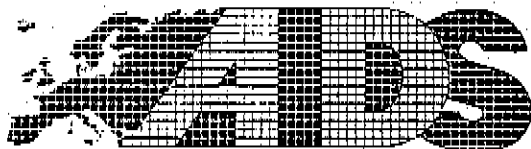




WHO

REGIONAL OFFICE FOR EUROPE



GLOBAL PROGRAMME ON AIDS

COMPREHENSIVE CARE FOR PEOPLE LIVING WITH HIV/AIDS



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1. Introduction

Although efforts to contain the spread of HIV/AIDS through information and education may in part be influential in reducing the expected increase in numbers of affected individuals, the fact remains that the pandemic continues to grow and raises new challenges for carers, policy-makers and the community as a whole.

The first clinical indications of AIDS in Europe were detected in the early 1980s, although the virus has probably been present since the late 1970s. Since then AIDS has spread rapidly, both geographically and numerically, and the number of new cases more than doubles each year.

All countries in the European Region, except Albania, have reported cases of AIDS, and by the end of March 1990 reported cases totalled 31 919. The highest numbers of cases in the Region are in France (8910), Italy (5307), Spain (4633) and the Federal Republic of Germany (4544). The estimated number of HIV-infected individuals in Europe is thought to be 500 000.

In the European Region, the first clinical symptoms of AIDS were seen in male homosexuals, followed by a growing epidemic among injecting drug users and then the appearance of congenital cases among children of infected mothers. Heterosexual transmission has been reported, and, although minimized by the media in a number of countries, the risk of heterosexual transmission is by no means exclusive to other regions. The most recent alarming outbreak of HIV infection among hospitalized children in Romania and the USSR, as a result of the use of unsterilized medical equipment and untested blood products, conveys the urgent need for more stringent hygiene precautions and safe therapeutic practices.

The long incubation period of the disease, the related stigma and psychosocial complexities, the present lack of effective treatment or vaccine, and the stark prognosis for a relatively young population have created a tremendous challenge for the health care sector as well as for communities at large.

The array of special needs for the infected individuals has made new and heavy demands on services regarding counselling, treatment of early symptoms and choice of care for the very ill during the last phases of the disease. Many Member States are concerned by the increasingly high cost of caring for rapidly growing numbers of people living with HIV/AIDS. Many innovative models of coordinated care, integrating the services offered by voluntary organizations with those provided by the statutory health care sector, have been developed in an effort to improve the quality of care and of life for people with HIV/AIDS.

The burden on hospital services is ever increasing, especially as far greater numbers of people will be affected in a more chronic way. As the number of individuals with HIV/AIDS continues to grow, the need for effective and appropriate provision of care will increase, including services provided for inpatient and outpatient care, home and community care. In addition, the special care needs of people with HIV/AIDS have exposed gaps in the continuity of available services.

There is evidence that care for people with HIV/AIDS in Europe is being planned and provided in a variety of ways reflecting local cultural, attitudinal and organizational traditions. The quality of care provided is

influenced by the degree of cooperation between the providers concerned, the involvement of consumers, the amount of resources allocated and the degree of sensitization of the policy-making bodies.

Care providers and people with HIV/AIDS are faced with similar concerns and problems throughout Europe, and international cooperation can facilitate exchange of experience, mutual support and identification and promotion of good models of care. Similarly, the occurrence of epidemics resulting from nosocomial transmission calls for greater international cooperation regarding training, technology and resources.

2. The concept of coordinated care

The concept of care encompasses a comprehensive, integrated process which recognizes the range of needs for wellbeing; it includes services and activities providing counselling and psychosocial support, nursing and medical care, legal, financial and practical services. The continuum of care model aims to ensure that identified needs can be met by coordinating an array of support services, sustained throughout the progression of the syndrome from pre-diagnostic counselling to diagnosis, symptom management, terminal care and bereavement.

People living with HIV infection have the right of access to services which are sensitive to their needs and wishes. People with HIV/AIDS, whether asymptomatic or with a fully developed disease and whether in hospital or at home, have an equal right to high quality care, independently of their social and economic circumstances. This includes the provision of services which are available, appropriate, effective, acceptable, adequate, timely, reliable, accessible and continuous.

Given the range of needs of people living with HIV/AIDS and the wide spectrum of services provided by different professional groups from both statutory and nonstatutory agencies, it is clear that these efforts should be coordinated. This can only be achieved through cooperation between the formal and informal systems providing services. A prerequisite for cooperation is an understanding of what can and is being provided by each sector, organization, agency and group.

There are many issues which are of particular concern when care is being planned for people with HIV/AIDS. These include hygiene precautions, improved home care, informed consent regarding diagnostic procedures and treatment, the acceptance of differing lifestyles and the making of care more accessible for gay and bisexual men, injecting drug users, etc., the provision of patient information services, improved quality of care for young people and alternative treatment.

The establishment of an integrated system for care has implications for the development of the following services:

- pre-test and post-test counselling;
- hospital-based and satellite ambulatory care services to provide generalized and specialized acute and chronic care and continuous medical supervision;
- home care and skilled community nursing services;
- hospice care;

- long-term care facilities, including appropriate nursing and psychosocial support;
- foster care and day-care services for adults and children;
- multidisciplinary medical and psychosocial care (infectious disease, oncology, pulmonary medicine, neurology, radiology, dermatology, psychiatry, social work, physiotherapy, dental care, nursing and nutrition);
- centralized case management (community or hospital based);
- health education;
- transport;
- recreation;
- housing;
- practical and emotional support for caregivers as well as for people living with HIV/AIDS.

Certain realities must be faced when a plan of comprehensive care for people with HIV/AIDS is developed. The medical as well as the psychosocial aspects of the disease provoke highly emotional responses which influence the provision of care; these pose a challenge both for the community as a whole and health professionals in particular. Attitudes and beliefs regarding differing lifestyles, for example, have to be confronted.

3. Meeting the need for quality of care

Quality of care will be improved when volunteers (including family members, friends, buddies, etc.) cooperate with professional health care providers. But cooperation between these groups of care providers is only possible when attitudes within them do not diverge greatly. An understanding of the factors that correlate with positive and negative attitudes towards people with HIV/AIDS is also relevant when coordinated care is being planned. Identifying these factors could influence the selection and training of care providers, both voluntary and professional.

A survey of health care workers' attitudes (1) was carried out nationwide in Denmark among physicians, nurses and aides to discover their knowledge of, education in and attitudes towards AIDS. Some striking findings of the study were that all the care professional groups overestimated the risk of transmission of HIV in the workplace (half the respondents felt that they were not sufficiently well informed to protect themselves at work), and almost half the respondents had one or more anxieties about caring for people with AIDS or else their partners were anxious about them doing so. More than 60% of the entire group felt that they were at risk in their work, and of these, 25% felt that the risk was considerable. Twenty-five per cent said they would not touch, examine or care for a person with AIDS.

Younger respondents demonstrated the greatest anxiety. Those with more liberal attitudes were less anxious; the most liberal attitudes to HIV-infected individuals were found among nurses (80%). The strongest anxiety

was evident in attitudes towards HIV-positive people and gay men rather than in relation to knowledge about HIV.

Since most countries have not been swift in their response to the needs of people with HIV/AIDS, nonstatutory advocacy and support groups have emerged to address the issues of prevention, education, care and support. The majority of these groups have been organized by gay men (and women). Suitable organizations to meet the needs of others affected by the disease have not been established at the same rate (for example, support networks for heterosexuals, children and injecting drug users.)

The emergence of a great number of voluntary agencies and nonstatutory services providing home care and other support services through buddies, family members and others has highlighted the gaps in the existing services available in communities. AIDS support groups have been established primarily because the groups of people who presented initially with HIV infection were perceived as being on the fringes of society; gay men needed to "come out" and establish their identity as a group.

It must be recognized that different populations with HIV/AIDS (heterosexuals, homosexuals, injecting drug users, children) require different strategies to meet their needs, and although work must be continued towards ensuring an equitable delivery of care for all, this diversity of consumers must first be recognized if specific needs are to be met.

One way to resolve this dichotomy is by ensuring, through education, that health care providers appreciate that the needs and feelings provoked by AIDS are the same for everyone. The education and training of health care providers should focus on the psychosocial as well as medical aspects of the disease and should allow trainees to examine their own feelings, attitudes and beliefs related to fear of contagion, sexuality and fear of dying.

New and innovative approaches to filling gaps in services and providing necessary support for people with HIV/AIDS have challenged the assumption that health professionals are the only appropriate providers of care.

Practical experiences of implementing a coordinated care model have revealed that care of equal quality is more likely to be achieved when there is close liaison between voluntary and statutory services so that their human and financial resources are used for common goals. However, when an effort is being made to coordinate services, it should be borne in mind that the medical and psychosocial aspects of the disease are not the only issues which may influence the provision of care and discrepancies in the quality of care provided. In addition, some members of communities in need of care are socially marginalized and unable to speak for themselves; services should be accessible and acceptable to all and special efforts must be made to respond to the needs of people that are hard to reach.

A consensus may not always be reached among professional and advocacy groups concerned with the complex issues of providing care and services for people living with HIV/AIDS. Policy-makers and planners therefore have an important role in assuring collaboration between government, physicians, health and social service providers and community-based organizations. Increased information about community needs and priorities enable state initiatives to serve communities better in their efforts to provide care for all those who are ill.

Many traditional health and social service agencies may be reluctant to affiliate and/or cooperate too closely with community-based organizations owing to the stigma associated with HIV/AIDS. In order to create a coordinated strategy for care, it is first necessary to develop a shared understanding of the needs and wishes of those cared for, to comprehend the professional and organizational parameters which will provide a framework for coordination, and to overcome the various conflicting interests which may exist.

4. Provision of care

In most countries in the Region, individuals with HIV infection and related illnesses are cared for in hospital units either designated as AIDS units or infectious diseases units. Outpatient care is provided through dermato-venerological dispensaries or departments of haematology. In the Federal Republic of Germany, for example, AIDS consultation centres have been established in each district to which symptomatic individuals are referred.

Inpatient and outpatient services are coordinated through the social services, and patients are followed up after discharge. Home care services are most often provided through national health schemes and private voluntary organizations and often also through the national Red Cross Society.

Although home care services exist, special training for staff is needed in caring for HIV-infected patients. Not all providers feel prepared to care for this group of patients: fear of contagion, fear of the unknown and attitudes towards risk behaviour groups are still factors which must be dealt with through training. Counselling skills should also be taught; pre-test and post-test counselling should include not only information and education regarding risk behaviour, the avoidance of transmission, and hygiene precautions but also sensitive, supportive counselling on such topics as sexuality, lifestyles and dealing with fear, anger and grief. Professionals and volunteers not directly working in this field also need to be made sensitive to these problems. As the number of affected individuals grows, it will also be increasingly necessary for health care providers in general to be well informed and able to support and inform people with HIV/AIDS appropriately.

The hospice concept, which originated in the United Kingdom for the care of people in the terminal phases of cancer, has not yet been broadly embraced in other countries. Gradually, however, other countries are acknowledging the need to provide caring environments for individuals requiring support during the last stages of life, especially for those who have little possibility of support in their homes. Established hospices, however, have usually not been prepared to care for individuals with AIDS. Since it is a relatively new illness, staff have been unprepared to cope with issues related to the illness itself, to the relative youth of the patients and the differing lifestyles they may represent. Questions also arise as to the appropriateness of hospice care for a relatively young client group, and to whether such care would reinforce the already stigmatized position of many people living with AIDS.

Better housing is needed for people who are unable to obtain or maintain adequate housing, for example due to discrimination either from family or landlords. Long-term care facilities, foster care and day-care services are needed for children and adults; respite care is required for intermittent needs.

Socially marginal individuals, members of ethnic minorities or injecting drug users may be hard to reach and maintain contact with in the community, and compliance may be difficult to sustain. Material incentives, such as the provision of accommodation, food and other facilities, may help to keep certain groups within the health services. Here a number of differing agencies and interest groups play a vital role in ensuring that information and support are available to all members of the community and may constitute the necessary link between the individual and the health services sector.

5. Models of care

Since far greater numbers of people will be affected by HIV infection in a more chronic way, the burden on the secondary health care services will increase and appropriate and accessible services outside hospital will be called for more urgently. A particular problem is that some groups in the population are not in contact with the primary health care services or are excluded from those services because of their lifestyles. They fear a lack of sensitivity or expertise on the part of the general practitioner. Various outreach programmes have been instrumental here in providing information, support and care for marginalized members of the community.

A basic principle of care for people with AIDS is the same as for any client group in the terminal stages of illness. This is a shift from diagnostic and therapeutic interventions towards symptom control and the emotional and spiritual resolution of issues concerning dying and death.

With no curative treatment available yet for HIV infection, clients with fully developed AIDS are in need of palliative care, although a clearly defined terminal phase is not relevant in the case of HIV-related disease. Even so, models of care for HIV/AIDS have been inspired by models of care for clients with cancer.

Since the 1970s, support teams in the United Kingdom have offered additional services to terminally ill cancer patients at home and in hospital. Teams have usually been multidisciplinary, including doctors, nurses and social workers with secretarial or administrative support. By 1988 there were over 250 teams in the United Kingdom, and palliative medicine had become an accepted subspecialty, dealing with the holistic care of patients who are in the late stages of illness and their loved ones.

The Bloomsbury Community Care Team (BCCT) in London has largely been based on the experiences of the multidisciplinary Bloomsbury Cancer Home Support Team, which caters to the needs of patients in the district who are dying of cancer at home. The broad principles of care are maintained in both support groups, namely to support patients and carers and to increase their choices of place of care and death by providing symptom control, emotional support, 24-hour cover, bereavement follow-up, support for other services and both formal education and one-to-one advice on diagnosis, nursing and terminal care requirements. Coordination is especially important because of the many agencies which may be involved in providing care for individuals with HIV/AIDS. The staff are given extra training in symptoms as well as the social, emotional, psychological and spiritual needs of different individuals with HIV infection (2).

Although hospital care is needed for acute episodes of illness related to HIV infection, particularly acute infections requiring intensive treatment, there is generally an increasing emphasis on the role of community care for

most patients. To provide for this, extra services are needed in the community to support patients and their loved ones, to provide expertise in the care of HIV/AIDS patients, to support and educate community professionals and to coordinate the various agencies that may be involved in care.

The BCCT was established in early 1988 and consisted of a consultant in palliative medicine, two senior nurses, a social worker, a research assistant and a secretary/administrator. Later an occupational therapist and a dietitian gave part-time input combined with other duties in the district. In Bloomsbury health advisers attached to the HIV/AIDS clinics work with clients in the early stages of care and offer help with social and financial problems. The BCCT aims to help in the later stages of illness or when there are difficulties with symptoms or home care. During the first 18 months almost 100 patients were referred to them, half of whom died at home while in the team's care.

A Support Team Assessment Schedule (STAS) was developed as an audit measure for professionals working with patients and families to apply when measuring needs. Patients were assessed at referral and fortnightly thereafter. Ten items of the STAS are concerned with the needs of the patient and his or her nearest carer or significant other, including symptom control, anxiety and spiritual and planning needs, and seven items are concerned with the necessity of providing services covering such things as finance, practical needs and coordination.

Since the introduction of the BCCT, hospital bed occupancy for HIV/AIDS in the district has halved and the percentage of clients dying at home is higher than the national figure (23% versus 15%). At referral, clients most commonly suffered from severe problems in the control of symptoms (including weakness, diarrhoea, muscle wasting, memory loss, visual problems and dyspnoea), family anxiety, their own anxiety and predictable uncertainty over the course of the disease and what types of care would be needed. After two weeks of support team care and by the last week of life, fewer patients had severe problems in these areas.

Although completing regular assessment schedules for all patients in care required time and added to already heavy caseloads, the staff found immediate gains from the assessments. These helped to clarify a patient's problems and needs: symptoms, anxieties, spiritual needs, etc. could be monitored and items of care could not be overlooked since staff had to attend to all needs if the assessment ratings were to improve.

Although it is impossible to say that the work of the team is solely responsible for change, analysis of the assessments from referral to death show that the requirements of patients were being met during care, and that the condition of the patients improved (based on the above-mentioned criteria).

6. Coordination with the nonstatutory sector

In the United Kingdom many health care teams have excellent relationships with voluntary organizations. The British Red Cross Society, for example, has traditionally cooperated with statutory agencies. The Red Cross operates a large auxiliary ambulance fleet and people with HIV-related infections requiring frequent transport to outpatient facilities may make use of this service. The Society also provides trained escorts to travel with patients and their partners.

The British Red Cross has recently introduced courses dealing with attitudes, sexuality and bereavement for volunteers. Support for caregivers, however, is at present uncoordinated and patchy. As services are organized by county branches of the Society, their availability sometimes varies and better organization is necessary.

Another example is that of AIDS Care, Education and Training (ACET), a Christian charity providing professional and practical home care for men, women and children affected by HIV/AIDS. A 24-hour telephone service provides links to the ACET physician, nurse or social worker.

ACET's education and training programme aims to combat the spread of infection and encourage positive attitudes to those affected by the disease. ACET educators who provide education and information in schools are first required to participate in the Home Care programme, gaining personal experience which gives greater impact to classroom teaching. The national network of volunteers is at present around 600, with six branch offices throughout the country.

ACET works closely in a complementary way with agencies in the statutory sector, but this is not the case with all organizations. The over 300 AIDS service organizations in the United Kingdom are not well coordinated, which often results in competition for funds and volunteers.

In Denmark, there is no history of voluntary organizations to meet health care needs nationally. The major voluntary group dealing with HIV/AIDS is the National Association for Gays and Lesbians. There is no national Red Cross Society involvement in AIDS care in the country. The buddy system is also less successful in Denmark than in some other countries, primarily because there is no history of voluntary activity.

The expense of hospitalization, as well as patients' own wish to spend more time at home than in hospital when their condition is stable, are factors which may well result in changes in attitude toward voluntary involvement in health care provision. At present, for example, the average length of stay in hospital for people with AIDS in Denmark is 100 days, compared with 15 days in San Francisco.

In many countries in the Region, home care is provided through local health services, with additional support from nongovernmental agencies. In Denmark, the need for additional support in home care provision has been recognized, but voluntary resources are not available. In 1988, a trial home care project was initiated by nursing staff at Hvidovre Hospital Infectious Diseases Unit, Copenhagen, to provide for the needs of patients whose condition is sufficiently stable for them to be cared for at home. As the staff recognized the limitations of the municipal home care services, especially during the terminal stages of illness, the project set out to hire volunteers who could provide support as extensively as required by the patient. The home help offered ranges from practical household help to companionship, nightsitting and relieving family members when they are at work or when they need time off (3).

The benefits of this trial programme are that home help is monitored by the hospital unit, which can provide technical support to the volunteers. The primary carers in the hospital unit function as coordinators of care. The limitation of the programme is that it is expensive to implement and necessitates special funding. Furthermore, the municipal home help service

has seen the project as competition to the services it provides, rather than as complementary to them. However the project is regarded as a successful alternative to hospitalization. After two and a half years, 50 patients with AIDS have been involved in the project of whom 34 have died in their own homes.

In Denmark, there is now a move towards respite care and day-care facilities for people with AIDS. Centres providing this care would also serve as sources of advice and support for family, friends or partners. Until this is implemented, however, most care will be provided at home. A feasibility study is planned to enable people with AIDS to purchase, with state subsidy, health care from a source of their own choice. This is now possible for other groups of people with chronic disorders and disabilities. This model, or one similar, could be very useful in providing ad hoc services for people with AIDS, such as domestic help and sitting services, which would greatly improve their quality of life.

The Noah's Ark/Red Cross Foundation of Sweden was set up in 1986 to help control the HIV epidemic and its consequences through activities in which compassion and care are reflected in practical action, by providing sensitive information and education about HIV/AIDS and by supporting those infected with HIV, their partners, relatives and friends. The Foundation is aided by a grant from the Ministry of Health and Social Affairs and is funded by local authorities and private donations (4).

With a staff of almost 30 and over 500 volunteers, the Foundation has six separate spheres of activity: information and education, counselling and support, the Guest House (a residence to provide respite care and support for limited periods of time for people with HIV infection), an AIDS Hot Line and newsletter and volunteer coordination. Separate associations have now been established in a number of other cities besides the Foundation base in Stockholm.

The initiatives taken and achievements made by Noah's Ark are an example of a good model of coordinated care. The Foundation has attracted considerable attention from Red Cross societies around the world, and it may prove to be a model for other countries. Noah's Ark is able to deal with the problems related to HIV infection and can provide sensitive and appropriate care in a country whose policies on HIV/AIDS have been regarded as restrictive (a court can rule, for example, that a person infected with HIV be confined to an institution against his or her will, if a physician has reason to believe that the person is not complying with instructions on avoiding transmitting the disease). As the Foundation's work is complementary to the statutory health sector, it is in a position to identify gaps in existing services and propose suggestions for working towards changing the provision of care in the statutory sector.

7. Community-based AIDS care: the Austrian AIDS Hilfe

The AIDS Hilfe is a private community-based AIDS service organization, founded in 1985, which emerged partly from the gay movement (5). It is a national organization, providing a wide range of services both to the general public, the groups of individuals mainly affected by HIV and certain professional groups. Throughout the country, the AIDS Hilfe operates eight counselling centres staffed with professional teams of psychologists, physicians and social workers who provide:

- anonymous face-to-face counselling
- telephone counselling
- psychosocial care and support for people with HIV/AIDS
- social work
- information and education
- street work
- anonymous HIV testing
- anonymous medical examinations (immune status)
- buddy services
- support to self-help groups among people with HIV/AIDS
- seminars on safer sex
- legal advice.

The AIDS Hilfe is not a self-help group. One of its principles is to offer professional help by experts in various fields, and all staff members except the "buddies" are therefore paid. The importance of special knowledge in relevant fields is also stressed, as is the expertise available among the people concerned and affected; homosexual men, former drug users and people with HIV/AIDS are therefore employed.

The AIDS Hilfe is the only AIDS service organization in Austria and is largely financed by grants from the federal government. It produces its own information material, conducts scientific studies and evaluation programmes and advises the Minister of Health. It is involved in policy-making at all levels as well as in national information and education campaigns.

In caring for people with HIV/AIDS, three areas are particularly relevant to the establishment of cooperation between city authorities and a community-based organization such as the AIDS Hilfe: policy-making, medical care and treatment in hospital, and community and home care.

On the political level, community-based organizations play an advocacy or lobbying role, exercising influence in areas such as non-discrimination (a fundamental precondition for a successful AIDS care programme) and avoidance of forced measures against risk behaviour groups or people with HIV/AIDS. In its own judgement, the Austrian AIDS Hilfe does not consider it has been successful in building alliances with government. It was not able to convince the Vienna councillor for public health to stop mass HIV screening, in many cases without informed consent, and it was not able to stop the introduction of pre-employment HIV screening, again in many cases without the explicit informed consent of job applicants. When this practice was publicized, the city government passed an anti-discrimination resolution guaranteeing that all persons detected as HIV-positive would be given nondiscriminatory treatment. Testing and registration still, however, create the fear of negative consequences in spite of anti-discriminatory resolutions.

As regards medical care, the community-based organization also lobbies for the best possible hospital care and exercises political pressure if it is not provided. Owing to the nature of the disease and improved treatment and medication today, life with AIDS is not a linear process: acute phases in which an individual requires intensive hospital care alternate with periods when he or she is fairly well and can lead a normal life.

The AIDS Hilfe has incorporated a medical office in each counselling centre, offering regular, anonymous HIV testing and medical follow-up, which can benefit from the close medical network established between the AIDS Hilfe physicians and the two AIDS wards in Vienna hospitals. These physicians take

part in team meetings at the hospitals, discussing common patients. Since the AIDS Hilfe staff physicians usually spend more time talking to their patients, they can inform and advise them more comprehensively. The additional advantages of this close cooperation are that the care and support programme can continue when clients are hospitalized, psychologists and buddies can provide emotional support, and social workers can visit clients to offer practical help. The AIDS Hilfe staff psychologists also supervise the nurses on the AIDS wards in the two hospitals.

Community-based organizations have the potential to build the strongest alliances with municipal authorities and institutions in the area of home and community care and social services. As no institution in Austria is responsible for caring people with AIDS, the AIDS Hilfe employs social workers in all its counselling centres; in Vienna five social workers are employed in a separate centre for social work.

On the understanding that people with HIV/AIDS should make use of the existing system of services and care, social workers in the AIDS Hilfe act as mediators between the social welfare system and individuals, either by informing and advising clients or by carrying out necessary practical tasks for them. Some examples of these are:

- applying for unemployment or housing allowance and social assistance
- finding a job or contacting the labour exchange
- securing money, furniture and clothes from charitable organizations
- finding housing
- arranging for remission of debts with the help of a lawyer
- providing legal advice
- procuring social services such as home helps and home care nurses.

The AIDS Hilfe has undertaken information and education activities for the benefit of municipal social care providers, to counteract their possible fears and prejudices about caring for people with HIV/AIDS. In general, the AIDS Hilfe has experienced excellent cooperation from the municipal authorities responsible for the provision of care and social services. Although social services for people with HIV/AIDS living at home are quite comprehensive (home nursing care, home help, buddies, meals on wheels, etc.) additional residential provision is needed for those people who do not need to be hospitalized but who cannot stay at home in spite of these services.

Although it is not necessary to create a special or new social and care service infrastructure, the existing services should be modified and adapted to the special needs of people with HIV/AIDS. Social and care service providers in existing institutions and organizations must be informed and educated about all aspects of AIDS so that they can deal with people suffering from HIV infection in a nondiscriminatory and fearless way.

8. Establishing service alliances

A delivery network in which as many services as possible are integrated could improve the coordination of care following discharge from hospital. Local authorities would have to take a leading role in the creation of a service alliance. The primary goal would be to enhance service integration, comprehensiveness, efficiency and policy coordination (6).

- (1) An alliance should facilitate continuity of care rather than act as an umbrella organization under which existing organizations are placed.

(2) The establishment of links with local government agencies (e.g. the health services, social services or agencies dealing with mental health and substance abuse) is a key element in an effective HIV-service alliance.

(3) The alliance should represent statutory and nonstatutory providers responsible for dealing with HIV/AIDS.

(4) The following groups should be considered potential members of an alliance: church groups, nongovernmental agencies, professional associations, gay community groups, elected officials, haemophilia associations, women's groups and people living with HIV/AIDS.

(5) The national AIDS committee should be included in a national alliance.

(6) The alliance should establish specific areas of responsibility to avoid duplication of services, and clearly define the role of each member.

9. The tasks of an alliance: developing a realistic, comprehensive care service plan

(1) The alliance should participate in planning the care system, starting with an assessment of needs and the identification of gaps in existing services and their requirements. The alliance should advise on budgets and the implementation and evaluation of the planned care system.

(2) The alliance should review any existing national AIDS programme plan that has been developed in the country or community.

(3) The top priority of the alliance should be the development of a realistic and comprehensive service plan. This plan must provide for continuity of care, including testing and counselling, specialized ambulatory care, medical and support services in the home, mental health resources, intermediate and long-term care, hospice services, case management and patient advocacy. Priorities should be assigned to each component based on the initial assessment.

(4) In developing this comprehensive service plan, the alliance should review the short- and long-term needs associated with continuity of care. This may foster a long-term commitment to the problems associated with HIV/AIDS.

(5) It is important that the plan's reliance on volunteers in the direct provision of support services should be kept to a minimum. A high volunteer-to-staff ratio leads to minimum supervision. The burden of giving care, exacerbated by inadequate supervision, can result in a high turnover of volunteers and insufficient continuity.

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