufferers could live for long periods and the 'Buddies' found it difficult to adjust to this (see Increased Life Expectancy). Secondly, new cases of homosexuals infected with Aids stabilized or diminished while heterosexual Aids increased and needed help. Experience in our groups showed that a redesigned 'Buddy-like' system could be developed to cope with these changed conditions. The Buddy system now has women as Buddies and women as clients and Buddies are used with minority group heterosexuals and drug users.
- Many of these adjustments are documented under the various Dissonances. Here we will mention only the tendency to form new alliances, to increase networking and co-ordination and to consider the possibility of establishing mergers as ways of managing with reduced financial support and related pressures.

DISSONANCE : INTEGRATION VERSUS SPECIALIZATION

This issue goes back to the distinction between Inclusive versus Exclusive organizations in the previous research. There is also some overlap with the Dissonance on Prevention versus Care.

One view voiced early in the project was that the issue of Integration versus Specialization is artificial and unnecessary because one needs both and in any case they are complementary.

However, it soon emerged that much of the new pressure for Integration came from government and was related to the need to reduce funds (see Dissonance on the Welfare State). There other important infectious diseases and there are other sexually transmitted diseases that have to be handled in state financed institutions. In the view of governments, it would save scarce resources if all health issues were integrated.

At the same time there were some practical reasons for integration in some circumstances, for instance in dealing with young people and with work in schools. A good practical case can be made for subsuming sex education within a broader subject like health particularly for schools. Such a more integrated schema will also be functional with, for instance, prostitutes or ethnic minority groups where specialized units are judged to stigmatize people who are seen to attend.

Furthermore, since the number of new cases is slowing down and the existing cases, while concentrating in large cities, are also dispersed over the country, specialization cannot always be justified.

Historically, Hiv/Aids as a new and threatening disease obtained specialized attention. Some people who have worked in this kind of setting for many years, have personal needs to continue in this way, are emotionally involved and resist change. Some of the original reasons for specialization are still valid and new reasons like the special skill to administer and monitor the triple drug treatment also argue for specialization (see Dissonance : Increased Life Expectancy).

The issue is clearly very complex. A distinction has to be made between prevention and treatment and primary and secondary prevention. (See Dissonance: Prevention versus Treatment).

Dissonance Reduction

Complete integration might lead to the disappearance of HIV/Aids from the political agenda and this would be counter-productive. The discussion and analysis led to the recognition that the conflict between integration and specialization could be reduced and often eliminated in two ways. One was by making clear functional distinctions which can be kept separate from institutional egocentrism and/or the economic policies of government

- the need to avoid stigmatization in general and for culturally sensitive groups in particular are functionally relevant reasons for integration. Similarly, dealing with HIV/Aids within a broader topic like health in approaching young people and handling this sensitive subject in school functionally justifies integration.
- However, outside these two specific situations, the argument that education about Hiv/Aids can be combined with other health care issues and include anti-smoking and healthy eating messages, etc. is not convincing and needs to be checked through research.
- A functional case for specialization is particularly clear in relation to treatment and especially with the complex triple drug therapy and the necessary compliance procedures (see Increased Life Expectancy).
- A functional case for specialization can also be made for attacking secondary prevention which is likely to be successful only under conditions where close contact and mutual confidence prevail. However, primary prevention can prosper under integration.
- Specialization can be functional in relation to target groups like homosexuals, drug users, prostitutes and possibly women.
- Specialization is functional with the use of care schemes like Buddies.

The second Dissonance Reduction derived from the suggestion to *Specialize Integration.*

- The concept Specialized Integration recognizes the advantages of both approaches from the point of view of the client as well as the financial sponsor. Integrated organizations are economical to fund and can be established in areas of a country where few people suffer from HIV/Aids.
- A specialized person would operate within such an Integrated organization either full time or part-time in relation to demand. The specialist might be peripatetic and operate in several units which combine Integration and Specialization.

- Similarly, within an integrated unit catering for a community, specialized needs for ethnic minority language facilities and health advice, etc. can be provided by a specialist on rotation and in this way combine the economy of Integration with the advantage of Specialization.

The reader will observe that the *Specialized Integration* solution should be handled by what we call Optimization rather than Maximization. There are situations when neither Specialization nor Integration can be maximized on their own and produce the best results. A superior solution is achieved by Optimization which has to carefully assess the contribution each factor can make in collaboration with the other factor. Optimization, as we saw in the case of Increased Life Expectancy, is not a compromise, but an original and designed solution.

DISSONANCE : PREVENTION VERSUS TREATMENT (PRIMARY PREVENTION VERSUS SECONDARY PREVENTION)

Government as well as medicine have, through a long tradition, given priority to Treatment and Care rather than to Prevention. This is clearly reflected in separate funding and usually separate institutional arrangements. In most cases, this makes it almost impossible to arrange formally for close collaboration. (see Dissonance: Integration versus Specialization). Furthermore total funding available for Prevention is minuscule although it can be argued that more successful Prevention would reduce the cost of Treatment ('Care is Prevention'). Most of the funding for Treatment comes through traditional channels like hospitals and a well established national health budget. Prevention has no such regular sources.

For technical reasons, Treatment, (particularly antiretroviral) is specialized, while Prevention offers a wider range of choice including integration with other HIV/Aids initiatives (see Integration v. Specialization and Under Represented Need groups). The importance of providing psycho-social care (see Increased Life Expectancy) could be an important link between Treatment and Secondary/Tertiary Prevention, but resources are often not available. These issues merge with considerations of Human Rights and the Quality of Life: people have a right to be protected.

The well known differentiation between Primary and Secondary (and Tertiary) Prevention provides various options with Secondary Prevention usually more specialized in clinics, certain language groups, school education, prostitutes, drug users. The effectiveness of Prevention varies enormously with the method, but not enough research data is available to distinguish between 'hands on' (direct contact) compared with 'arms length' (advertising etc). Secondary Prevention is given very limited resources.

No Dissonance Reduction, but some learning

- The rigid budgetary and structural separation between Prevention and Treatment prevents Dissonance Reduction for the time being.
- There was agreement that efforts should be made to overcome these barriers and some informal collaboration has taken place. The logical as well as humanitarian case for more investment in Prevention was, in theory, widely accepted. The Directorate V of the European Commission supports the case for more emphasis to be given to Prevention.
- Care can easily integrate Prevention. The *added value* of joining Secondary (and therefore Tertiary) Prevention resources to existing and funded Treatment activities in hospitals (through psycho-social counseling), with ethnic minorities, drug users, prostitutes etc., is considerable.

DISSONANCE: ETHICS (DISCRIMINATORY LAWS, AGE OF CONSENT, NEEDLE EXCHANGE, COMPULSORY TESTING, THE SANCTITY OF THE BODY ETC.)

As the subtitles indicate, Ethics covers a number of issues and therefore several Dissonances. It is a large complex and deeply emotional group of subjects. Nobody wants to be on the wrong side of the dividing line, but the line is shifting. It has moved even in the two years of this project. There are personal value standards, cultural mores , national laws and inadequately developed international guidelines (quasi- laws). Where do 'politically correct' views fit into all this? We should hope to achieve progress rather than solutions.

Many contentious issues were raised. On some there was immediate agreement (the need for pre- and post-test counseling), on others, a reasonable consensus was gradually forged

(pregnant mothers in vulnerable groups could be persuaded to undergo tests (for HIV as well as hepatitis) since their children might then receive better treatment). Inevitably, a few differences remained (the right of the sero-positive person to practice unsafe sex, versus the right of the partner to be told).

The difficult issues revolved around an individual's right to control his/her own body (and the right to decide whether to know or not to know) versus the rights of other people, including the community, to be free from the disease. For instance, if 95% of children with HIV are not native to the host country, should testing of women from this ethnic minority be encouraged? required? If two-thirds of the HIV positive heterosexual population belongs to a particular minority, should this information be made available?

Discrimination of every kind was condemned, but non-discriminatory automatic testing of all blood (collected routinely from blood tests for whatever reason) from everybody was not favoured.

The reality has to be faced that in some countries asylum seekers are tested, in other countries, foreign students are tested and in many places, people undergoing surgery in hospitals are illegally but routinely tested. Given this situation, psychological damage could be minimized by skilled pre- and post-test counseling. Since the influence available to our experts and their institutions is limited, it may be reasonable to concentrate policies on achievable objectives like the introduction of skilled counseling. At the same time, extended dialogues could influence the imperfect values sustaining existing national and institutional practices.

We agreed that, on balance, laws can and often do change behaviour, but should be reinforced by education and dialogue between institutions and further strengthened by a monitoring procedures. When a clear legal transgression takes place, HIV/Aids organizations should fight the issue through the courts (and have been successful in doing this).

Extensive clarification and some Dissonance Reduction

Given the diversity of the issues under the broad heading of Ethics, one looks more to learning and clarification on specific subjects than to a dissolution of the Ethical dilemma. On a general level, there was agreement that health issues and human rights are closely intertwined. By keeping this symbiotic relationship clearly in the foreground when tackling specific ethical issues, dissonances become opportunities for understanding and stepping stones for conflict resolution. Thus, for instance, starting from recognition of a widely accepted principle, such as the symbiotic relation between health and human rights, opposition to needle exchange for drug users becomes untenable and age discrimination for homosexuals more difficult and widely opposed.

Several other examples of learning and clarification have already been given. The overall reduction in dissonance on many of the ethical issues raised was due to a gradual and subtle shift in the position of the arguments over time. It seems that there is now a wider acceptance that sex is a natural and enjoyable activity and not necessarily linked only to traditional marriage, genders or ordained objectives. As a consequence, catching a disease through a natural and enjoyable activity is a misfortune, but not a disgrace. From this it follows, that people who contract HIV/Aids can be treated like sufferers from other infectious diseases, the difference being that this one, at least for the time being, is lethal. Consequently, sufferers from this disease deserve our sympathy and must be helped, and others must be protected from the infectiousness of the disease, but there is a little less need now to shield the sero-positive from condemnation for reprehensible, unnatural and unethical activity. However, our experts thought that people have a right not to know their sero-state. This change in attitudes and values has only just begun and has to go much further so that sero-positives will not be prevented from competing on an equal level for jobs and sharing other activities.

Dissonance reduction as a consequence of this changed ethical imperative has shifted, or made more flexible, the ‘politically correct’ position on some of the issues under discussion.

CONCLUSIONS

Many circumstances relating to the epidemic HIV/Aids have changed rapidly over the last few years and a lively rate of change is likely to continue. Consequently there is a need to develop ways and means of facilitating organizational learning through longitudinal action oriented research, longitudinal evaluation and systematic exchanges of experiences, preferably through cross national networks.

The precise nature of political-economic changes in Europe cannot be foreseen, but anticipating the likelihood of reduced resources and requests for re-structuring can be anticipated. Pro-active measures are more effective than compliance with imposed decisions (see Restructuring the Welfare State).

Epidemiological developments maybe rapid and require flexible responses based on a careful balancing of the Dissonances described in this report. In particular, medical technology has to operate within a framework of psycho-social resources (see Increased Life Expectancy). Innovation has to be encouraged by appropriate institutional leadership balancing semi-autonomy with networking (see Innovation versus Tradition and Networking versus Autonomy).

In general, the results from the four-phase action project lead to the conclusion that Dissonances that is to say, critical differences between alternative strategies cannot be satisfactorily resolved by saying that “both are necessary”. For instance: Integration versus Specialization, Prevention versus Treatment, Networking versus Autonomy, Innovation versus Tradition, Well-represented versus Under-represented Need Groups. Reducing these Dissonances or learning from their analysis requires a careful functional examination of the issues.

We believe that in each case the outcome was a significant improvement on the position from which we started the project.

Since our findings are not country-specific and have evolved over two years, they may provide a useful starting point for dialogues with other European centres engaged with HIV/Aids patients or with preventing the spread of the disease.

SUMMARY TABLE OF DISSONANCES AND OUTCOMES
Organizational Learning through Dissonance Reduction

THE DISSONANCES	ORGANIZATIONAL LEARNING
Restructuring the Welfare State (Reduction in State Funding) *See Innovation v. Tradition*	There is an urgent need to anticipate the problem and find new or additional sources of finance and/or to seek expansion of quality assured voluntary work (i.e the Buddy system etc.)
Increased Life Expectancy due to HAART	Exclusive reliance on the 'triple cocktail' (HAART) is dysfunctional. Professional social work should be integrated with the technology of drug administration in a financial package.
Under-represented Need Groups Socially and economically disadvantaged groups	Solutions are not available, but more knowledge (through research) on specific needs is a priority. Empowering under-represented groups through dialogue and self help resources and facilitators is recommended.
Networking versus **Autonomy** **Leadership, Power & Evaluation**	Inappropriate power concentration is the common obstacle for this multifaceted dissonance; hence more participation and/or delegation is necessary. For instance, Evaluation should be grass root designed, not imposed. Hence need to anticipate events.

Integration versus Specialization Inclusive versus Exclusive	nplete integration is dysfunctional, but useful in some contingencies: i.e. Sex education in schools and work with some cultural groups. Explore 'Specialized Integration' Solution.
Prevention versus **Treatment** Primary v. Secondary Prevention Historically, treatment received priority.	Existing financial etc structures and Tradition prevents a solution, but some learning on how to fight the barriers and support Human Rights argument.
Ethics Dissonances	Several old established issues with deep emotional involvement. Progress rather than solutions were established. Main issue is the conflict between the rights of the individual against rights of others (who are also individuals!). Agreement on preventing discrimination.

RECENT EPIDEMIOLOGICAL DEVELOPMENT IN SELECTED EUROPEAN COUNTRIES

By June 1999, a cumulative total of 224,359 Aids cases were reported in the WHO European region. 60% of those diagnosed with Aids have died.

The recent epidemiological figures suggest that the Aids-epidemic is at a turning point. Since 1996 there has been a decline in Aids-incidence, which continued in 1999, although at a slower rate.

This development results from both the increasing use of effective antiretroviral treatment (HAART), which has been available in many European countries since 1996, and the patterns of past HIV-incidence, which peaked in the mid-eighties. The current decline in the incidence of Aids, however, does not mean that there is also a decline in HIV-incidence. Unfortunately, it is hard to obtain sound figures for HIV incidence and prevalence.

However, persons who were not aware of their HIV infection at the time of Aids-onset account for an increasing number of the newly diagnosed Aids-cases: while this group accounted for 28% of all Aids-cases in 1996, the proportions were 39% in 1997 and 44% on 1998. This can be seen as an important development with respect to policy considerations, since this group cannot benefit from early HIV-treatment for obvious reasons.

There are also some considerable changes in the distribution of transmission groups among Aids cases, which reflect underlying HIV transmission patterns, although they might also be influenced by differential access to counseling and treatment. Overall, there is a decline in all transmission groups, in particular when it comes to homo- and bi-sexual transmission (a decline of 24%) and transmission through injecting drugs (28% decline). While transmission through heterosexual contact also declined (-10%), it has become the predominant transmission route among new Aids cases in many European countries, including France, Sweden, and Norway. Mother-to-child transmission has also been reduced substantially in Europe, which is seen as an effect of successful prevention intervention (counselling, testing and treatment).

In parallel with the trend in Aids incidence, Aids deaths have also been declining since 1996 (e.g. -32% in 1998), which is also due to more effective treatment options. These figures suggest, however, that the number of people living with HIV is expected to increase in the medium term.

Although in this report we are concerned only with countries from the European Union, where 90% of all Aids cases from the WHO European region were reported, it is worth mentioning that the Aids incidence actually has increased in the Central and Eastern part of that region. Strongly increasing trends have been observed in countries such as Ukraine, Romania, Yugoslavia, and Slovenia. Overall, the increase in Central and Eastern Europe was about 18% between 1997 an 1998. It is anticipated that Aids incidence will greatly increase in several Eastern European countries, including the Russian Federation.

The following table presents Aids cases and Aids incidence rates for the four participating countries (Source: European Centre for the Monitoring of Aids. HIV/Aids Surveillance in Europe. Data reported by June 1999 and adjusted for reporting delays.)

Table: *Aids cases and incidence rate (per million population) by country and year of diagnosis*

Country	1992	1993	1994	1995	1996	1997	1998	1999 (01-06)	total
Austria	190 (24,4)	230 (29,3)	165 (20,8)	201 (25,3)	137 (17,1)	91 (11,4)	102 (12,5)	39 (4,8)	1915
Belgium	246 (24,6)	253 (25,2)	253 (25,2)	243 (24,0)	204 (20,1)	167 (16,5)	140 (13,8)	87 (8,5)	2599
Netherlands	509 (33,5)	469 (30,7)	468 (30,4)	503 (32,4)	409 (26,2)	311 (19,8)	213 (13,6)	65 (4,1)	5054
Sweden	127 (14,7)	182 (20,9)	185 (21,2)	190 (21,7)	134 (15,2)	72 (8,2)	59 (6,6)	45 (5.1)	1663