Funding policies for HIV and AIDS: time for change

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Funding for HIV and AIDS in England has been allocated to regions by a formula based on the number of cases of AIDS and HIV infection and on population size. Regions have distributed the resources directly to hospitals and community services. A survey of staff and managers in North East Thames region showed that funding arrangements have led to unsatisfactory development of services for HIV and AIDS. Firstly, because hospitals are funded according to current numbers of patients services are highly developed at the central London hospitals and underdeveloped in outer districts. Secondly, specialised community care teams have been established rather than integrating care for HIV and AIDS into generic primary care. Thirdly, the information on district of residence of infected patients is inaccurate, limiting allocation of funds according to population needs. Fourthly, prevention of infection has been given far less attention than treatment and care despite the lack of effective treatment. In future allocations for HIV and AIDS should be made to purchasers rather than directly to providers.

HIV infection has been the major new epidemic of the past decade. In the United Kingdom 7341 cases of AIDS were reported between January 1982 and March 1993 with 4572 related deaths.[1] The infection is widespread, with cases occurring in all regions but especially in the south east of England.

Resources for HIV and AIDS have grown commensurately. The allocation for 1993-4 is £214m, an 18% increase over the previous year.[2] Of this, £130m (61%) is for direct treatment and care, £52m (24%) for indirect care (including testing, counselling, staff training, information, and capital facilities), £21m (10%) for local prevention, and £11m (5%) for services for drug misusers. No funds are allocated directly to family health services authorities. Other national spending includes funds for the Health Education Authority, research, and grants to local authorities.

The formula used by the Department of Health to allocate regional funding for HIV and AIDS uses two approaches. Funds for prevention and indirect care and the HIV and AIDS contribution to services for drug misusers are allocated according to the size of the region's population. Funds for direct treatment and care are allocated according to a formula that uses the number of people with AIDS, categorised by the region where they were first reported and also by their region of residence; the formula also includes the number of people with positive HIV test results, categorised by the region where they were first reported.[3]

Guidance for the annual allocations has changed over time. In 1988-9 the Department of Health ring fenced all funds allocated to regional, district, and special health authorities for HIV and AIDS. From 1993-4, however, this policy is under review.[4] Similarly until this year funds for HIV and AIDS have been allocated directly to providers (mainly hospitals) rather than to purchasers. From 1993-4 the department will allow regions to fund districts according to the number of residents with AIDS or HIV infection.

The prevalence of HIV infection is highest in the south east of England, and more than half of all AIDS cases have been reported in the two north Thames health regions. In an interview survey of 77 staff and managers caring for people with HIV infection and AIDS in seven districts of North East Thames Region[5] we identified four important consequences of the funding arrangements described: centralised services, unnecessary specialisation of community care, inaccurate information, and lack of funding for prevention.

Centralised services

Services for HIV infection and AIDS have encouraged self referral, as for other sexually transmitted diseases, and sought to maximise use of the service by ensuring confidentiality. The growth of treatment at central London hospitals led to most HIV positive people using these hospitals until they became too ill to continue travelling. However, while some patients chose to go to a central London hospital for care if their local service was not well developed, for others there was no alternative. Local services remain underdeveloped, which causes problems for HIV infected patients who find it difficult to travel for treatment, especially drug misusers and those with young families.

The allocation of funds for HIV and AIDS according to numbers treated by providers rather than catchment population has perpetuated this imbalance. To maintain their funding the central hospitals have strong incentives both to encourage open access (for example, same day HIV testing) and not to refer patients back to their local district hospital. It will not be surprising if the central hospitals try to resist the Department of Health's move towards funding by district of residence.

Specialist care

Several larger providers receiving funding for treatment and care of HIV and AIDS have also developed specialised community based teams. But these teams have tended to work independently of generic community based services. The funding has encouraged a two tier system of care: the quality of community based health care received by patients in areas served by specialist teams tends to be higher than in districts with generic services. The specialist services have led to a concentration rather than dissemination of knowledge about management of AIDS and reinforced the belief, still held by many staff not caring for people with HIV infection or AIDS, that HIV infection differs from other chronic conditions and that existing health care providers are unable to manage such patients.

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MILDMAY MISSION HOSPITAL

Mildmay Mission is dedicated to patients with AIDS but other hospices in the region have not accepted AIDS patients

General practitioners and district nurses are (or can be enabled to become) skilled in control of symptoms, assisting with anxiety and emotional support, liaising with other community services and organisations, and communicating with hospital services. Such skills are fundamental for continuing care in the community for all patients and the opportunity to use these skills for the benefit of patients with HIV infection and AIDS has been missed. Patients with AIDS and HIV infection are becoming more widely distributed and it is time to disestablish specialist teams and ensure higher standards in generic care services.[6]

Special funding arrangements for palliative and terminal care have also contributed to separating AIDS patients from other district services. Since 1990 regions have been given special funding to support independent hospice and palliative care services,[7] but this money could not be used for services provided by the NHS. Although one independent hospice specifically for AIDS patients was established within North East Thames, other hospices receiving the new palliative care funding had not admitted AIDS patients. AIDS funding was used to support two dedicated domiciliary palliative care teams for patients with AIDS, but none of the funding for palliative care could be used to strengthen existing domicilliary nursing.

Information

The funding received by regions for treatment and care is based on numbers of patients with AIDS reported to the Communicable Disease Surveillance Centre. Although 80% of AIDS cases nationally are believed to be reported,[2] we found evidence that the data considerably underestimate the numbers living in some districts. For example, one district had collected postcode data from treatment centres across London which showed a cumulative total of 112 patients with HIV infection or AIDS by the end of 1991, including six deaths, but the surveillance centre data showed 32 cases, including nine deaths. Another district had data indicating that 47 of 366 HIV tests carried out in 1990-91 gave positive results. Of these 47 people, 21 had AIDS or AIDS-related conditions and five died. This compared with surveillance centre data showing fewer than 10 cases of AIDS and no new positive HIV antibody test results for the same period.

Part of the difficulty with information on AIDS and HIV is that some genitourinary medicine clinics are reluctant to identify patients by address because of confidentiality required by the 1920 Venereal Diseases Act. However, when patients attend other outpatients clinics with HIV infection or AIDS, or are admitted to hospital their name and diagnosis are recorded normally. AIDS is a new disease and requires new decisions not dependence on 70 year old legislation. It has been decided not to make HIV infection and AIDS notifiable. Adequate safeguards are required to protect confidentiality of diagnosis in all settings and to avoid inadvertent or prejudicial disclosure of HIV antibody status while allowing recording of information for accurate mapping of patients needing care. The accuracy of residence coding for hospital care of all patients has improved greatly since the data have been used to allocate funding, and similar results would be expected for HIV services once residence based funding is agreed.

Our survey showed that North East Thames region had not rigidly applied the Department of Health formula when allocating funds to districts and had encouraged bids for development of community care. Nevertheless, districts which had accurate data to substantiate their bids for development of services were more likely to be successful; and in the absence of accurate data on residence districts with high usage of service—that is, those in central London—were more generously funded, even though respondents suspected that many people using the service lived outside those districts. Because information on the number of people with AIDS in each district is poor districts with lower prevalences have either failed to recognise the need to develop community care services or failed to show the region their need for more funding.[5]

Prevention

The most striking consequence of the system of funding for AIDS and HIV has been the low priority given to prevention. While there is no effective cure for HIV infection prevention must be the preferred policy. Yet specialised hospital services have received the bulk of funding. In Camden and Islington, where there are large teaching and research centres, a prevention strategy is only now being agreed,[8] and funding for prevention is much less than for hospital treatment.

The priorities for prevention include ensuring wider use of condoms, focusing resources on the male homosexual population, and improving knowledge on AIDS and HIV in the general population.[8] In contrast, expensive "look back" procedures[9] (notification of patients after contact with a health care worker infected with HIV should be given lower priority, as these are unlikely to identify new patients with AIDS or HIV infection and treatment before symptons develop seems to be ineffective.[10]

Conclusion

Sexual health is one of the five key areas in the government's health strategy, *The Health of the Nation*. Bringing the method of funding for HIV and AIDS into line with the mainstream purchaser-provider relationship will have important benefits; the opportunity for districts given in recent guidance should be taken with both hands. One way of maintaining the quality of existing services while enabling districts with low prevalence to develop services is to place HIV and AIDS coordinators in purchasing authorities. These coordinators could contract for services on behalf of the local population: this should be more effective than the current position, in which developments are led by the service providers. The prime issue for HIV and AIDS coordinators would be to use the available resources to maximise health gain. For many districts

this would mean transferring funds away from specialist centres into primary care and prevention.

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"War on drugs" continues in United States under new leadership

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Criticism of the "war on drugs" pursued under Republican administrations has grown in the United States. With the election of Bill Clinton many experts expected a shift from law enforcement policies to an approach favouring treatment and prevention. The budget announced in April, however, revealed no such shift in allocation of resources. Although the war on drugs has apparently failed to reduce the supply of cheap heroin and cocaine to the United States, the prevention strategy favoured by its opponents—school based prevention programmes—has not yet been shown to be effective in dealing with the concentration of drug misuse among the socially disadvantaged. In looking for new strategies Clinton must satisfy both liberals and conservatives in Congress, and community policing might therefore prove to be a politically expedient option.

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After months of anticipation of fundamental changes in the United States government's approach to the country's drug problem, the budget announced recently by President Bill Clinton's administration showed virtually no shift in emphasis from that of its Republican predecessor.[1] Most of the $13·04 billion to be spent in the next year remains allocated to law enforcement and interdiction ($8·30 billion), and only $4·74 billion will go to treatment and prevention. This is essentially the same two thirds to one third division that existed under the Bush administration and that came under increased criticism due to its reliance on apparently ineffective strategies designed to reduce supply.[2]

MARKEL-LIAISON/GAMMA/SPOONER

Despite the war on drugs, heroin and cocaine are still readily available

Shift to reducing demand was anticipated

Expectations of change had been raised in part because Clinton appeared to be listening to people criticial of the emphasis on law enforcement and interdiction. Notable among these was Mathea Falco, who was an advisor to Clinton during his presidential campaign and who recently wrote a book on the drug problem that received the endorsement of Vice President Al Gore.[3,4] In the book's first chapter on the "supply-side seduction," Falco documents the failure of recent policies either to prevent the flow of cheap drugs into the United States or to reduce the ease with which they can be purchased in most large cities.

The case against the "war on drugs" policies that the Reagan and Bush administrations pursued with such enthusiasm is that they have failed to achieve their most basic objective, to reduce the supply of heroin and cocaine to the United States. Despite the billions of dollars spent over the past 12 years and increased numbers of drug seizures and drug related arrests, the purity of heroin and cocaine sold on the streets has increased while prices have fallen and the disease and social disorder resulting from the trade in illicit drugs has escalated, especially in inner cities. For example, in New York City the retail price of a gram of cocaine was $70-$100 in 1986 while in 1991 it was $50-$90.[5]

Other recently published books have also drawn attention to the limitations and inadequacies of prevailing policies,[6,7] and such criticism is increasingly finding its way into the popular press.[2,8] Where the critics part company, however, is in the alternatives they propose—these include decriminalisation of illicit drugs[6] and substantial investment aimed at rebuilding America's inner cities.[7] In this respect Falco is more pragmatic by asking for a shift to reducing demand, arguing that it is justified not only because attempts to reduce supply have failed but also because there are now effective treatment and prevention programmes. She does not suggest a huge increase in public spending or a dramatic turn about in social norms concerning drug use but rather a redistribution of existing resources and a shift in emphasis in how the United States views its drug problem.

In terms of prevention Falco follows the prevailing trend by lavishly praising the "social influences" approach, which teaches adolescents to identify pressures to use drugs (said to come mainly from the adverstising media and peers) and the skills necessary to resist such influences. Instruction tends to follow a set curriculum and is typically delivered in schools to