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HIV-AIDS and Social Care

by Keith Tolley, Alan Maynard and David Robinson

DISCUSSION PAPER 81

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Preface

As the number of those with HIV-AIDS increases, an important concern is to understand the pattern and range of social care needs and how best these can be met. This paper relates to the report of a two-year project, funded jointly by the Department of Health (DH) and the Scottish Education Department (SED), and based at the Universities of Hull and York.

The Hull-York study investigated, in brief, the range of HIV-AIDS-generated demands for formal and informal social care; the nature of the delivery, management and coordination of that care; the development by Social Services Departments (SSDs) in England and Wales and Social Work Departments (SWDs) in Scotland of their patterns of provision; and the direct and indirect costs of social care for those with HIV-AIDS.

The investigation comprised three complementary components:

* a questionnaire-based interview survey, in five localities, of 181 people with HIV-AIDS to determine what SSD-SWD, private, voluntary and informal social care is used and desired. In addition, 46 of these people were followed up and 14 informal carers were interviewed.

* a study based on semi-structured interviews with SSD-SWD staff in the same five localities - Hammersmith and Fulham, Kensington and Chelsea, Lothian, Manchester, and Westminster - to detail the patterns of social care provided by the authorities. In addition key health service staff in the localities were interviewed and self-administered questionnaires were completed by the staff of housing and environmental health departments and of 102 voluntary organisations.

- a national postal questionnaire survey of 65 SSD-SWDs, to show in broad outline the range of social care provision and plans in England, Wales and Scotland.

The focus of this paper is the relationship between the demand for and the provision of social care for people with HIV-AIDS. Identification of the demand for social care and support services by people with HIV or AIDS provides the basis for assessing the appropriateness of HIV-AIDS service supply of local authorities and the voluntary sector. This paper outlines a supply framework that can be used to examine actual service provision and innovative practices in HIV-AIDS service supply and the resources required to meet service demands. Other aspects of the research will be explored in subsequent publications.

Contents

1. THE MARKET FOR SOCIAL CARE IN HIV-AIDS

A market is a network of buyers (demanders) and sellers (suppliers). In the market for social care many of the services are not traded and, as a result, the user (the patient or client) receives assistance arising from decisions by a "guardian" which, following the Griffith's Community Care reforms, is to be the local authority care agent. This agent will be the budget holder and will contract with suppliers to ensure that the social care needs of clients are met in a cost effective manner.

One category of social care clients are those who are infected with the HIV virus. The spread of this virus in the British population has slowed but its true prevalence is unknown. It is likely that there is a substantial hidden "iceberg" of infection which, given the nature of the virus, will develop from covert HIV, into explicit ARC and fatal AIDS over a period of 7-12 years.

Thus the total level of demand for social care will increase and the particular needs of clients will vary according to the stage of the infection. To acquire an insight into the service use of people with HIV infection or AIDS and their unmet needs, the results of a survey of 181 HIV-AIDS clients in London, Lothian, Manchester and Birmingham have been used in this paper. Asking vulnerable and often very unwell people what services they need and what services they use is obviously a complex task and the results may be particular to the personal circumstances of the client interviewed (eg gay or a drug user) and the environment in which he or she lives (eg more affluent London opposed to less affluent Lothian).

The major merit of the client based approach to determining service use and social care needs is that it facilitates the quantification of the complex individual social care packages used by people with HIV-AIDS. It is evident, for instance, that many respondents were not satisfied with social work services and tended to use voluntary agencies to a greater extent, which they regarded as more user friendly.

Information such as this enables the purchasers to determine what alternative social care packages are used, ie what combinations of services provided by statutory, voluntary and private agencies and friends are used by the clients. Also it enables purchasers to identify unmet needs and informs the complex task of matching needs to demands which can be financed from a cash limited budget.

Inevitably there will be needs, such as for social care, housing and training services, which can be identified but which will not be met. Purchasers are required to prioritise competing needs and it is inevitable that some people will be denied care from which they could benefit.

Which people should be denied care? In the USA some States legislatures are deciding to deny MEDICAID benefits (available to a sub-set of the poor) to those people with full blown AIDS. Such a decision in the NHS would have significant effects on the allocation of social care in the UK. Without such a prioritisation decision in the UK, people with HIV and limited ARC are likely to be deprived of social care, whilst resources will be focused on people with ARC and AIDS.

Once needs and demands are measured and priorities are determined, the purchaser has to contract for the supply of social care services from competing suppliers. The statutory social services are only one source of supply. The purchaser may buy services from the NHS (eg for post-HIV test counselling) and from voluntary and self help groups as well as from social workers and home helps. In addition the skilful use of public funds can be used to induce increased supplies of support and care from relatives, "buddies", partners, friends and neighbours.

Often the price of these services is difficult to determine and the problems of identifying quality-performance standards and the relevant attributes of service supply are complex. At present both suppliers and demanders seem to have made only modest progress in evaluating the allocation of public funds used to purchase social care from both public (ie the statutory services) and private suppliers.

In addition to identifying and quantifying the volume of social care demanded and supplied it is possible to cost these service flows in a social care supply framework. This is a versatile method of examining what is spent, what could be spent and what is needed to meet all service demands. It serves to heighten awareness of the fact that demands will exceed the supply of care and that some difficult rationing decisions are unavoidable.

It is clear that those with HIV-ARC-AIDS suffer from social problems which reduce the quality of their lives considerably. Isolation, depression, declining resources and major problems with housing and the handling of the tasks of daily living as the infection progresses are factors which pose major challenges for clients and social care purchasers. The management of these demands and the supply of social care is rapidly becoming more focused, especially in the five study areas, and it is evident purchasers can learn much from each others' experiences.

2. THE DEMAND FOR SOCIAL CARE

Overview

The Hull-York survey of 181 respondents who were HIV positive sought to identify the impact of HIV infection on their daily lives, their use of practical and emotional support services provided by the statutory and voluntary sectors, and their opinions about existing services and consequential demand for social care. Some of the immense detail collected in this survey is presented below to identify what social care services are needed and demanded by clients who are HIV positive.

2.1 People Living with HIV-AIDS

The questionnaire-based interview survey in the five study localities - Hammersmith and Fulham, Kensington and Chelsea, Lothian, Manchester, and Westminster - was designed to assemble a group of people ranging from those newly-diagnosed as HIV positive to those with well-established AIDS. The broad categorisation of the sample is presented in table 1.

Table 1: The Nature of the HIV-AIDS Sample

Respondents Characteristic	Number	Percentage
HIV positive only	106	59%
ARC (pre AIDS, symptomatic HIV etc)	35	19%
AIDS	40	22%
	181	100%

Invitations to participate in the survey were distributed by local voluntary and self-help groups. The invitations consisted of a 'pack' containing a covering letter, a short project outline and a consent form. By this 'opportunistic' method it was hoped to reach not only people with HIV-AIDS in contact with statutory health and social services but also those whose only source of social care was the non-statutory sector. In addition, respondents were recruited via advertisements in the Body Positive and Frontliners newsletter and from 'packs' distributed by the genito-urinary medicine clinic at the West London Hospital. The recruitment role of 'key workers' and other interviewers was particularly important in Manchester and Lothian where it was difficult to gain the wholehearted cooperation of the voluntary agencies.

All respondents in the survey had had their HIV status confirmed by antibody testing: 83% at their local hospital, with very few using private clinics or general practitioners (5%), although 16% of the Scottish sample were tested by their GP due mainly to their presenting simultaneously with problems concerned with drug use. The main reason for seeking a test was the general suspicion of having the virus because of current or past sexual or drug-related activity (60%) and/or because of the onset of ill health (48%). Nine per cent stated that they had sought a test to confirm that they did not have the virus.

There were a number of people (14%) who did not know they were being tested and who, therefore, received no pre-test counselling. In addition, a further 47% of the sample had no pre-test counselling. The data suggest that the availability of such counselling has increased over time: 23% of those tested in 1984 received counselling whereas by 1989 the figure had risen to 67% (table 2). As far as post-test counselling is concerned 38% of the sample received none (table 3). Half of those people who had been tested without their knowledge received neither pre- nor post-test counselling.

<u>Table 2</u> <u>Pre-Test Counselling Received</u>

Year of diagnosis	Pre-test counselling: Number	per cent	No pre-test counselling: Number	per cent
1983	-	-	3	100%
1984	3	23%	10	77%
1985	8	21%	30	79%
1986	11	34%	21	66%
1987	14	39%	22	61%
1988	20	54%	17	46%
1989	14	67%	7	33%
1990	-	-	1	100%

Table 3 Post-test counselling received

Year of diagnosis	Post-test counselling: Number	Per cent	No post-test counselling: Number	Per cent
1983	3	100%	-	-
1984	8	62%	5	38%
1985	20	53%	18	47%
1986	20	63%	12	37%
1987	20	56%	16	44%
1988	25	68%	12	32%
1989	15	71%	6	29%
1990	1	100%	-	-

The background characteristics of the 181 respondents were:

* gender; 93% were male, with Scotland having the highest percentage of women (16%)

* age; ranged from 19-64 years with 47% clustered in the 26-35 age group. 37% of London respondents were over 40 compared with only 9% in Scotland

* marital/family status; 61% were single, 29% were partnered including gay partnerships

* living unit; 52% reported living alone, with Manchester having the highest percentage (63%) and Scotland the lowest (32%)

* education; 45% of Lothian respondents had academic or professional

qualifications, while Manchester had the highest figure, 79%

- money; Lothian respondents had the lowest income levels with 45% earning less than £50 per week compared with 36% in Manchester and 15% in London.

A total of 40 respondents (22%) stated that they were ex or current drug users with the highest proportion in Scotland (48%) and the lowest in Manchester (9%). Since knowing of their HIV status 43% of drug users said that they had stopped using drugs. Twenty three per cent reported 'no change', while 15% said they used less and 7% more. Twelve per cent reported that they used drugs 'differently', such as no longer injecting/sharing equipment, or using different drugs.

The impact of living with HIV-AIDS shows itself in a variety of ways in relation to key aspects of everyday life; such as: support in the home, health maintenance, accommodation and amenities, employment, transport and finance.

2.2 Support in the Home

Respondents were highly selective about to whom they revealed their HIV status. The survey showed that (ex) partners, parents, siblings and friends were more likely than not to be informed. In 9% of cases the respondent had not informed any of their personal contacts about their HIV diagnosis, mainly for fear of rejection. Table 4 demonstrates the response of those who were told was largely supportive, especially from friends and partners, as opposed to actively unsupportive or too distressed/shocked to respond. The experience or expectation of causing severe distress to parents was emphasised and, as with siblings, the news of HIV status was more likely than with other close contacts to be withheld until severe/terminal illness made it absolutely necessary.

Table 4: Reaction of personal contacts to the respondents HIV diagnosis.

Personal Contact	Percentage of all contacts		Percentage of contacts: Supportive	Unsupportive	Distressed/ unhelpful	Unknown reaction
Friends	42%	(n=143)	74%	11%	11%	4%
Parent(s)	21%	(n=71)	48%	8%	20%	24%
Partner & ex-partners	20%	(n=66)	74%	11%	14%	1%
Siblings	14%	(n=48)	62%	4%	17%	17%
Other	3%	(n=11)	73%	-	18%	9%
	100%	(n=339)				

Eighty-six per cent of the sample said that they could identify someone who would be able and willing to provide informal help and 39% knew of two or more such persons with the most frequently cited sources of help being friends (59%), family (45%) and partners (35%). Informal carers provided both emotional support and practical help (shopping, transport, lending money and cooking etc), although there were differences according to diagnostic category (table 5).

Table 5: Type of Support Provided by Informal Carers

Respondent characteristic	Practical help - percentage of respondents receiving help	Emotional Support - percentage of respondents receiving help
HIV+ (n=106)	30%	80%
ARC (n=35)	49%	80%
AIDS (n=40)	68%	90%

The question of practical help in the home was addressed in a number of ways. Almost 50% of the sample said that they had required help with some practical activities such as shopping, housework, laundry and cooking, with the proportion receiving help varying according to diagnostic category: 28% of those HIV positive only mentioned receiving help, 63% of those with ARC, and 70% of those with AIDS. Although a wide variety of practical help was being given by friends and partners, and to a lesser extent by family members, to substantial proportions of respondents in each diagnostic category, only a small number of people were able to identify someone who they would define as 'a carer'. It may be that there was a reluctance to define friends or partners as carers in so far as the term implies a relationship based on dependency. Or it may be that the help given was considered to be part of normal social interaction which characterises life for all, whether people with HIV-AIDS or not.

Not withstanding the amount of practical help given, there were many people who were able to identify specific sets of unmet needs for help in the home (table 6). In relation to housework, shopping, laundry and cooking, between 7% and 14% of the total sample identified either an absence or an inadequate level of help with such activities. In terms of respondents who specifically stated they required such practical help, the level of unmet need was between 27% and 33%. Despite this unmet need there was very little use of statutory or voluntary domiciliary care services. Only nine out of 181 respondents were receiving the assistance of an SSD/SWD home help at the time of the survey. Just as many people in the sample were unwilling to identify friends and relatives as 'carers' so they were reluctant to call in outside formal help for routine practical help in the home even when it was needed. Only five respondents (all in London) received help from an SSD/SWD or voluntary agency meals service.

Table 6: Unmet Needs for Practical Help in the Home

Activity	Number of respondents: No help received	More help required	Total Number	Percentage of sample	Total Numbers requiring help	Percentage with unmet need(1)
Housework	19	7	26	14%	80	33%
Shopping	15	7	22	12%	75	29%
Laundry	14	3	17	9%	56	30%
Cooking	10	2	12	7%	44	27%

(1) Defined as the proportion of all respondents who require help with each activity whose needs are not fully met or who receive no help at all (ie the figures in column 3 as a percentage of those in column 5).

The fact that nearly half of the sample required some form of assistance in the home but only 5% of respondents were receiving statutory assistance confirms the importance placed on informal care. The services provided currently by SSD-SWDs and similar agencies are often seen as being for people with severe disability or terminal illness. Where the demand for help fluctuates because of episodic ill-health then respondents felt it inappropriate to apply for formal care. Overall nearly a third of people requiring help with shopping, housework, laundry and cooking -within the remit of statutory home-help services - were not receiving help with one or more of these activities.

2.3 Health Maintenance

Although only 5% of respondents reported having experienced 'no symptoms', 39% judged their health at the time of interview to be 'excellent' or 'good'. Those with AIDS were, of course, more likely to describe their health as 'poor' or 'very poor'; 47% compared with 28% of those with ARC and 16% of those HIV positive only. Scottish respondents assessed themselves as being in the poorest health. When asked about specific health problems 50% of respondents reported depression-anxiety, 29% candida and 20% fatigue/weakness. Other problems included loss of weight (10%), night sweats (9%) and diarrhoea (8%). Eighteen per cent of the sample were officially registered as 'disabled' and 13% as 'chronically sick'.

Respondents were asked in what ways, if any, they had attempted to maintain or influence their health since knowing they were HIV positive. Only 17% of the sample were not taking some prescribed medication at the time of the interview, while 50% were taking three medicines or more. Ninety different drugs, medications or supplements were mentioned; the most frequent being AZT (52% of the sample), Acyclovir (24%), Fluconazole (18%) and Pentamidine (12%). In addition, 46% of respondents made purchases from herbalists, chemists and health food shops with the most popular preparations being skin creams, evening primrose oil and royal jelly. Approximately 20% of the sample had taken advantage of therapies organised by various groups and clinics. The most frequently cited were massage, meditation/relaxation, aromatherapy and autogenic training.

In addition to medication, preparations and therapies, many people changed other aspects of everyday life in an attempt to maintain or influence their health. Sixty per cent of respondents had changed their drinking habits since diagnosis as HIV positive with 80% of them either stopping or drinking less. Thirty per cent of the sample had changed their smoking habits with 60% of these either stopping or smoking less. A series of questions were asked about diet and eating patterns since people with HIV-AIDS are encouraged by medical advisors and by peers to maintain a healthy, balanced diet. Forty two per cent of the sample mentioned receiving advice on diet with the major emphasis on eating fresh produce and increasing protein intake. However, the majority of people in each diagnostic category had made dietary changes: 59% of those HIV positive only, 65% of those with ARC and 75% of those with AIDS. As for sexual activity, 32% of the sample stated that they had needed specific advice concerning, for instance, safer sex and the risks to self and others. Approximately 90% of respondents said that they had made changes in their sexual lives since diagnosis.

2.4 Housing and Amenities

The importance of suitable housing and domestic amenities was particularly stressed by respondents for whom there was a clear relationship between anxiety, deterioration in the immune system, and a concern for future well-being in terms of an appropriate and relaxing environment. Since being diagnosed, 28% of the sample had moved house for some HIV-related reason such as 'harassment', facilities no longer being suitable, or altered relationships. At the time of the interview 32% of the sample were actively seeking a change of accommodation, with Scotland having the highest proportion of potential movers (55%).

Specific problems within the home included difficulties with stairs, mentioned by 49% of respondents, heating (48%) and damp (19%). Also reported was an increased use of domestic appliances since the HIV diagnosis; such as the telephone (47%) washing machine (34%) microwave oven (30%) toilet (26%) bath (25%) shower (18%) and refrigerator (17%). Similarly, many people had acquired domestic items such as food processors, humidifiers, answer phones, vacuum cleaners and fan heaters, which they felt would minimise fatigue or improve the management and quality of their daily life: 48% of those with AIDS, 37% of those with ARC, and 19% of those who were HIV positive only had bought such things.

Most respondents made recommendations on the type of housing and associated facilities which should be available for people with the virus, and many went into considerable detail, reflecting again the importance attached to housing issues. At the head of a long list of specific demands in relation to housing came the need for ground floor accommodation, followed by internal and external adaptations to increase mobility, proximity to clinics, and the prevention of 'ghettoisation'. On the matter of appliances and specific internal facilities approximately half of the sample stated that they now required something such as a washing machine (33 people), microwave (21), clothes/spin drier (15), telephone (15), shower (12), refrigerator (10).

2.5 Employment

The impact of having HIV-AIDS on working life or on the motivation to continue or seek work was explored. Thirty nine per cent of the overall sample were employed at the time of the interview, with Scotland having the lowest proportion (19%). In terms of current diagnosis: 47% of those who were HIV positive only were employed compared with 33% of people with AIDS and 17% of those with ARC. Among the employed, several had changed jobs or working positions to relieve stress or better accommodate HIV-AIDS-related health problems. Of those who had worked since being diagnosed HIV positive, 63% reported that their working conditions had adversely affected their health. Most frequently cited were fatigue and the strain of working in a situation where their HIV status was unknown to colleagues.

Forty per cent of those employed since diagnosis gave examples of hostility or discrimination at work because of their known HIV status or because of fears that it would be revealed. On the other hand, almost as many respondents spoke of their colleagues being supportive in terms of rearranging work schedules, allowing time off and being understanding. There was some evidence of employers (38%) and unions (10%) being known to have formally-agreed policies covering HIV positive employees. Fifty nine per cent of the sample said that their motivation to work had changed since being diagnosed HIV-AIDS; with four out of five being now less motivated to work because of problems encountered or feared.

Over half of the sample spoke of the need for increased education for the public, employers and employment agencies and a further 37 expressed a demand for increased counselling and support and a similar number wished to see the establishment of further HIV policies in the workplace.

One third of the sample was actively involved in one or more voluntary or self-help organisations, most of which were HIV-AIDS specific such as Terrance Higgins Trust, Act-up, Body Positive, Frontliners, etc. Not surprisingly 81% of those involved said that their association with voluntary/self-help organisations had increased since being diagnosed and 93% reported gaining benefit from the work. The most frequently expressed comment was that there was personal satisfaction and fulfilment gained from helping, giving and sharing. In addition, being part of a group provided a structure, focus or 'purpose' to life and enabled people to live better with their HIV status.

2.6 Transport

Problems with day-to-day transport increased with the severity of diagnosis, with 33% of people who were HIV positive only, 54% of people with ARC and 65% of people with AIDS experiencing difficulties. More Scottish respondents (74%) than others reported a transport problem. The most common problem, mentioned by 33% of respondents, was inaccessible transport and exhausting travel. Allied to this were complaints about infrequent and unreliable services. The most difficult to reach places were outpatient clinics/hospital (mentioned by 25%), shops/post office/chemist (15%), relatives (14%) and leisure/friends (11%). A further 13% said that they had difficulty reaching 'everywhere'. One third of the sample reported changing their transport arrangements because of the virus with, in particular, the change from public transport to taxis.

In response to a general question about the need for practical assistance, 40 people (22% of the sample) mentioned their need for assistance with transport. One hundred and five respondents made one or more recommendations about transport such as improved public facilities (63 people), financial assistance with fares - particularly taxi fares and better administrative arrangements in relation to the provision of concessionary fares.

2.7 Finance

The respondents in the survey received income from two main sets of sources: i. wages/salary and ii. benefits, occupational pensions, interest from shares/savings and other miscellaneous sources. Seventy eight out of the 181 respondents received money from source i: on average £205 per week for those with HIV only, £113 for those with ARC and £198 for those with AIDS. One hundred and sixteen respondents received money from source ii: the sums were £62 for those who were HIV positive only, £68 for those with ARC and £95 for those with AIDS. The total average weekly income for those in each diagnostic category was HIV positive only £139, ARC £87 and AIDS £105.

In order to put these figures in context it is important to make an assessment of the impact on income of having the virus. The virus-related costs were identified in relation to lost income; additional home maintenance requirements, health maintenance; regular expenditure such as gas, telephone, insurance etc; and leisure and recreation. The impact of HIV-AIDS related changes in expenditure on these items varied according to diagnostic category and are shown, in outline, in table 7.

Table 7: Personal financial impact of living with HIV-AIDS

Average Change in Personal Cost per individual experiencing a change since HIV diagnosis		HIV+ (n=106)	ARC (n=35)	AIDS (n=40)
Earnings loss per week(1) (over past 2 years)		£36	£55	£123
% of respondents		17%	29%	23%
Long term unemployment(1) (ie exceeding 2 years) Loss of earnings since(2) diagnosis	high	£47,500	£27,300	£57,700
	low	£23,800	£13,600	£43,200
% of respondents		12%	41%	26%
Household equipment cost per week		+£1.28	+£1.32	+£1.37
% of respondents		13%	26%	28%
Food cost per week(3)		+£7.84	+£8.19	+£12.12
Health products cost per week		+£2.56	+£4.91	+£3.26
% of respondents		47%	49%	43%
Sexual products cost per week		+£2.94	+£2.66	+£0.92
% of respondents		17%	31%	10%
Alcohol cost per week		-£6.72	-£7.74	-£11.46
% of respondents		72%	77%	72%
Regular household bills - cost per week(3)		+£3.30	+£5.40	+£4.95
Leisure/social costs per week(3)		-£6.24	-£31.78	-£41.98

Notes

A negative sign demonstrates a reduction in expenditure, a positive sign an increase in expenditure (1989 prices)for respondents experiencing a change in costs incurred since having the virus.

(1) Not including income from benefits/other sources.

(2) High estimate based on the assumption that 100% of long-term unemployment was due to the virus; low estimate based on 50% of HIV+/ARC, and 75% of AIDS, long-term unemployment was due to the virus.

(3) Covers average change in costs for all respondents in the sample.

2.8 Service Use

2.8.1 Voluntary Organisations

Earlier it was shown that approximately one third of the sample was involved in some form of voluntary group activity (section 2.5). A much higher proportion (75%) made use of such a group for some service related to their HIV status: with 52% having used more than one voluntary or self-help group. The respondents in London used a wider range of services which reflected the much greater availability including multi purpose centres such as the London Lighthouse and the Landmark Centre. Respondents used self-help or voluntary organisations for a variety of purposes ranging from one-off requests for a particular service to longer term group support and social contact. The most frequently cited reasons were peer group support, understanding and counselling (36% of the respondents), legal and financial assistance (21%), health maintenance and related advice (10%), leisure and social contact (7%) and housing (6%). Not surprisingly, compared with those who were HIV positive only, twice as many people with ARC/AIDS required legal and financial assistance and transport and three times as many required help in the home and with holidays. It was found that 20% of those using voluntary services had received help in the home: in the form of cleaning and decorating as well as counselling and massage. Twelve people mentioned having a 'buddy' to provide support and/or practical help.

Respondents using the voluntary sector (136) were asked whether there were any services that they preferred to obtain from such groups rather than from elsewhere. Forty six per cent replied "yes" and cited the quality of counselling and personal support and the unbiased information provided. Fifty four per cent of respondents said that they had used a voluntary group because they believed that the help or service they sought was unavailable elsewhere, with the proportion making this comment being highest in Scotland (83%) due in part no doubt to the extensive use of voluntary groups by drug users. Although the great majority of voluntary group users consider them to be excellent or very useful, there were reservations about specific aspects of the services. One set of comments (41) concerned structure and organisation - disorganised, no back-up, too busy, underfunded (so unable to provide sufficient services), need for better communication between groups etc. A second area of dissatisfaction (20 respondents) referred to atmosphere or 'ethos' and the extent to which people were not felt to be welcome. The third concern (14 people) related to poor support or buddying difficulties while the fourth set of stated concerns (15) referred to perceived gaps in the services provided. In all, 53% of those using voluntary services voiced some concern or complaint.

2.8.2 Social Services

Eighty three respondents (46% of the sample) reported that they had seen a social worker since they were diagnosed HIV positive. Fifty four per cent of these had seen a general or area social worker, 38% had seen a hospital social worker and a further 6% had seen a probation social worker. The most frequent route of referral was from hospital (55.8%) followed by self-referral (15.1%). The main reason for seeking the services of a social worker was for advice and information, financial help and access to the practical help which social services provide.

Thirty three per cent of the sample reported that a social worker had arranged particular services for them or had acted as an intermediary in gaining access to services. Almost half of the instances of assistance were in relation to practical matters such as receiving help with housing, bus or travel passes and home help services, with ARC-AIDS respondents not surprisingly receiving more practical help than others. Twelve per cent of the sample reported that they had been referred to other service providers by a social worker, the great majority being to health services, housing and voluntary organisations.

Fifty three respondents stated that they had found at least one aspect of social service helpful. The most frequently mentioned were financial assistance and advice, general advice, and counselling. On the other hand, 36% of those in contact with social workers had some reservations, either general dissatisfaction or specific complaints such as delays, 'personality clashes' or breach of confidentiality. When asked about their general views on social workers the majority of respondents felt that social workers were good at providing practical help whereas only just over a third felt that they were good at providing emotional support (table 8). Overall, respondents who had actually used social work services themselves had a higher regard for them and expressed more positive opinions than those who had not.

When asked to say whether there were any social services that they would like to see provided, 60 people mentioned one or more forms of advice or assistance. As for social services generally, 85% of the sample also agreed with the statement that "it is better for services to be provided by workers who specialise in HIV work" rather than those with general workloads. Specialists, it was felt, would be better trained and better able to understand the needs and feelings of people with the virus.

Table 8: Attitudes to Social Worker Services

Statement (n=181 for each statement)	Strongly Agree	Agree	Disagree	Strongly Disagree	No/varied opinion	Total
	Response Percentage who:					
Social workers are good at providing practical help	7%	59%	19%	6%	9%	100%
Social workers are good at providing emotional support	5%	34%	36%	10%	15%	100%
Social workers take your own needs and wishes into account	5%	59%	22%	5%	9%	100%
Social workers consult you before changing plans/arrangements	5%	40%	24%	7%	24%	100%
Social workers are good at keeping things in confidence	12%	39%	15%	7%	27%	100%

2.8.3 Health Services

Although the prime focus of the study is social care, there is considerable overlap with health care in respect of HIV infection. Respondents were asked about their use of and views of outpatient services, inpatient services, domiciliary care, general practitioner services and dentistry.

Only six respondents were not in contact with an outpatient department. Not surprisingly, 93% of the sample said that they had used outpatient departments more since knowing of their condition: for regular check-ups and occasional visits to specialist clinics. Of the 45% who said that they were usually accompanied on their outpatient visits, all but one person was accompanied by a friend or partner or family member to give moral support and reassurance. It should be noted that the departments were felt by only a minority of respondents to be good at providing emotional support. 37% of outpatient users reported one or more problems associated with the visit such as inconvenience and discomfort, emotional distress and upset, appointments and waiting times, and lack of privacy and confidentiality.

Almost half of the sample (46%) had been admitted to a hospital ward because of the virus, with Scottish respondents showing the highest percentage (65%) and, as would be expected, different rates for different diagnostic categories: HIV only 21%, ARC 66% and AIDS 95%. The most frequently cited reason for admission (41%) was a respiratory disorder: PCP, pneumonia, tuberculosis, chest infection etc. Seventy eight per cent of people who had been patients gave one or more example of pleasing aspects of their stay, such as the caring qualities of the staff both nursing and others such as consultants, chaplains and dieticians and the provision of counselling support and privacy. On the other hand, 48% of respondents who had been patients made one or more complaints about the ward/hospital regime (29%), food and conditions (27%), segregation/attitudes (23%) and treatment (16%). Clearly, for some, a single or small separate room is 'privacy' to be welcomed, while for others it is 'segregation' to be criticised. Approximately one in four people described facing problems following their discharge from hospital: mobility, housing costs, the lack of needed amenities, and the emotional impact of the hospital stay. Only a minority of people had had any discussion concerning their home circumstances prior to discharge. When asked a number of general opinion questions, those who had actually been an inpatient gave much more favourable responses than those who had not.

Only 10% of the sample had received medical or health related care in their home from someone other than general practitioner and this was most likely to have been for people with ARC-AIDS. Provision of care was from home support team, district nurse, occupational therapist and others, with the majority of visits being to provide support or to monitor progress.

Since medical care for people with HIV-AIDS is most often organised via specialist hospital services and specialised clinics and units, the role of general practitioners is, to date, relatively limited with the possible exception of those GPs involved in the care of drug users. While 86% of the sample were registered with a local doctor only 66% of the sample said that their doctor knew of their HIV status. It is clear that there may be many general practitioners who believe that they do not have any HIV-AIDS patients when in fact they do, since 31% of people with ARC and 30% of people with AIDS said that their GP was not aware of their HIV status. Of the 51 respondents who said that they had not seen a doctor since their diagnosis was revealed, 14 said that they had 'no need' while a further 27 said that all their requirements for health care were catered for by an HIV clinic. A further nine were deterred by their GPs assumed lack of knowledge or sympathy. Over a quarter of the sample had changed their GP since knowing they had the virus, this had most frequently occurred in Scotland (45%). When asked about problems, over a quarter said that they had one, the most common being the 'attitude' of the GP towards people with the virus and drug users (table 9). In response to general attitude questions those who had actually used a GP since knowing they had the virus were more likely to make favourable responses.

Table 9: Attitudes to GP Services

Statement (n=181 for each statement)	Response Percentage who: Strongly Agree	Agree	Disagree	Strongly Disagree	No/or varied opinion	Total
Local Drs are good at providing practical help	3%	41%	41%	10%	5%	100%
Local Drs are good at providing emotional support	3%	23%	46%	20%	8%	100%
Local Drs take your own needs and wishes into account	4%	40%	35%	8%	13%	100%
Local Drs consult you before changing plans/arrangements	3%	42%	23%	5%	27%	100%
Local Drs are good at keeping things in confidence	5%	57%	11%	3%	24%	100%

A dentist had been visited by 71% of the sample since knowing that they had the virus. Thirteen per cent of the sample had been refused dental treatment because of their HIV status including one person who had been refused treatment while in prison. Many spoke of being made to feel stigmatised. One in three of the sample had changed dentist since knowing of their HIV status, the great majority in response to a treatment refusal or the unsatisfactory attitude of the dentist.

Only a small proportion of the sample (8%) had paid for practical services in the home such as cleaning, painting and decorating, moving and repairs while 15% reported that they had paid for special treatments and therapies to promote their physical and psychological well being. The majority of those who were willing to pay for special treatments and therapies said that they did so because such treatments were not available from statutory health services. Only 18 respondents belonged to a private medical scheme and all but two had joined before they were known to be HIV positive. Eleven people said that they had paid for private medical treatment either because they needed a doctor immediately or because of dissatisfaction with the NHS.

2.9 Costs of Meeting Demand

The data on social care service use from the HIV-AIDS questionnaire survey were used to calculate a set of low and high cost estimates (at 1989 prices) for social care and support services used by people who were HIV positive only, had ARC, and those who had progressed to fully developed AIDS. The package consisted of five types of service use: SSD/SWD social workers, home support, practical equipment/services, health maintenance therapy and goods, practical advice and emotional support services (other than that provided by family, friends or partners). This, as shown in table 10, produced a total cost estimate of £37 - £45 per week in 1989. The higher costs of service demand by people with AIDS is apparent from Table 10: £88 - £105 per week compared to £17 - 19 per week for respondents who were HIV positive only. This costing covers services provided by the SSD/SWD, voluntary agencies, specific staff employed by the NHS, private sector, and informal carers (for practical home support services only).

The data in Table 10 show the importance of practical home support services as a component of the cost package (covering help with shopping, laundry, cooking and housework), contributing two thirds of the total cost (£31 per week for the high cost estimates). For people with AIDS such support made up 78% of the total cost of the social care they used (high cost estimate). The cost of informal carer time was included within the home support package. This cost was significant, representing an estimated 60% of total home support costs and 41% of total social care use costs for the whole sample (table 11).

Table 10: Average Weekly Costs of Social Care Service Use (1989 prices)

Type of Social Care Support	HIV+ (n=106)	ARC (n=35)	AIDS (n=40)	Total (n=181)
Home Support(1)				
Average cost of service use per person				
Low cost est. (£s per week)	10.35	26.07	70.45	26.67
High cost est. (£s per week)	10.87	32.74	82.78	30.99
High cost est. as % of total cost	56%	64%	78%	69%
All other social care(2)				
Average cost of service use per person				
Low cost est. (£s per week)	7.06	13.46	17.66	10.47
High cost est. (£s per week)	8.54	18.39	23.06	14.13
High cost est. as % of total cost	44%	36%	22%	31%
Total social care package				
Average cost of service use per person				
Low cost est. (£s per week)	17.41	39.53	88.11	37.14
High cost est. (£s per week)	19.41 (100%)	51.13 (100%)	105.84 (100%)	45.12 (100%)

Notes

Low cost estimate - based on assumption that service supply was by a non-specialist, 'low' apportionment of on-costs; low estimate of service use.

High cost estimate - based on assumptions (where appropriate) that service supply was by a HIV specialist; 'high' apportionment of on-costs; high estimate of service use.

These estimates are derived from the services used in the 5 study authorities.

(1) Includes informal care, statutory domiciliary care, voluntary agency help in the home

(2) Includes social workers services, practical goods and services, health maintenance services, practical advice and emotional support.

Table 11: Average Weekly Cost of Informal Care Used[1]

Informal care costs	HIV+ (n=106)	ARC (n=35)	AIDS (n=40)	Total (n=181)
Average cost of informal care(2) received per person (£s per week)(3)	9.15	15.69	44.97	18.61
Costs as a percentage of total home support costs (4)	84%	48%	54%	60%
Costs as a percentage of total cost of social care (4)	47%	31%	42%	41%

Notes

The data are from the 5 study authorities.

(1) The costs of the time of informal care has been valued at the equivalent payment rate for an SSD/SWD home help.

(2) i.e. friends, family and partners.

(3) Includes the cost of time spent helping with housework, cooking, shopping and laundry.

(4) As a percentage of the high cost estimate (table 10).

These cost estimates can be used to produce a rough estimate of the aggregate costs of the potential demand for HIV-AIDS related social care in the UK based on a total of 1623 people with AIDS at the end of June 1990 (table 12). This produces a national cost of service demand by people with AIDS of £143,000 - £172,000 per week or £7.4 million to £8.9 million over one year (i.e. weekly cost multiplied by 52 weeks). Similarly, there were 14,090 people who were known to be HIV positive only in June 1990. Using the average cost estimates produces a total potential demand cost of providing social care for people who are know to be HIV positive for the UK of £245,000 to £275,000 per week or £12.7 million to £14.3 million over one year. If it is assumed that the 14,090 HIV+ people also includes people with ARC, the total national cost of providing social care to people who are HIV positive, have ARC or AIDS is estimated at £388,000 to £447,000 per week or £20.1 million to £23.2 million per year.

Table 12: Average and Aggregate(1) Cost of Demand

Average/Aggregate costs		Low cost estimate	High cost estimate
Average cost of service use per person with AIDS	- £s per week	88.11	105.84
Aggregate costs of service use by people with AIDS(2)	- £s per week	143,000	172,000
	- £s per year	7.4 million	8.9 million
Average cost of service use per person HIV+ only(3)	- £s per week	17.41	19.41
Aggregate costs of service use by people HIV+ only(4)	- £s per week	245,000	275,000
	- £s per year	12.7 million	14.3 million
Total aggregate cost of service use by people HIV+, with ARC or AIDS(5)	- £s per week	388,000	447,000
	- £s per year	20.1 million	23.2 million

Notes

(1) The aggregate cost estimates represent the cost of providing the same level of service nationally as has been received by the respondents in the five study areas.

(2) Based on a figure of 1623 people alive with AIDS as of June 1990 (calculated by CDSC/CD(S)U).

(3) Based on a figure of 14,090 people known to be HIV+ as of June 1990 (calculated by CDSC/CD(S)U).

(4) The HIV+ cost estimates have used the social care package data (in table 10) and assumed the cost of HIV+ and ARC social care packages are the same. This assumption is made because it is not possible to distinguish HIV+ and ARC cases in national data provided by CDSC/CD(S)U although it is, from the Hull-York survey, possible to distinguish service cost differences for these groups (table 10).

(5) Based on the total number of people known to be HIV+, have ARC or alive with AIDS (i.e. 14,090 + 1,623 = 15,713).

These figures provide a crude estimate of the true cost of providing the same level of service nationally as has been received by the respondents in the survey from the five areas in which the demand for social care for people with HIV-AIDS is already well established.

3. SOCIAL CARE SERVICE SUPPLY

3.1 A Social Care Supply Framework (SCSF)

An accounting framework has been developed to examine resources directed to several complementary areas of service provision. This social care supply framework (SCSF) can be applied to assess the service provision of a range of agencies. In this paper it is applied to the HIV-AIDS related service supply of services by local authorities.

In this context, the SCSF consists of six key components, which combine to produce a total service supply (SS). The framework has the following structure:

$$SS = MC + T + PE + H + SC + ME$$

where SS = service supply, MC = service management and co-ordination, T = training, PE = HIV related prevention and health education, H = housing, SC = direct social care and support, ME = monitoring and evaluation. The framework can be extended to incorporate service supply by the voluntary sector (+ V) and by informal carers (+ IC). A more detailed breakdown of the areas of activity included within each component of the SCSF is set out in appendix 1.

This framework was developed from the experiences of HIV-AIDS service provision within the five high profile authorities who participated in the study. The objective was to use it to assess local authority involvement in HIV-AIDS services from two inter-related perspectives:

a) the key organisational/policy issues involved in local authority HIV-AIDS service supply and indicators of 'good service practice'.

b) the costs to the local authority of providing an HIV-AIDS related service.

To examine the local authority organisational/policy response to HIV-AIDS, data were collected from the SSD/SWD, housing, education and environmental health departments of each of the five local authorities. These data were supplemented by information from 65 SSD/SWDs which participated in a national (ie England, Scotland and Wales) survey of HIV-AIDS related social care supply patterns and plans, and by information derived from questionnaires completed by 102 voluntary agencies based in and around the study localities. Aggregate cost estimates were made for the five local authorities only.

The analysis of the five authorities in the study showed that each was involved in a wide variety of HIV-AIDS related service initiatives, either through the use of special programmes and/or the use of existing services. In spite of this, HIV-AIDS service planning had largely been undertaken without a clear and ordered framework within which to assess the organisational and cost consequences on an authority-wide basis. The SCSF provides an explicit and logical framework with which to attempt this.

By way of an example, the framework can be used to examine the resource division by a local authority between the components of HIV-AIDS service supply. The costs of the SC component of the framework are affected by the level of resources directed to each other component. Sufficient inputs into

MC, T, PE, H and MC components may result in efficiency gains in SC, the suppl of social care and support, without any reduction in service quality.

3.2 The Context of Local Authority Services

There are a number of important factors that affect the organisational/policy and resource response of local authorities in the UK to HIV-AIDS service supply. Five factors are:

a) The actual and potential demand for HIV-AIDS services which are supplied by the local authority

b) The availability of Central Government grant for the development of HIV-AIDS service

c) Assessments of particular local HIV-AIDS service requirements by managers in individual local authorities.

d) The role of the voluntary sector in HIV-AIDS service provision

e) The impact of the Government's Care in the Community reforms on the development of HIV-AIDS services.

Local authorities in England, Wales and Scotland are at varying stages of HIV-AIDS service development, ranging from SSD/SWDs whose involvement to date has been the production of an HIV-AIDS policy statement, to others with a large task-force of HIV-specialist and trained non-specialist workers providing or ready to provide a service for people affected by HIV infection.

Therefore, the strategy adopted in this paper is to focus on the findings relating to actual impacts within the five study authorities, supported with evidence from the national survey of SSD/SWDs, in so far as this provides generalisable evidence of the potential organisational impact on a local authority HIV-AIDS service of each of the five factors considered above. This is attempted in section 3.3, and in section 3.4 the costs of service supply are explored by combining the SCSF with the experiences of the five study authorities.

3.3 Organisational Impacts

3.3.1 Actual and Potential Demand for Social Care

Each of the five study authorities operated with figures of local HIV-AIDS prevalence with which to assess the total potential demand for social services. With the exception of Hammersmith and Fulham, the estimates of residents HIV positive only and with AIDS (columns 1 and 2 of Table 13) were derived from figures made available by the district/regional health authorities (the Health Board in Lothian). The study authorities also produced their own estimates of actual numbers of HIV-AIDS users of statutory social services during 1989/90 (column 3 in Table 13). It appears that approximately 45% to 64% of the total numbers of residents known to be HIV positive only or to have AIDS were users of the services of the London SSDs in 1989/90. In contrast, SWD service use in Lothian was estimated to be 30% of known potential demand, and in Manchester 34%, although both these figures were based on crude guestimates of actual service use.

Table 13: Estimates of residents HIV+, AIDS and HIV-AIDS service users

Local Authority	Estimate of Number of residents (Feb 1990) HIV+	AIDS	Estimate of Number of Service Users 1989/90	Service Users as a percentage of HIV-AIDS residents 1989/90
Hamm & Fulham	380	120	279	56%
Ken & Chelsea	675	212	400	45%
Lothian	1036	50	320	30%
Manchester	116	16	45	34%
Westminster	410	140	350	64%
Total	2617	538	1394	44%

The actual and potential demand for SSD/SWD services was highest in the areas covered by the London authorities which has resulted in an emphasis on the supply of social care (the SC component) for people affected by the virus. Despite relatively high numbers of estimated service users in Lothian (320, as shown in Table 13) most of these were HIV positive only with a relatively low intensity of social service use.

Where numbers of HIV-AIDS service users were largest, an emphasis was placed on the creation of HIV-specialist social care services. This occurred in both Westminster and Kensington and Chelsea, where HIV-specialist hospital and community social work, home care and community care teams and posts and other specialist budgets have been developed. Outside of hospital social work, the other three study authorities adopted a generic supply philosophy but had also developed a number of HIV specialist initiatives.

At low levels of demand a potential problem is the underutilisation of specialist resources and possible tensions between HIV specialist teams and generic service providers from the identification of HIV-AIDS as a 'special service'. However, as the number of people with HIV infection or AIDS requiring statutory social care services increases, pressure to use specialist resources for its supply is also likely to increase. This depends on the capacity of generic resources to cope with increased demand in terms of the availability of worker time for both necessary HIV training and for the actual provision of social care for people affected by HIV-AIDS. The evidence from the study authorities is that the rate at which HIV training has been provided to generic social service/work staff would not be sufficient to enable a comprehensive generic focus for the supply of HIV-AIDS social care. Insufficient numbers trained and an insufficient breadth of knowledge among generic fieldworkers exists currently to provide a service equal to that provided by HIV specialist teams/posts in the five study authorities.

3.3.2 Central Government Grant to SSDs

In England, the availability of DH AIDS Support grants since 1989/90 for SSDs has promoted the rate at which local authority HIV-AIDS services have developed (Tolley and Maynard, 1990). In 1989/90, this consisted of a direct grant of £7 million for which SSDs had to bid. SSDs were required to meet a minimum of 30% of total estimated expenditures on HIV-AIDS social services from mainstream budgets (DH Circular LAC(1), January 1989). The bids were guided by the three categories of funding determined by the DH. These were a maximum of £1 million for each authority with the greatest concentration of people with AIDS and people at risk of infection; a maximum of £300,000 for other authorities with a major treatment centre for people with AIDS; and a maximum of £14,000 for each other SSD making a successful bid.

The three London authorities in the in-depth study each fell into the highest funding category in 1989/90, with Hammersmith and Fulham receiving an initial grant of £630,000, Kensington and Chelsea £500,000 and Westminster £420,000. The fact that this funding was allocated to the SSD in each case meant it was largely used in creating budgets for HIV specialist managers, social care service provision, the HIV training of social service staff and, to a lesser extent, the monitoring of HIV related expenditures in these areas. This last area of resource allocation was largely due to this being a DH requirement for the provision of AIDS support grant. One result of this allocation procedure is that in each of the London study authorities there has been only a relatively small involvement of the housing, education and environmental health departments in the development of HIV-AIDS related prevention, health education and housing initiatives.

In contrast, Manchester City Council, through adopting a corporate approach to HIV-AIDS service development, has been able to use the AIDS Support grant it received in 1989/90 (£300,000 initially) to enhance its authority-wide HIV service stance. In Manchester the SSD has been the account holder for the support grant, but expenditures from it have been incurred in the environmental health, housing, education and social services departments on a wide range of HIV related managerial, prevention/health education and social care initiatives. The merger in Kensington and Chelsea of the social services and housing department in 1990 provides an opportunity for a closer linkage between two key components of community care for people with HIV or AIDS - adequate housing and social care and support. It will be interesting to see if this merger will enable an increased access to AIDS Support grant for financing any HIV related housing institutes that may be proposed.

Although the special DH money has enhanced overall service development in the authorities that have received it, there is a danger of over-reliance on its continuation, especially if it has been used largely to finance HIV specialist resources (such as in Kensington and Chelsea and Westminster). Managers in Lothian SWD, where no special funding has been provided and Manchester City Council, which has dispersed the HIV funds across a wide range of activities, have created a firmer HIV-AIDS resource base than the other study authorities. However, the greater financial integration that has been achieved in Lothian and Manchester in itself poses a problem in terms of accurately accounting for the expenditures on HIV-AIDS social care and related activities.

Nationally, the majority of SSDs without a high incidence of people with HIV infection or AIDS used their £14,000 maximum grant to finance an 'HIV Co-ordinator' to oversee HIV policy and service development. It may appear that the London SSDs, with the highest numbers of people with AIDS, benefited most from the DH AIDS support grants, receiving in total 66-70% of all DH funds made available in 1989/90 (table 14). However, the average allocation per person living with AIDS in the London SSDs (for 786 people) was lower at £7,700-£6,600 than that for all other SSDs in England at £11,600 per person (for 195 people). The AIDS related grant provided by the Welsh Office to SSDs in Wales represented an average allocation of only £3,200 per person alive with AIDS (for 12 people in Wales as of March 1989). As the allocation of grant was based on SSDs 'bidding' for funds, some SSDs with relatively low numbers of residents with AIDS were successful in obtaining money for 'non-care' initiatives such as those aimed at the prevention of HIV, staff HIV training and general service management.

Table 14: DH AIDS Support Grant Allocation per Person Alive with AIDS (at March 1989)

SSDs	1989/90 Total grant allocation	People Alive with AIDS (March 1989)	Average grant per person alive with AIDS
	£000's	No.	£s
London	4,500(1)-5,200(2)	786	5,700(1)-6,600(2)
Rest of England	2,300	195	11,600
Wales	39	12	3,200
Total	6,800(1)-7,500(2)	993	6,800(1)-7,500(2)

Notes

(1) Not including 3 year joint finance funds provided to some Inner London SSDs from 1988/89.

(2) Including 3 year joint finance funds provided to some Inner London SSDs from 1988/89.

In Scotland, the Scottish Office has for 1989/90 and 1990/91 identified HIV-AIDS as a separate service heading in its annual 'Grant Aided Expenditure' (GAE) calculations, which are used to determine total levels of expenditures to be supported by Government revenue support grant (Scottish Office Finance Circular 10/89, September 1989). In total, £2.48 million in 1989/90 and £3.42 million in 1990/91 was distributed to Scottish SWDs under the HIV-AIDS element of the GAE, of which the major recipients were the SWDs of Lothian, Strathclyde and Tayside (£2.32 million in 1989/90, £3.01 million in 1990/91). It is not possible to estimate how much, if any, of this is extra funding as (according to Scottish Office officials) the purpose of the GAE calculations are solely to provide a method for allocating pre-determined levels of mainstream funds equitably between local authorities.

3.3.3 Assessments of Local Service Needs

The in-depth study of five authorities produced evidence of two complementary but distinct areas of specific assessed service need by local authority managers which affected the organisation of the HIV-AIDS service provided: direct community services, and managerial and support services.

Direct community services

The assessed need for direct community services for HIV-AIDS (ie the provision of social care services, HIV prevention and health education and other local community initiatives such as housing) corresponds with the SC, PE and H components of the SCSF. In the study authorities the outcome was a range of specific initiatives which can be fitted into each of these HIV service components. For example, HIV managers in Kensington and Chelsea SSD (through a 'caring landlord/lady' scheme for people with HIV or AIDS) and Lothian SWD (through a Supported Accommodation Team for AIDS-SATA) had attempted to link the provision of social care and accommodation to meet dual needs in both service areas. In both cases these were small scale initiatives that aimed to meet the specific needs of a particular group of local people affected by HIV or AIDS (in Kensington and Chelsea approximately 7-10 people with HIV or AIDS had been provided with such accommodation by March 1990; in Lothian 14 properties were being used as HIV-AIDS supported accommodation by the end of 1989).

A number of specific educational initiatives have been developed by the study authorities in relation to HIV-AIDS. For example, Manchester City Council (through the Education department and the HIV-AIDS Unit) and Edinburgh Education Department identified a specific need to provide HIV awareness and related health education sessions for both school pupils, and teachers/school governers. This was developed and implemented through the use of AIDS in Education Teams (consisting of secondary school teachers and support from local authority, health authority and voluntary sector personnel). In the other study authorities the involvement of the education departments has been limited to "discussing the issue".

The development of specific initiatives such as those above may assist the production of a diverse local authority package of direct community services related to HIV-AIDS involving a wide range of departments and external agencies (health service, voluntary sector). However, the opportunity cost of such specificity is likely to be less availability of resources for the provision of mainstream social care services for people with HIV or AIDS, such as domiciliary care, community social work services and meals services (as seen in the service provision of Westminster and Kensington and Chelsea).

Managerial and support services

The importance attached to managerial and support service requirements associated with HIV-AIDS, can result in differences in organisational structure between authorities adopting different approaches. This area of service activity covers local authority strategy decisions concerning issues of HIV policy guidelines, overall service management and co-ordination, the promotion of a high quality service through the training of staff in HIV issues, and efforts to provide a cost-effective HIV service through the development of HIV service monitoring and evaluation systems (this last area of service activity is deferred for discussion in section 3.3.5). This corresponds to the MC, T and ME components of the SCSF.

There were a number of similarities in the organisation of managerial and support services for HIV infection across each of the five study authorities. Each had developed policy guidelines for HIV-AIDS services (within the SSD/SWD at least) covering such issues as confidentiality, working with people with HIV infection and anti-discrimination. HIV working groups/forums existed and HIV co-ordinators had been appointed in all the study authorities. Each also had a programme of staff HIV training operational at the time of the study managed and co-ordinated by a specialist HIV training officer.

However, differences in organisation were marked. For instance, the role of the HIV co-ordinator varied. In the London SSDs they were the essential link between service planning and actual provision. In Lothian SWD, the appointee had a specific responsibility for the planning and co-ordination of the authorities involvement in drugs misuse services and related issues. More divorced from actual HIV service provision were the 'corporate' HIV co-ordinators appointed by Manchester City Council and Lothian Regional Council, who had an authority-wide service overseer role. The national survey of SSD/SWDs demonstrated the variation in duties of HIV co-ordinators in those participating authorities that had appointed for such a post (Table 15).

Table 15: HIV Coordinator Posts: Job Specifications - The National Survey

Duties Required	Number of Posts Where Activity Undertaken
Develop training strategy	19
Active involvement in training staff	14
Liaison with other statutory and voluntary agencies	20
Inter-departmental liaison	20
Develop HIV/AIDS policy guidelines	15
Monitor effectiveness of policies or practice	8
Define future departmental requirements	10
Collate epidemiological data and information of HIV-AIDS	14
Direct involvement with clients	6
Input into HIV-AIDS budgets or associated funding matters	2

Note: All HIV Co-ordinators had more than one duty.

The five study authorities also differed in terms of the overall importance placed on HIV service management and co-ordination. Manchester City Council was the only authority to have adopted a planning focus separated from the SSD/SWD which directly involved other departments in day-to-day management. The management model in this authority consisted of an HIV-AIDS Unit nominally based in the Environmental Health and Consumer Protection department. This contained seconded managers from a range of key departments (Education, Personnel, Environmental Health, Social Services but with no housing representative) and a number of HIV specialists with responsibility for specific areas of work such as HIV prevention/drugs, co-ordination with the voluntary/health sector and accommodation issues. In addition, AIDS Liaison Officers were created in almost every department to act as contact points for council staff requiring information on HIV-AIDS issues.

This authority-wide approach was adopted to avoid the impression that HIV-AIDS had no implications for other local authority departments. It has the advantage of enhancing opportunities for a well-balanced and 'democratic' response to HIV-AIDS policy and service development. In general, this model is easiest to implement in authorities currently experiencing low levels of HIV-AIDS related social care demand, enabling the focus of service development to be directed away from the SSD/SWD.

Managerial efficiency may be best served by the creation of integrated central HIV-AIDS teams as has occurred in Manchester City Council and Hammersmith and Fulham SSD. However, the disadvantage of this is that HIV managers may become isolated from non-specialist management colleagues who might otherwise, through daily workplace interactions, provide an important contribution to the general development of HIV-AIDS service policy and provision.

In addition, differences existed in the effectiveness of the joint planning forums used for HIV-AIDS service co-ordination in each of the five study authorities. Kensington and Chelsea, Hammersmith and Fulham and Westminster used the existing Joint Care Planning Team mechanism to form HIV-AIDS sub-groups with several overlapping DHAs. The main difficulty of this arrangement was a lack of co-ordination regarding joint local authority-health authority-voluntary sector responsibilities for devising, financing and operating HIV related prevention and health education initiatives in the community. This was less of a problem in Lothian where there is coterminosity between the Regional Council and Health Board, and both are represented on the main HIV-AIDS joint planning forums in Lothian. As a result, joint HIV prevention and health education initiatives have been well co-ordinated (eg. as seen in the joint SWD-Health Board 'Take Care Campaign' involving explicit or implicit health education messages such as safer sex and the use of clean needles for injecting drugs). By contrast, Manchester City Council has foregone the use of formal planning mechanisms, favouring instead a more informal practitioner group involving statutory and voluntary sector workers and others involved or interested in HIV-AIDS community service issues (known as Manchester AIDS Forum). This lacks any direct policy influencing power but has been useful for the discussion of important issues.

In each of the five study authorities, two types of HIV training has been provided to staff: basic awareness sessions, and more advanced courses covering particular skills. However, in many cases the inevitable limitations on resources have led to a trade-off between the number and range of local authority staff able to be trained and the scope of courses that can be provided. For example, Manchester City Council initially adopted a strategy of training all council staff in basic HIV awareness (a half day course). This target had not been achieved by the end of 1989 and meant that at the time limited emphasis was able to be given to equipping potential front-line fieldworkers in the social services department (eg social workers, domiciliary care) with the more advanced skills they may require in providing a social care service for people with HIV infection or AIDS. Such courses on topics such as counselling and bereavement skills and drugs misuse generally last between one to three days and so are costly in terms of the staff time of those who participate. Where such courses have been provided (eg for Lothian SWD staff) the demand has far exceeded supply.

The result of ambitious training strategies with limited resources is a partially trained workforce. If the focus of HIV-AIDS service supply is generic, then this may have serious implications for the quality of care given to people with HIV infection or AIDS.

3.3.4 The Role of the Voluntary Sector

The voluntary sector plays a significant part in the provision of HIV-AIDS related services. This covers the direct provision of social care and support for people living with the virus or affected by the virus (family, friends, partners), the development of accommodation initiatives, involvement in HIV prevention campaigns and providing public and specific group training in HIV related issues. Each of the high profile study localities contained many new (ie started since 1984) HIV specific voluntary agencies involved in such work (eg London Lighthouse, Mildmays, Red Admiral, Body Positive, Frontliners, Scottish AIDS Monitor, Manchester AIDSLINE).

HIV-AIDS related community work has also become a major issue for the non-HIV specific voluntary sector, with several hundred agencies in Britain having an interest in, and providing a direct service for, people affected by the virus. This includes major organisations such as the Red Cross and the Citizens Advice Bureaux (essentially public bodies), Samaritans and local agencies whose work brings them into contact with people who are HIV positive. For example, the network of drug users support agencies in Lothian are finding that the vast majority (up to 90% in many cases) of the users of their services have a dual problem of drug addiction and HIV infection.

It is almost impossible to assess exactly how many voluntary agencies are involved in HIV-AIDS related work in Britain. A glance at the National AIDS Manual (Scott, 1990) demonstrates the large numbers of agencies able to provide a service. The Hull-York researchers contacted over 400 HIV specific and non-specific voluntary agencies in London, the Manchester area and Scotland/Lothian to complete a special questionnaire. The criterion for inclusion in the survey was a willingness, if required, to provide a service for people affected by HIV infection (for many the need had not yet arose). The response rate to this questionnaire was approximately twenty five per cent. From the responses to this survey the main types of service being received by people affected by the virus from both HIV specific and non-specific agencies was counselling and emotional support and health care advice (especially from non-specific agencies), practical help (eg buddies) and financial assistance (especially from HIV specific agencies) and general advice and information (both sets of agencies). Table 16 outlines the pattern of voluntary agency service use.

The existence of this voluntary agency input has had two main impacts on the HIV-AIDS service organisation of SSD/SWD and other local authority departments. These are: an increased need for inter-agency coordination, and an increased transfer of funds from local authorities to the HIV-related voluntary sector.

Table 16: Pattern of Voluntary Agencies Service Use (numbers of agencies providing services) - voluntary agency survey

Type of Service Provided	HIV specific agencies providing service (n=23)	Non-HIV specific agencies providing service for people with HIV-AIDS (n=37)	Total Number (n=60)	Percentage of all Agencies Providing Service
Advice and information(1)	13	19	32	53%
Counselling and emotional support	10	22	32	53%
Practical help(2)	14	8	22	37%
Health Care advice and information	3	13	16	27%
Advocacy	4	8	12	20%
Drop-in	3	5	8	13%
Accommodation	2	4	6	10%
Helpline	4	-	4	7%
Alternative therapy	3	1	4	7%
Other(3)	6	4	10	17%

Notes

(1) Includes "buddying"

(2) Advice and information on a wide range of issues including welfare rights, legal issues, local authority services - excludes health care advice and information and advice and information via newsletters.

(3) This item covers residential help, workshops, newsletter advice, support groups.

Inter-agency co-ordination

There has been an increased need for co-ordination between the statutory and voluntary sector to minimise any duplication of work effort around HIV-AIDS in the community. This has been achieved to varying extents in all five study authorities. It depends crucially on the effectiveness of both the formal (and less formal) local joint forums for discussing HIV service issues (eg joint working parties, discussion groups) and the less structured network of informal liaison and contact between HIV service managers in the local authority and voluntary agency workers. This latter connection is, arguably, a major responsibility of the SSD/SWD HIV co-ordinator. There is an argument that the duplication of services for people with HIV infection or AIDS should be encouraged because it enhances choice, but this can be criticised on efficiency grounds, especially as much of the voluntary sector activity is financed by public sector funds.

Funding the Voluntary Sector

The transfer of funds from local authorities to voluntary agencies for HIV related initiatives has represented a new area of statutory expenditure (although in the English study authorities such grants were largely financed from the DH AIDS Support grant). Table 17 provides a summary of the voluntary sector grant allocated by the five study authorities in 1989/90, totalling £1.67 million, broken down according to the primary area of activity of the receiving voluntary agencies. In the main this funding was allocated to HIV specific agencies.

Table 17: Grant allocations to voluntary agencies by the Five study SSD/SDWs 1989/90

Local Authority	Prevention/ Education/ Training £000's	Housing/ Accomm. £000's	Social Care/ Support £000's	Total £000's
Hamm & Fulham	43.0	-	307.0	350.0
Ken & Chelsea	16.0	33.0	170.0	219.0
Westminster	55.0	8.0	-	63.0
Manchester	57.3	25.0	158.1	240.4
Lothian	180.0(1)	479.1(2)	144.1	803.2
Total	351.3	545.1	779.2	1675.6

Notes

(1) Includes Lothian SWD element of joint capital/revenue funding (with Lothian Health Board) of a Drugs Crisis Centre.

(2) Includes Lothian SWD element of joint capital/revenue funding (with Lothian Health Board) of an AIDS Hospice.

There are several key questions that SSD/SWD HIV managers need to address in relation to the financing of HIV-AIDS related activities in the voluntary sector. Four of these can be summarised as:

a) Should we fund voluntary agencies located outside of the local authority boundary?

b) Are the decisions regarding the allocation of HIV-AIDS related grant among voluntary agencies based on a clear strategy or set of criteria?

c) Does the HIV-AIDS related grant that we provide to voluntary agencies have specific service requirements attached to it, and is there an effective system for monitoring its use?

d) How can co-ordination with neighbouring authorities (especially in London), reduce the incidence of non-borough specific voluntary agencies having to negotiate for funding with several individual authorities?

The view that the work of the voluntary sector is carried out by large teams of volunteers supported by private fund raising and donations certainly does not apply to the HIV-AIDS sector. The voluntary sector role in HIV-AIDS service provision is headed by large-scale organisations such as Terrance Higgins Trust and London Lighthouse employing sizeable teams of professionals as well as volunteers. A small scale assessment was made of the funds available over one year (1988/89) to 32 HIV specific/drugs agencies who provided detailed financial information. A total of £4.19 million was received by 23 agencies from public sector sources (ie Central Government, local authorities, health authorities/boards), with a median allocation of £55,900 (table 18). This represented 60% of the total funding of £6.94 million received by the 32 agencies. A total of 22 agencies received £2.23 million from fund raising and donations (median of £33,500) and 16 agencies received £520,700 from other private sources (median of £15,000).

Table 18: One Year Funding of 32 HIV-Specific/Drug Related Voluntary Agencies (1988-89)

Source of Funding	Number of Agencies(1) No.	Total Funding £mn	Median income £000's
Public Sector Funds(2)	23	4.19	55.9
Fund raising/ donations	22	2.23	33.5
Other private Funds(3)	16	0.52	15.0
Total income	32	6.94	68.4

Notes

(1) Includes drug-related agencies based in Lothian.

(2) Grants by Central Government (DH, Scottish Home and Health Department, HEA), local authorities, health authorities/boards.

(3) Charitable funds, trust grants, sales of goods and services.

3.3.5 Care in the Community Reforms

A factor that will affect increasingly SSD/SWD service planning and provision in the 1990s is the implementation of the Governments Care in the Community reforms. Currently SSD/SWD managers are assessing the likely impact this will have for service delivery after 1993.

The creation of a market place for social care is likely to have several important impacts on the organisation of SSD/SWD services supplied to people with HIV infection or AIDS. Three issues discussed here relate to budgets for social care, the assessment of needs for and design of care packages, and the role of the SSD/SWDs as the 'enabling authorities'.

HIV budgets

SSD/SWDs are likely to create budgets specifically for the 'purchase' of social care and related services for residents affected by HIV-AIDS. HIV service managers in Hammersmith and Fulham SSD have already developed a central HIV budget for 'buying-in' care services from its own department, from other local authorities, and from the voluntary and private sector. Services have been purchased, through a series of 'service agreements', from several HIV specific voluntary agencies located in and around the Hammersmith area. This has been viewed by central and local government as a test-case for the use of service packages and budgets in other areas of social service provision, such as that for elderly people. On a smaller scale, Kensington and Chelsea SSD have developed a special budget for purchasing specific services such as massage and special therapy from both private and voluntary sector agencies for its residents with HIV infection or AIDS.

One consequence of a fee-for-service or contract system is that greater control over the expenditures of the voluntary sector may be achieved by statutory service managers of HIV budgets. Such control may affect HIV-AIDS service levels and quality and requires effective integration of the purchaser role of SSD/SWDs and the provider roles of statutory and voluntary agencies.

SSD-SWDs will need monitoring systems which facilitate the costing of the range of services provided to people with HIV infection or AIDS in order to determine specific expenditures from the HIV-AIDS budget. The system would need, for example, to be able to record the time spent by social workers and other care providers on providing HIV-AIDS services. To be effective, managers will need to define what constitutes an HIV-AIDS-related service for costing purposes and consider imposing limits on the time staff spend on administration associated with the provision of social care for people affected by HIV-AIDS. Of the five study authorities, Hammersmith and Fulham SSD had made most progress in the development of a monitoring system capable of recording and analysing generic staff time spent on HIV-AIDS related service provision.

Care package needs assessment and design

SSD/SWDs will have two main roles in the provision of social care and support for people affected by HIV-AIDS. In addition to determining the actual supply of social care by members of SSD/SWD staff, managers will be involved in the assessment of the need for, and the design and financing of various packages of care to be supplied by a combination of statutory, voluntary and informal providers. It is this latter role that is likely to become of greater relative importance as Government community care reforms are implemented.

The "key worker" model offers one method by which SSD/SWDs can undertake the assessment of the individual social care needs and the design of appropriate care packages. Kensington and Chelsea SSD operates an AIDS Care Organiser scheme. Each care organiser (one for each of the three districts in the borough) acts as a "gate-keeper" who facilitates access to the authority's HIV specialist care services. In an expanded role, the AIDS care organisers could have more responsibility for designing (and financing) individual care packages which include a range of statutory, voluntary and private sector inputs.

Similarly, through their individual client assessments, SSD/SWD occupational therapists are in a good position to carry out initial assessments of social care needs to feed into the design of individual care packages. However, both the study of the five authorities and the national survey of SSD/SWDs showed that this role for occupational therapists is not currently being exploited. More scope for their use in this way may occur following the implementation of the community care reforms.

SSD-SWDs as "Enabling Authorities"

If SSD/SWDs become the 'enabling authorities', they will have a greater role in the overall management and monitoring of HIV-AIDS services. The creation of purchaser-provider relationships will focus attention on the overall supply of social care packages for people affected by HIV or AIDS and reduce the distinction between the statutory and voluntary sector providers.

In terms of the SCSF, the local authority MC and ME will be expanded while PE, H or SC will be apportioned between the voluntary, private and health sectors. Under the care in the community reforms, SSD/SWDs can be expected to manage and monitor a variety of service contracts drawn up with HIV-specific agencies, similar to the HIV-service agreements of Hammersmith and Fulham SSD.

3.3.6 Good Practice Issues

The supply of social care by SSD/SWDs has been placed in context of the involvement of the local authorities in other aspects of HIV-AIDS services. The SCSF provides a framework for examining interactions and trade-offs between the components of HIV-AIDS service from a local authority perspective. In the light of issues discussed in Section 3.3, a number of illustrative good practice points can be made in relation to each component of the SCSF. These are presented in Appendix 2.

3.4 Costs of Service Supply

3.4.1 Costing Methodology

The resources included in the costing were staff time, specific and general materials and expenses (eg training materials, leaflets, travel, postage, stationery), central overheads (eg central management and support services, gas and electricity, office space) and premises. Where there were overlaps in resource use between components of the SCSF costs were apportioned according to a series of weighted estimates of the appropriate division of the use of each shared resource [full details of the methodology used are available in the main report to the DH and SED].

3.4.2 The Cost Estimates

In Table 19 the estimated full one year costs of HIV-AIDS service supply for the five study authorities are presented using 1989 prices (this represents the potential one year cost of all resources used during 1989/90, whilst actual costs refers only to the cost of resource use incurred during the 1989/90 financial year). The total one year cost for the five authorities was estimated at £5.06 million compared to an actual estimated cost for 1989/90 of £4.1 million. Highest one year costs were estimated for Kensington and Chelsea at £1.20 million. For Hammersmith and Fulham (£1.17 million), Lothian (£1.08 million) and Westminster (£944,000) the one year costs were near to £1 million. The lowest one year cost (£665,000) was incurred in Manchester, primarily due to the lower social care (SC) component cost compared with the other authorities.

Table 19: Total one year costs(1) (using the SCSF) of HIV-AIDS Service Supply for the Five Study Authorities - resources used in 1989/90

SCSM Resource Component	Hamm & Fulham	Kensing & Chelsea	Westmin	Manch	Lothian	Total
MC £000s	223.7	127.3	52.9	181.3	124.4	709.6
% of total	19%	11%	6%	27%	11%	14%
T £000s	121.7	126.3	114.3	140.6	114.7	617.6
% of total	10%	10%	12%	21%	11%	12%
PE £000s	157.4	143.9	128.1	202.3	287.7	919.4
% of total	14%	12%	13%	30%	27%	18%
H(2) £000s	n/a	24.9	5.2	34.5	0	64.6
% of total	-	2%	1%	5%	-	2%
SC £000s	612.0	757.2	612.8	101.7	540.9	2624.6
% of total	53%	63%	65%	16%	50%	52%
ME £000s	50.8	25.3	31.3	5.0	10.0	122.4
% of total	4%	2%	3%	1%	1%	2%
TOTAL £000s	1165.6	1204.9	944.6	665.4	1077.7	5058.3
%	100%	100%	100%	100%	100%	100%

Notes

(1) The costs represent the full one year cost for 1989/90 of resources incurred by the local authorities in providing an HIV-AIDS service. This represents a maximum one year cost estimate because all costs are assumed to have been incurred from the start of the 1989/90 financial year. It is higher than the actual cost for 1989/90 as adjustments are made to incorporate the full year effect of staff recruited during 1989/90 and other service developments starting at different times throughout the financial year.

(2) The costs of H (Housing and accommodation) includes only specific staffing resources and estimated expenditures known to have been incurred on providing housing advice to people with HIV-AIDS in 1989/90.

The costs presented in Table 19 reflect the five factors affecting service supply considered in section 3.2. With a constraint on the total resources or total budget available for HIV-AIDS, the SCSF can be used to examine the consequences of organisational developments within the components of service supply. The cost of directing resources to any one component is the loss of using the equivalent amount of resources across each of the other components. For example, the choice may be to use resources to increase the amount of HIV related training available to staff (incurring additional opportunity costs in terms of the time staff require to attend the courses) or for recruiting an HIV specialist social worker. If it is decided that both are necessary, then the cost will involve a reduction in service supply in either the HIV-AIDS sector or elsewhere, for example, in social work services for elderly people. The use of the AIDS support grant in England has concealed these opportunity costs even though the social cost of AIDS expenditure is the loss of benefits from social care services for the "Cinderella groups".

The SCSF can be used to examine the distribution of the resource costs to the local authority across the components, or be used as a financial accounting framework so that, for example, each component could represent a specific budget heading, with sub-budget headings incorporated within. The former approach has been adopted here and used to present the costs in Table 19. It therefore includes an estimate of the opportunity costs of staff time on HIV training courses (under T) and teachers/others attendance at AIDS in Education Team seminars in Lothian and Manchester (under PE).

The SCSF could be extended further to include assessments of informal carer costs of providing care and support, and personal costs incurred by people affected by HIV through the use of social (and other local authority) services. The data in table 19 does not include the HIV grants to voluntary agencies as this is a transfer of funds to the voluntary sector for service provision. The notion of the 'costs' approach is that only the costs of final services provided by the local authority should be included within the SCSF framework. If the SCSF was used for financial accounting purposes only, then the grants outlined in table 17 would also be included within it.

To elaborate this distinction between the cost and financial accounting approaches further, the SCSF, used in an opportunity cost sense, should not include any fees paid by the SSD/SWD to voluntary agencies for specific HIV-AIDS services (as is likely to occur with care in the community reforms). Such payments are a transfer of funds for the provision of services by the voluntary sector rather than a use of resources. The costs of services provided by the voluntary sector in return for this payment would be included within a cost model covering voluntary agency services. The exclusion of fees from the local authority model will make more explicit the resource implications of the role of the SSD/SWD as HIV-AIDS service purchase managers and co-ordinators (MC component) and in service monitoring and evaluation (the ME component) following the care in the community reforms. This is important as currently there is little additional cost incurred by the five authorities in terms of the management and monitoring of the grants they provide to HIV specific voluntary agencies (table 17, see also section 3.3.5). In contrast, a financial accounting approach will incorporate the budgets for the purchase of HIV social care and related services within the SC component.

3.4.3 SCSF Component Cost Variations

The data demonstrating the variations between the one-year component costs of the five study authorities, presented in Table 19, reflect the differences in their organisational and policy responses to HIV-AIDS service supply and the factors affecting this response, which were discussed in section 3.2. and 3.3.

The social care and support component (SC) represented the highest element of the one year cost (£2.62 million, 52% of total cost) and was between 50% and 65% of total one year costs in four of the study authorities (Manchester being the exception). With limited budgets, a concentration of resources on social care inevitably means that less resources are available for other service inputs. From table 19, the costs of HIV service management and co-ordination (MC), staff training (T) and HIV prevention and health education (PE) represented only 36% of the total one year costs of the HIV service supplied by the three London study authorities in 1989/90. In contrast, resources used in these areas of HIV activity represented 61% of total SCSF costs for Lothian and Manchester combined. The relatively low priority for the use of resources to provide social care for people with HIV or AIDS in Manchester was due largely to low numbers presenting for service. In this authority HIV-AIDS related social care represented only 15% of total potential costs (£101,700).

Specialist resources represented 93% and 84% of the total social care costs of Westminster and Kensington and Chelsea compared to only 67% and 40% in Hammersmith and Fulham and Lothian. These variations reflect the different specialist/generic strategies of the authorities. A high relative proportion of the social care costs incurred through specialist resource use in Manchester has occurred (83% of SC costs, £84,400) in spite of the local generic supply philosophy. However, this is largely due to the low current demand for social care services (from low numbers of people with AIDS) in Manchester and uncertainty concerning the actual use made of generic services due to

Manchester City Council's strict confidentiality of service policy for HIV-AIDS. Any new demand is likely to generate an increase in the generic proportion of the social care costs.

Social care costs have varied between the five study authorities according to the amount of different types of social service supplied, the service strategy adopted and the availability of Central Government funds. Table 20 demonstrates the wide variation in costs both within and between the authorities for six main areas of HIV related social care and support services. This cost pattern reflects differences in the package of social care provision of each of the five study authorities. For instance, there was an emphasis on:

- the use in all authorities of HIV specialist hospital social workers employed by the SSD/SWD;
- HIV specialist domiciliary care teams in Westminster and Kensington and Chelsea;
- the use of community social work as the basis for service provision in Hammersmith and Fulham;
- the use of special goods and services budgets in Kensington and Chelsea and;
- areas of HIV-AIDS community based work other than direct social care provision in Manchester.

Table 20: Total One Year Costs(1) (using the SCSF) of the HIV/AIDS Social Care Component (SC) for the Five Study Authorities - resources used in 1989/90

Social Care Service	Hamm & Fulham £000s	Ken & Chelsea £000s	Westmin. £000s	Manch. £000s	Lothian £000s	Total £000s
Hospital social work	172.9	156.5	127.5	28.0	94.8	579.7
Community social work	358.2	16.7	134.9	58.1	80.3	648.2
Domiciliary care	31.4	180.6	224.1	0	48.0	484.1
Occupational Therapy	1.7	54.7	83.2	0	8.1	147.7
Goods and Services	37.4	130.0	10.0	15.0	0	192.4
Other (2)	10.4	218.7	33.1	0.6	309.7	572.5
TOTAL	612.0	757.2	612.8	101.7	540.9	2624.6

Notes

(1) See footnote (1) to table 19.

(2) 'Other' includes meals, residential and day care, fostering and adoption, supported accommodation/caring landlord/lady schemes, town clerks scheme and prison social work (in Lothian).

4. CONCLUSIONS

Social care managers face a challenge in meeting the needs of people affected by HIV infection. They need not only to provide support to people living with the virus but also for their partners, family and friends on whom much of the burden of providing everyday emotional and practical support falls. People with HIV-AIDS are not a homogeneous "client group", for whom a standard package of care can be devised. The virus can directly affect a broad cross section of members of society in terms of sexual orientation, age, gender and socio-economic status. Each individual living with the virus has a unique demand for care and support.

This diversity of need covers a wide range of activities and amenities, such as employment, accommodation, health maintenance, transport, finance, home support and emotional support needs. The Hull-York survey found that no one provider agency met the social care needs of any particular individual affected by the virus. The appropriate care package that can be designed for an individual living with the virus is likely to involve inputs from the voluntary, private and statutory sectors. The evidence from the Hull-York survey was that effective practical and emotional support in the home was provided by partners, friends and family with more specific supportive and practical needs (eg for particular items of equipment, help with transport and health maintenance) being provided by HIV specific voluntary agencies. The direct role of SSD/SWD service providers was limited. For example, only nine out of 181 people in the sample had made use of an SSD/SWD domiciliary care worker, despite there being clear demand for practical help in the home. Users are critical of the care, regarding sensitivity, understanding and confidentiality, provided by the statutory sector.

Variability exists in the level of demand for social care and support. For example, many of the drug users in the sample, who were often facing severe social problems, made little use of available services other than local drug user support agencies. This may be due to a lack of knowledge of alternative services or no desire to use them, or due to the desire of other HIV specific and non-HIV specific voluntary agencies not to include such people within their network of users/members.

The cost of meeting demand for social care on a national scale could be considerable. If the level of social care and support used by respondents in the five study areas was provided nationally the cost of meeting this demand would exceed £20 million.

The Government's community care reforms will create an explicit network of purchasers and providers of social care services. The service use demand patterns of the respondents in the Hull-York survey indicate that, subsequent to the reforms, the SSD/SWDs may have a service management, purchase and monitoring role for HIV-AIDS, with the main supply of formal care coming from the voluntary sector. For SSD/SWDs to be able to undertake this role effectively, their managers will have to undertake a variety of complex tasks: the identification of appropriate HIV budget to provide to managers with which to purchase social care; the effective co-ordination of the local authority, the voluntary and health service sectors; and the effective use of the Government AIDS Support Grant. The effective financing and monitoring of voluntary agency service provision will also need to be developed.

The social care supply framework provides a useful method for assessing the structure and costs of a comprehensive HIV-AIDS service. For instance, given a fixed budget for HIV-AIDS, a concentration of resources on the provision of social care has consequences for the resources available for other aspects of HIV-AIDS service supply, such as HIV related prevention and health education and staff training. Use of the SCSF can enable authorities to identify areas of under- (or over) resourcing in relation to particular HIV service needs in their locality, and to identify a role for the key departments of environmental health, housing and education in HIV service supply. It provides a systematic and explicit framework for managing social care options.

The social care market for people with HIV-AIDS has developed substantially and unequally across the United Kingdom during the 1980s. The social care needs of the HIV-AIDS population are considerable and inevitably compete with service demands for other vulnerable groups such as the elderly and the handicapped. As a consequence, prioritisation is inevitable and the efficient development of services requires careful evaluation of the needs of clients and the characteristics and benefits of alternative care packages.

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Appendix 1 Breakdown of the Social Care Supply Framework (SCSF) Components

MC Management and Coordination

- HIV/AIDS Co-ordinators and HIV/AIDS Units.
- Other HIV/AIDS central posts
- Multi-disciplinary working parties
    * internal SSD/SWD groups
    * inter-departmental local authority groups
    * joint working parties (local authority, health authority, voluntary sector)
- General leaflets etc

T Training

- SSD/SWD staff
- Other local authority department staff
- Non-statutory training

PE Prevention and Health Education

- SSD role in public education, presentations, leaflets
- Schools/youth work
    * SSD/SWD role
    * Education Department role
- Environment Health Department role
- Needle exchanges : SSD/SWD involvement

  : Environmental Health
- Other drugs initiatives

H Housing/Accommodation

- Housing Department role
  - : specialist accommodation
  - : mainstream accommodation
  - : temporary accommodation

SC Social Care and Support

- hospital social work
- community social work
- domiciliary care
- occupational therapy
- adult/children residential and day care
- other adults services/other children's services
- voluntary organisation grants

ME Monitoring and Evaluation

- Numbers monitoring
- expenditure monitoring
- consumer satisfaction/service evaluation

V Voluntary Sector

- HIV/AIDS specific organisations and self help/support groups
- Other HIV/AIDS related agencies eg, Gay Bereavement Trust, Streetwise Youth
- Drugs agencies
- Housing Associations/Agencies
- Trusts

- Other charities (national/other)

  eg,
  - hospices
  - CAB
  - Red Cross

<u>IC</u> <u>Informal Carer</u>

- Partner, family, friend
- Significant other

Appendix 2 An Illustrative Checklist of Good Practices

The checklist below presents 'good practice' issues for local authorities involved in developing an HIV-AIDS related service. These are grouped according to the components of the SCSF. Officials in authorities at different stages of developing an HIV-AIDS service or with a particular approach to service supply can use the checklist to identify areas of good practice.

The items in this appendix are not recommendations, rather areas which can potentially represent good practice: they form a focus for discussion and further analysis rather than a definitive set of recommendations.

Social Care and support (SC):

i) The development of HIV specialist teams for social care supply should be based on a clear assessment of HIV-AIDS service requirements and well-integrated into existing organisational and budget structure of SSD/SWDs. If demand for HIV-AIDS social care is very low or unknown, the creation of a post for an HIV specialist social worker or domiciliary care teams may be less cost-effective than using generic workers (trained in HIV issues).

ii) The SSD/SWD should identify a key worker or workers based in the community, but with close links with central HIV managers, who can operate as the focus for social care service access for people with HIV-AIDS. This would involve co-ordinating access to services provided by other agencies, the voluntary sector, health service, private sector. A current practice model for such development is provided by the AIDS Care Organiser posts developed by Kensington and Chelsea SSD.

iii) Occupational therapists (or other similarly skilled workers such as the support workers employed by Lothian SWD Supported Accommodation Team for AIDS) could be used for the initial assessment of packages of social care required (and desired) by people with HIV-AIDS.

iv) Ensuring the adequate integration of all hospital social workers with HIV-AIDS caseloads with other community based social care services in order to ensure efficiency in the continuum of service supplied to these people. Because the hospital social worker is often the first point of contact with social services for many people with HIV or AIDS, SSD/SWD managers should ensure these workers are integrated into any emerging HIV-AIDS planning, advisory and service supply structure.

v) The development of specific budgets for HIV-AIDS related social care controlled by the HIV-AIDS 'key worker(s)' or HIV managers can be used by SSD/SWDs to purchase social care from its own department or from other service providers (statutory or non-statutory).

vi) HIV managers should consider the creation of locally designed support networks for local authority staff involved in the direct provision of services to people with HIV-AIDS, in particular for HIV-specialist workers.

Management and co-ordination (MC):

i) If possible, authorities should promote a 'corporate' approach to HIV-AIDS service development. This means a strategy that involves, at least, close collaboration between the four "frontline" departments of social care:

social services/work, education, environmental health and housing. The local authority HIV-AIDS planning structure must reflect this 'corporate' involvement through equality of representation.

ii) Authorities should appoint an HIV Coordinator who is responsible for promoting and overseeing HIV-AIDS service development in the locality. A location for this post is in the SSD/SWD, possibly as the head of a HIV Unit (consisting also of other HIV service managers). An HIV-AIDS budget for the local authority should be created and controlled by the HIV Coordinator.

iii) Each of the four frontline departments should identify or appoint a lead officer to be responsible for the management and co-ordination of a corporate HIV-AIDS service. These specialist managers would be based in their own departments in order to disseminate rapidly policy decisions and information but would hold regular planning meetings and have access to the local authority HIV-AIDS budget. The overall responsibility for co-ordinating their activities would be located with the HIV Co-ordinator based in the 'HIV Unit'.

iv) Frontline departments should have clear guidelines at an early stage on key aspects of service policy relating to HIV-AIDS. For example, statements on policy regarding the employment of HIV positive staff (i.e. equal opportunities), providing services to people with HIV infection (i.e. anti-discriminatory) and service confidentiality (i.e. confidential). The adequacy of the guidelines should be periodically evaluated.

v) Forums for 'informal' discussions on HIV-AIDS community care issues involving representatives of the local authority, voluntary agencies and district/regional health authorities should be promoted e.g. such as Manchester AIDS Forum (MAF). These should complement more formal planning mechanisms such as Joint PLanning Teams for HIV-AIDS. The latter should have sufficient power to implement decisions concerning the provision and financing of HIV-AIDS community care (ie Joint Planning Teams for HIV-AIDS).

Staff HIV Training (T):

i) Authorities should employ a lead officer for HIV-AIDS Training to develop and initiate a training strategy that has clear objectives. Depending on the training resources available this post will have an authority-wide training brief, or a more limited brief to train frontline workers in, for example, SSD/SWD.

ii) Authorities placing most emphasis on the generic supply of social care for people with HIV-AIDS should target the staff likely to come into contact with people with HIV-AIDS for training in both HIV awareness and more specialist skills. To ensure comprehensive coverage some element of compulsion to attend HIV courses should be considered for staff targeted for such training. Introducing 'compulsion' would 'legitimise' staff time spent attending HIV courses, but would require specific funds to be identified in a training budget to cover the costs of replacement cover.

HIV Prevention and education (PE):

i) Local authorities should develop their HIV prevention and health education role as an important component of an integrated HIV-AIDS policy. For example, Manchester City Council AIDS Unit gives particular attention to prevention and health education issues both because of (and in order to keep) client numbers requiring social care low.

ii) The development of HIV prevention and health education initiatives could be a duty of the corporate HIV Co-ordinator or, better still, the responsibility of specialist HIV prevention/education officers (eg such as Manchester AIDS Unit Public Education Officers for 'injecting drugs uses', 'men who have sex with men' and 'schools/growth service').

iii) Prevention and health education is a multi-dimensional activity that requires inter-organisational co-ordination (ie between local authority/health authority/voluntary sector). Prevention and health education should be a separate issue for joint planning. The first aim of such planning is to clarify the type of initiatives local authorities should be involved in and the financial responsibilities (ie general public education campaigns, target groups - drug users, sex industry workers, schools youth service - needle exchanges).

iv) Environmental Health Departments possess most latent expertise regarding prevention and health education. This needs to be harnessed effectively by ensuring the appropriate Environmental Health Officer, one included in HIV-AIDS policy's planning and practice groups.

v) An AIDS in Education Team could be developed by Education departments to take HIV prevention and health education into local schools/youth services. Lothian Education Departments AIDS in Education Team - annually seconded teachers - provides a simple workable model for initiating and implementing an HIV educational package; the planned turnover of teachers brings in fresh ideas and ensures the explicit involvement of the Education Department in HIV/AIDS issues. Further development could involve the construction of a multi-agency team such as Manchester AIDS in Education Group, but would require additional resource and time commitment guarantees from the personnel involved.

Housing policy (H):

i) Local Authority housing departments should produce a specific policy for HIV-AIDS, if only to demonstrate a commitment to providing a non-discriminatory service for such people. Guidelines for good HIV-AIDS housing practice should be drawn up, implemented and monitored.

ii) Housing departments could consider the identification of a lead officer for HIV-AIDS within the Housing Department to identify the need for and, if appropriate, develop specific accommodation initiatives for people with HIV-AIDS. Manchester City Council and Hammersmith and Fulham SSD have created such posts; a lead officer is actively involved in Kensington and Chelsea.

iii) The development of a specific HIV budget within the housing department could be used for assessing the special accommodation needs of people with HIV or AIDS. This would involve the production of appropriate packages of temporary/permanent accommodation for people with HIV/AIDS. The budget could, for instance, be used to purchase placements for HIV-AIDS clients in housing association or voluntary agency accommodation schemes.

iv) Co-ordination between housing departments, SSDs/SWDs and non-statutory agencies should be encouraged to develop innovative supported accommodation schemes for those people with HIV-AIDS in need of such a service. SATA in Lothian and the HIV 'caring landlord/lady' scheme in Kensington and Chelsea provide examples of this, although there has been little involvement of the authorities housing departments or of non-statutory housing agencies in their planning.

Monitoring and Evaluation (ME):

i) The development by the SSD/SWD of a comprehensive HIV-service monitoring system will be required for on-going examination of met and unmet demands for statutory and non-statutory social care by people with HIV-AIDS. Ideally this should involve the creation of a full time specialist post for HIV monitoring and evaluation.

ii) Internal evaluation of the social care, housing and related needs of people with HIV-AIDS should be attempted, eg along the lines of the Housing needs survey conducted by Kensington and Chelsea Housing Department.

iii) The monitoring of SSD/SWD generic and HIV-specialist staff time and services associated with HIV-AIDS suffers from the low priority staff give to filling in the necessary forms. Guidance from senior management that HIV service monitoring is a high priority aspect of work (as important as direct client contact because of the benefits it can have for the effectiveness of service provision) may help it to be viewed as an integral part of the job rather than as a marginal task to be fitted in if possible.

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