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ADVICE, SUPPORT AND COUNSELLING FOR THE HIV POSITIVE

a draft report for DHSS

by

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LIST OF ABBREVIATIONS USED

ADSS - Association of Directors of Social Service.

AIDS - Acquired Immune Deficiency Syndrome.

ARC - Aids-Related Complex.

CDSC - Communicable Diseases Surveillance Centre.

DDU - Drugs Dependency Unit.

GUM - Genito-urinary Medicine.

HIV - Human Immunodeficiency Virus.

IVDA - Intravenous Drug Abuser.

NACTU - National AIDS Counselling Training Unit.

NASA - National Advisory Service on AIDS.

PGL - Persistent Generalised Lymphadenopathy.

PHLS - Public Health Laboratory Service.

RHA - Regional Health Authority.

SSD - Social Services Department.

STD - Sexually Transmitted Disease.

INTRODUCTION

1.1 The purposes specified by the DHSS for this study were to identify from existing work:

- the most effective and economical ways of providing necessary advice, support and counselling to those who are HIV positive, and
- any indicators which may distinguish those likely to be in need of more intensive provision.

The background assumption was that heightened public consciousness of AIDS and awareness of the availability of an HIV antibody test will lead to increasingly large numbers of people of diverse kinds presenting for the test, and a rising proportion of them discovering that they are HIV positive.

1.2 The DHSS brief specified for examination that (often lengthy) phase of the patient's "career" running from presentation for testing to the development of clinical symptoms of PGL, ARC or frank AIDS. We therefore excluded from consideration the use of HIV antibody tests as part of diagnosis in symptomatic individuals or in programmes of anonymised screening. The reference phase is clinically asymptomatic, but the engimatic nature of seropositivity and the presumption of life-long infectiousness create needs for advice, support and counselling, thus making it important to identify good practice and effective economical ways of deploying resources. Within this phase it is convenient to focus upon three particular periods where considerations arise concerning the purpose, nature and source of intervention. These are:

- the immediate pre-test period
- the post-test/immediate post-result period
- the continuing period of post-result adjustment

1.3 Because it is based on existing work and has been completed in six months, this study consists of intelligence-gathering, analysis and commentary rather than systematic original research. The information used was gathered from:

- published and unpublished reports, memoranda, accounts of practice and other papers; and
- selected persons or agencies identified as possessing relevant experience or knowledge.

Some persons and agencies were visited, while others were written to or telephoned. A list of those contacted is provided in Apendix 1. It is a characteristic of those at the forefront of AIDS work that they are extremely occupied

and in great demand. They are therefore difficult to contact and we were not succesful in all our approaches, but it was our general experience that if contact could be made this led to generosity with time, information and papers.

1.4 The brief presumed the existence of a range of well-established service packages, or components of packages, which our study could aim to identify. However, significant "hands-on" experience is very concentrated and the AIDS situation is fast-changing. We frequently learned that arrangements were only newly instituted or "under review" or due for early change, and that papers were seen as "out-of-date" or were "being revised". The consequence is that there exists no large range of well-tried packages.

1.5 The earliest service responses seem probably to have been pragmatic adaptations to newly identified problems, and only more recently have packages begun to crystallise. These are still often seen as provisional and developing in the light of experience, frequently earmarked for review, and too new to have been evaluated. In places away from the few main centres experience of HIV and AIDS is limited, and here there exist not so much established packages as plans or intentions or provisional arrangements which are recognised as subject to change and to tests of viability. In some areas it appeared that a prescient officer was initiating action while still striving to alert managers or elected members whose consciousness of AIDS was low. In particular, local authority awareness around the country is very varied. Reasons such as these led us to focus our study as much on principles of provision as on particular existing patterns of delivery. By this means we established that there is considerable consensus on certain principles, and from these we have abstracted a framework for HIV counselling which we show as a chart in Section 6. In Section 7 we provide some vignettes of actual counselling arrangements in order to show that the framework can be differently implemented in practice, and our report then explores some service delivery issues which arise and the training and support needs of HIV counsellors.

1.6 A further consideration which shaped our work is that much of what is going on or being planned relates to the time when illness is experienced rather than to the earlier asymptomatic phase. It is with ARC and AIDS that the real pressure lies for the provision of care, especially within the community services, where the needs of asymptomatic carriers may be comparatively unattended. For example, the House of Commons Social Services Committee noted Hammersmith and Fulham as a local authority with a particularly comprehensive range of care (1), but this range of care is for people with AIDS and does not include

provision for asymptomatic individuals. In addition, where care for seropositives is provided this is not necessarily as a discrete arrangement. In some systems, longer-term counselling of the HIV positive extends over into care for people with ARC or AIDS, and includes bereavement counselling. It can be artificial, therefore, to rigorously detach consideration of the asymptomatic phase from other aspects of AIDS provision, although we have kept our central focus on this phase.

1.7 Throughout our work we have been made very aware of the rapid pace at which new knowledge of HIV and AIDS supercedes previous conclusions, but we are conscious also of the large areas of remaining uncertainty and of the tentative (and often undocumented) nature of service response. This leads us to consider that our report may have interest for a diverse audience, and we have written it with this in mind. We believe that firm recommendations about best practice cannot yet be made, but that experience has revealed aspects of good practice which can serve for guidance until firmer conclusions can be drawn.

2. COUNSELLING - A PROBLEMATIC TERM

2.1 CONCEPTUAL DISTINCTIONS

2.1.1 The research brief identified advice, support and counselling as the relevant forms of intervention for study. For working purposes we distinguished these as follows:

- Advice - the imparting of authoritative information, explanation, guidance, clarification of options.
- Support - the provision of encouragement, enhancement of morale, maintenance of sociability etc, together with specific practical asistance.
- Counselling - the skilled and principled use of relationship to facilitate self-knowledge, emotional acceptance and growth, and the optimal development of personal resource.

2.1.2 In practice these conceptually different interventions may be delivered by the same person and blended in the same activity or session. However, the distinctions we make draw attention to the differences between informational, social, practical and emotional needs which an individual may have, to potential interaction between them, and to the possibility that they may vary in balance at different times. The significance of this is that different forms of intervention call upon different skills and capacities and may thus identify different potential providers, as well as carrying resource implications.

2.2 HIV COUNSELLING

2.2.1 In the present context it is a source of some difficulty that in the AIDS milieu the term 'counselling' is used in a variety of senses, and that activities which are analytically distinct are conflated under this single term. In medical settings, for example, counselling is commonly understood as a more prescriptive and directive process than would be the case, say, for the British Association for Counselling (1). More generally, the term tends to be applied to all the activities which may be carried out by someone with the title or function of HIV counsellor. These may include not only advice, support and counselling as we define them above but also health education and training activities (2). The problem with these different understandings is that mandatory requirements for counselling in association with the HIV antibody test are liable to be differently interpreted by different people. Claims that counselling is provided are therefore not self-evident in meaning, and may lead to misunderstanding.

2.2.2 The aim here is not to rank activities or promote a mystique of counselling. The point rather is that it is helpful to reserve a term to distinguish a type of therapeutic encounter which is theoretically-based and incorporates defined skills and objectives. Some of these skills may well be used in other professional or social contexts, but this is a different matter from their trained application within a purposive counsellor-client relationship. Similarly at the group level, there is a difference between peer support groups and the case where therapists or facilitators are applying trained skills in pursuit of group work objectives.

2.2.3 Counselling as we define it above still comprises a spectrum which has blurred edges. Nevertheless, to distinguish it from other activities in this way serves to indicate that different forms of intervention may be appropriate at different points within the continuum of provision. As a generalisation, pre-test counselling and post-test counselling with the seronegative are weighted towards advice, whereas the longer-term care of the HIV positive may have more emphasis on support and counselling (all as defined in 2.1.1). Experienced workers stress that role-clarity within an HIV team is essential, and this clarity can be facilitated by distinguishing different elements in provision. For convenience, from now, we use the term "personal counselling" to refer to the activity defined as counselling in 2.1.1 above. The overall provision of test-associated service and care we shall call HIV counselling. Other uses of the term counselling will be indicated by a qualifier (eg pre-test counselling or longer-term counselling). Such phrases thus do not necessarily indicate that "personal counselling" is undertaken within the activity described.

3. THE DEMAND FOR HIV COUNSELLING

3.1 Rational anticipation of needs and planning of provison for HIV counselling require better information than is currently available on the prevalence and rate of spread of infection. Accurate projections are frustrated by the unknown size of the two present major risk groups (1), inability to gauge individual risks of infection within these groups, and the possibility of changes in life style which will alter the risk. Forecasting trends amongst the population outside the recognised risk groups is even more hazardous. Current known prevalence is low, but knowledge about patterns of sexual behaviour is lacking, and the existence of bridges between high and low risk populations is assumed to carry the potential for a much wider dissemination of infections than so far experienced (2). The Communicable Diseases Surveillance Centre (CDSC) has reasonable confidence in its count of cases of AIDS but not of HIV infection. At the end of June 1987 there were in the UK 6349 persons identified as HIV positive, but the CDSC warns that these constitute only an unknown fraction of the total actually infected (3). Conventionally this total is estimated at 30 - 40,000 but much higher figures have also been suggested, and all estimates have been referred to as guesses.

3.2 The CDSC provides a breakdown of known HIV infection by Region, but warns that this may be an unreliable guide to geographical distribution (4). Furthermore, Regional estimates may be insufficiently informative for planning purposes within sub-Regional authorities. Some of our contacts expressed a wish for further disaggregation of the statistics, and the report HIV Infection in Scotland advocated reporting by postcode sector or town (5). Attempts have been made to forecast growth in infection rates on a localised basis, and to cost their implications. The relevant reports, however, acknowledge the uncertain basis of the assumptions employed and "high" and "low" forecasts vary by significant magnitudes (6).

3.3 Uncertainty concerning the size or even the reality of future demand militates against a sense of priority in planning. On an implied basis of approximately 5:1 unrecorded to recorded cases of HIV infection, and omitting Scotland and the three Thames Regions of major AIDS concentration, estimates of unrecorded infection in the other Regions would range from some 200 to 1500 (7). From the viewpoint of any particular local area such figures may not seem to necessitate or make worthwhile the anticipatory allocation of additional resources for HIV counselling.

3.4 Information is required not only on total numbers and distribution but also on category of client because, as we discuss later, the nature of "case-mix" has implication for HIV counselling. The CDSC reports offer classifications of known seropositives by sex and risk category, and these

indicate how different is the mix as between Scotland and the rest of the UK (8). Differences of this kind may well imply a need for locally-differentiated service response.

3.5 Professor Adler has pointed out that we lack reliable assessments of the distribution of people at any one time over the spectrum of AIDS-related conditions, and of the rate at which they move from one condition to another, if they do (9). In respect of HIV counselling, information on the duration of the asymptomatic phase would reveal the duration of ongoing commitment and also the phasing of transition to other conditions with a potential need for wider social care. Overall, the asymptomatic period may be from one to five years, but it could be longer (10), and new drugs may change the course of HIV infection, with perhaps a prolongation of the asymptomatic phase. It is not clear what proportion of the HIV positive will move to symptomatic status. Estimates are becoming more pessimistic, but it is known that some people remain asymptomatic for many years. What is not known is the degree and pattern of need for advice, support and counselling such people may exhibit.

3.6 The statistics of infection are important for many purposes, but it is vital to note that the resource burden of HIV counselling as a whole is governed by the numbers presenting to discuss the test rather than by the numbers infected. According to current policy, all who attend to consider the test need pre-test counselling and all who take the test need post-result counselling. With HIV negative results the post-result counselling focuses on risk-reduction behaviour; with HIV positive results, on this but also on much wider issues, with the possibility of longer-term intervention. The consequence is that a proportion of HIV counselling is undertaken with persons who are either not tested or not infected, and the evidence suggests that this may be the major proportion.

3.7 Little is know of what determines the volume of demand for voluntary antibody testing, except that media campaigns promote large increases. At St. Mary's Hospital, Paddington, the numbers attending for the test rose from 100 per month in mid 1986 to 475 in November, at the time of the popular press campaign on heterosexual spread of the virus. They rose further still to 700 as a consequence of "AIDS week" in March 1987, although they fell thereafter (11). These striking rises are confirmed by the experience of the Division of Virology at St. Mary's Hospital (which services other hospitals), by the 300 per cent increase in test requests at the Middlesex Hospital between September and mid-November 1986, and by evidence from provincial centres (12).

3.8 Further analysis of figures from these sources indicate an intense negative gearing between those attending for test and those found to be HIV positive. Of 847 attenders at the

Middlesex Hospital some 24 per cent were not tested after pre-test counselling. Of the 641 who were tested, 5.7 per cent were HIV positive (4.4 per cent of the original attenders). At St. Mary's Hospital over a period, 23 per cent declined testing after pre-test counselling, and of 1792 tested 10.6 per cent were found HIV positive (13). Between August 1986 and April 1987 no client in the group with no known risk factor was found seropositive by the St. Mary's Division of Virology. These figures clearly confirm that most of the HIV counselling effort is directed towards the non-tested and the antibody negative.

3.9 The justifications usually offered for this expenditure on clients not shown to be infected are that an important function of HIV counselling is to educate clients (especially those at high risk) to avoid the spread of the virus, and that work with individuals is the most effective means of motivating the needed behavioural changes (14). However, there is a lack of reported evidence on the effectiveness of HIV counselling in this respect, particularly amongst those who are antibody negative. There is some evidence suggesting that knowledge of seroposivity may be a profound motivator (15), but there is evidence also that people who know themselves to be seropositive do not necessarily cease risky sexual activities (16). Because one-to-one counselling is by definition resource-intensive, some detailed evaluation of the effectivenss of HIV counselling in securing compliance in risk-reduction behaviour would clearly be desirable.

3.10 The volume of demand for testing is likely to be affected by the extent of promotion of the test itself, as against promotion of general AIDS consciousness. At the moment, policy here seems to strike an uncertain note. According to the Chief Medical Officer of the DHSS it has been government policy to make the test available but not to promote it (17), and there are reports of uncertainty in the Regions (18). On the other hand, some consultants advocate an enthusiastic promotion not only of voluntary testing but of contact tracing (19). Contact tracing would generate additional workload both via more counselling and testing and via the tracing work itself. It would also pose issues for those test sites which lack the expertise of GUM clinics in this sphere. Furthermore, because of the intense sensitivity of the confidentiality issue in respect of HIV infection, it is possible that an aggressive programme of contact tracing would carry implications for the nature of the relationship between counsellor and client. So far, the overall policy on contact tracing appears unclear.

3.11 It is evident in respect of HIV counselling that various aspects of quantitative uncertainty present difficulties to those who are providing or planning to provide a service. If the imperative of test-associated counselling is maintained, then agencies must calculate the resource demand

this creates, but planning currently has to occur in a partial vacuum. A more certain basis for forecasting is required if either under- or overprovision is to be avoided.

4. THE NEEDS OF THE HIV POSITIVE

4.1 Those infected by HIV may progress from the asymptomatic phase through a spectrum of conditions including PGL, ARC, frank AIDS and the degenerative neuropsychiatric changes know as AIDS dementia. Even with full progression, however, the disease has an episodic profile, so that in-patient treatment alternates with longer periods when community care is needed rather than hospitalisation. In the full AIDS career, patients and their social intimates may need a wide variety of practical supportive services from local authority Social Services, Housing and Environmental Health departments, and from other sources (including voluntary organisations), as well as domiciliary medical care. This is particularly so if a community care model is adopted.

4.2 Needs for such varied resources present difficulties of mobilisation and co-ordination which are familiar from other areas of community care. These include problems of joint planning and funding, lack of co-terminosity amongst authorities and obstacles to the marshalling of multi-disciplinary teams. Many areas have appointed an AIDS co-ordinator with responsibilities concerning the development of corporate policy, joint planning, and the servicing of AIDS working parties, but these officers are not normally responsible for organising direct care at specific client level. Approaches to co-ordinating direct care for people with ARC or AIDS include the appointment of a ward discharge co-ordinator (as at St. Stephen's Hospital, London), an AIDS community care organiser (as in the Kensington and Chelsea Social Services Department), and the notion of a hospital-based home-care team (including a social worker) as described by Professor Adler (1). As will be seen later, however, in some arrangements the original HIV counsellor is intended to maintain responsibility throughout full progression, from pre-test to bereavement counselling. Where this is not so issues arise concerning the demarcation and transfer of responsibilities as the patient progresses in condition. Problems may arise where HIV counselling is essentially clinic-based, with home visiting not provided for, and where clients are geographically dispersed so that local agencies may be unknown quantities to the primary counsellor. This is one reason why role clarity is vital, and why provision for HIV counselling in the asymptomatic phase must be considered in relation to what follows the progression to illness. Even in areas where levels of known HIV infection are currently low it would be convenient if SSDs designated a lead worker to whom reference could be made regarding the direct care needs of people with AIDS (2).

4.3 Experience evidently suggests that asymptomatic clients are much less likely to draw upon practical support services than are people with AIDS. Nevertheless, some practical

issues can arise. In respect of housing, for example, there may be problems of harassment, unsuitable accommodation or eviction and homelessness, and unlike people with AIDS, the HIV positive are unlikely to be defined as vulnerable under the Homeless Persons Act 1977 (3). There may also be problems of harassment in employment or job loss where the client's seroposivity becomes known. Here there may arise needs for legal and other assistance. Clients on low incomes may experience difficulties in affording a health-boosting diet, suitable accommodation, or even the condoms recommended in risk-reduction advice. Notwithstanding such possibilities, asymptomatic clients commonly have a more or less normal work and home existence and seem not to make heavy demand on practical services, at least not as a consequence of HIV infection.

4.4 There are, however, three particular periods within the asymptomatic phase when needs for HIV counselling arise, and these are:

4.4.1 Pre-test. In order to be able to give informed consent clients need to understand the nature and medical implications of the antibody test, and the purposes it may serve. They need also to consider the social and emotional implications of a positive test result for themselves and their close associates, as well as the possible adverse practical consequences in respect of, for example, insurance and mortgages. In addition, clients need to appreciate that whether or not the test is taken, and irrespective of result, the implications for changes in life style and sexual habits may remain the same, and certainly so for those in high-risk categories.

4.4.2 Immediate post-result (HIV negative). If the test result is negative there is need for advice regarding risk-reduction, and on possible re-testing if high-risk behaviour has been recent and seroconversion remains a possibility. For the antibody negative HIV counselling normally ends here, but from this group emerge those known as the "worried well"; clients whose fears of infection reach obsessive proportions and for whom HIV seems to act as a vehicle for psychological vulnerability (4). Such clients can be a burden on counselling resources and often require referral for psychological or psychiatric help.

4.4.3 Immediate post-result (HIV positive). Positive results require a more complex response. Risk reduction (to self and others), health-boosting, who to tell and various practical issues must be discussed, but reaction to a positive result is commonly characterised by shock and distress, and strong emotions may be ventilated. Seropositivity deprives individuals of previous expectations, and subjects them to fears and stresses and to a distressing uncertainty concerning the direction their infection may take. Depression or anxiety may result, and

the list of possible fears and anxieties is lengthy (see Tables 1 and 2 of Appendix 2 for a summary). A positive result may also act as a catalyst for underlying emotional or relationship problems, or other destructive themes may emerge in the client's response, such as guilt over sexual or drug-abusing behaviour. If left unattended these reactions may have serious consequences not only for emotional health but also for risk avoidance and physical health. Anxiety can undermine capacity for constructive health management and behavioural change, and chronic emotional stress may itself be immunosuppressive (5). Because there is much ground to cover and the client may be too numbed to give full attention, post-result counselling of the HIV positive may require a further interview. In some systems a repeat interview within a few days is routinely arranged, and for some clients the need for help extends into a lengthier process.

4.4.4 Longer-term adjustment. The needs of HIV positive clients may persist over sometimes lengthy periods. The topics noted in 4.4.3 have continuing significance, and new circumstances may arise to be dealt with. Other possible issues include maintenance of morale, relationship difficulties, and "coming out" to the family not only as HIV positive but as a homosexual or drug user. In this period, as more immediately after the test, there may be a need for referral to specialised care or other helping agencies.

4.5 Seropositivity affects the lives of close associates, so that partners, spouses or family members may also need advice, support and counselling. Anxieties about the client's well-being, their own antibody status and the risks of living with a seropositive person may be involved, and sexual partners are necessarily affected by the adoption of safer sex practices. If difficulties lead to the breakdown of intimate relationships, clients are left even more vulnerable and exposed to isolation. According to Miller, levels of adjustment stress amongst close associates may equal or exceed those of the infected person, so that additional demand is created for HIV counselling (6).

4.6 There are no measures available of the volume or frequency of uptake of the various aspects of continuing HIV counselling provision. In principle some estimates could be derived from the records of agencies which have dealt with significant numbers of clients, but the labour to analyse these has not been available. Evidently some clients do not need or want continued service, at least from the agency HIV counsellor, and it is not known how far they seek help elsewhere. However we found ample testimony that antibody testing does generate needs for advice, support and counselling, and there is a widespread agreement that testing should occur only in the context of such provision.

4.7 A significant element in the context of HIV counselling is that two of the major groups so far at high risk of infection have been stigmatised social minorities. Profound and stressful social reactions to AIDS have been compounded with negative evaluations of homosexuality and drug abuse in ways that sometimes create an atmosphere of blame, leading to harassment and aggression. This means that unlike others with life-threatening conditions, people who are HIV positive cannot rely upon sympathetic support from those arond them, and issues of confidentiality and secrecy are peculiarly acute. Clients are usually advised to exercise great discretion in revealing their conditon, but where secrecy is maintained emotional support cannot then be sought from associates. If secrecy is not maintained the client may experience a degree of isolation either from rejection or from a need felt by others to be cautious in their dealings with those who are infected. Individuals may thus be bereft of social and emotional comfort at a time when their needs are great, and fears of exposure are added to the burdens of adjustment to an uncertain but perilous future.

4.8 The stigmatisation of HIV conditions is often advanced as a justification for distinctive or designated supportive provision in the form of HIV counselling. Inevitably the conditions of HIV counselling are affected by this wider context. Members of marginalised minorities may be alienated from official provision. Some of those in high-risk categories are hard to reach, and ability to make contact with them is effected by the test site's accessibility and reputation. In addition, the social and sexual values of HIV counsellors themselves may influence the effectiveness of counselling arrangements, and this has implications for training which are noted in section 10.

5. DIFFERENCES AMONGST THE HIV POSITIVE

5.1 HIV infection may impose some problems which are common to all who suffer it, but people who are antibody positive do not constitute a homogeneous group. The avoidance of stereotyping is important because needs and characteristics vary not only between the currently recognised risk categories but also within them. Furthermore, the groups involved also vary in their capacity to generate self-help and mutual aid. The nature of HIV counselling provision needs to be sensitive to differences within and between groups, and it is appropriate to note some of these.

5.2 MALE HOMOSEXUALS

5.2.1 Despite stigmatisation the homosexual community has a demonstrated capacity for collective response and sophisticated self-provisioning in respect of HIV, and the early practical response to AIDS in the UK came largely from this source. Very prominent here is the Terence Higgins Trust, which although not self-defined as a gay organisation has greatly depended upon the homosexual community for finance and volunteers (1). In addition, many helplines owe their origins to gay groups, peer self-help groups such as Body Positive and charities such as CRUSAID have emerged, and in Scotland the Scottish AIDS Monitor functions like the Terence Higgins Trust. The networks of the gay press, clubs and switchboards made it possible to alert many homosexual men to the dangers of AIDS, and to promote risk-reduction information before the advent of official media campaigns.

5.2.2 This distinctive capability for self-provisioning has some clear advantages. The resulting networks and organisations are better placed to communicate with potential users and to understand their needs, and thus may be more "user-friendly" than official services. They also widen the range of sources of help, and peer groups are particularly apt for meeting some needs for social and emotional support. However, self-provisioning has its limits (2). Volunteer Labour may be defined by availability rather than necessarily by suitability, there is a high rate of "burn-out" amongst volunteers, and voluntary resources are inadequate to meet all needs. Furthermore, not everyone requiring help can be reached through this route, even although the resources concerned may be in principle open to all.

5.2.3 Beyond this, although many homosexual men are well-informed, the gay "community" is in fact differentiated in behaviour and life style. Some men do not declare their homosexuality through use of gay clubs

and self-organised groups, and those lacking an established social circle or unable to form lasting relationships may live in some isolation. Where sexual activity has been a major source of social contact, seropositivity threatens sociability. In addiiton, not all homosexual men are comfortable with their sexuality, and HIV infection can revive unresolved conflicts and guilt. Established sexual partnerships may be threatened by HIV, while those for whom multi-partnering is a means of homosexual affirmation face a critical check. For many, family suport is not readily available, either through mobility or because of conflict (3). Members of this risk group thus have needs for advice, support and counselling which cannot all be met through peer provision, so that formal provision of HIV counselling remains necessary. Nevertheless, the resources created by voluntary effort have great significance, and these are further discussed in Section 9.

5.3 INTRAVENOUS DRUG ABUSERS

5.3.1 " None of our evidence provides much advice on how to deal with the problem of AIDS and HIV infection in the drug-abusing population".

This comment by the House of Commons Social Services Committee (4) illustrates both the general dearth of knowledge about drug abusers and the difficulties of combatting AIDS amongst them. Although sexual spread is also important amongst IVDAs, the central issue is the sharing of infected injection equipment because direct innoculation is such a highly efficient means of HIV transmission (5). HIV prevention is thus closely compounded with the general anti-drugs programme. Currently the problem is centred in Scotland, but other areas are not immune. A recent finding of potentially sinister significance concerns the number of Edinburgh-based drug abusers who have shared injection equipment in other towns throughout the UK (6). Given the rapidity with which infection has spread amongst IVDAs in Edinburgh following the introduction of the virus in 1983, it is evident that the revealed pattern of mobility amongst drug abusers represents a considerable threat of further dissemination of HIV.

5.3.2 According to the McClelland Committee (7), a central task in the fight against AIDS is to draw IVDAs within reach of a programme designed to:

i) prevent experimentation with injection;
ii) persuade established IVDAs to abandon injection;
iii) persuade those who will not abandon injection to adopt hygienic injection practice; and
iv) encourage and support individuals to drop drug use.

These objectives introduce the role of agencies which can develop contact with IVDAs. Drug abusers lack the apparatus of communication and sociability developed by the homosexual community. Although some ex drug abusers are active in drugs agencies, there is no equivalent in the UK of the Dutch "Junkiebonden", and so intervention must come from external agencies. Among these, the role of statutory Drugs Dependence clinics may be limited because their restricted access and emphasis on withdrawal lead many IVDAs to see their services as not worth pursuing.

5.3.3 The voluntary drugs agencies with their greater outreach are therefore crucial, but they too have limitations. They are precariously funded and seem often to be under-regarded and insufficiently supported by local Social Services Departments and Committees. According to a report by the Social Services Inspectorate (8), some agencies have under-developed models of care, or employ contradictory models, or attempt too many tasks. Problems arise from reliance on volunteers, and general overloading has been increased by the advent of AIDS as a new issue. Further difficulties, we were told, are that training has not yet fully assimilated the HIV phenomenon and that drugs workers are inexperienced in counselling on sexual matters.

5.3.4 Despite these difficulties it seems widely agreed that drugs agencies have acknowledged the issue and are incorporating HIV education and counselling into their work. There is a consensus amongst drugs workers that successful outreach will require flexible and innovative approaches, although there is no surplus of suggestions for these. There seems to be no equivalent in the UK of the "bus" projects operating in Amsterdam and Sidney (9). However, needle exchange schemes incorporating information and counselling on AIDS have been instituted and, despite original scepticism from some, preliminary experience suggests that these schemes are drawing in new contacts (10).

5.3.5 For many agencies, however, there is the dilemma that measures which may limit the spread of HIV may also conflict with what they see as good practice in countering drug misuse. To many drugs workers, prescribing the means of injection or maintenance dosages of oral substitutes for heroin, or distributing bleach for the cleaning of equipment, defeat the treatment objectives of abstinence and rehabilitation. Conflict thus exists between harm-reduction in respect of AIDS and previous aims. The McClelland report gave clear priority to HIV objectives, and there seems to be a widening conviction that this is appropriate (11).

5.3.6 The drug-abusing population differs in many way from other major risk groups. IVDAs are stereotyped as chaotic, fatalistic, antisocial and unreachable, but this is misleading because there is a range amongst drugs misusers and variation in patterns of drug administration. Episodic and controlled use, fastidious injection hygiene and stable life style are not absent, although those so characterised may already be accessible to HIV programmes or not in particular danger of HIV infection. Those groups nearest to the stereotype are hardest to reach. They are relatively averse to agencies and unresponsive to publicity campaigns, and may perceive the HIV phenomenon as representing an intensification of outsider status. It is of concern that Release has noted an increase in the injection of stimulants (12) because these substances often imply a "binge" pattern of use and erratic behaviour.

5.3.7 Other characteristics of the more unreachable and at-risk IVDAs are that they tend to be young and not well-resourced either personally or financially. They are apt to cluster in socially deprived areas, are often particularly vulnerable to accommodation problems, and their links with conventional institutions are attenuated. General health and immune systems are frequently undermined by drug abuse and malnourishment (13). Often they are involved in crime and prostitution (both male and female) to service their habit, and prostitution constitutes a potential outward route for transmission of HIV. From a quarter to a third of their number (in Lothian at least) are women. This creates an additional area of counselling need in respect of contraception, abortion and the potentially serious consequences of pregnancy for women already HIV positive. Experience suggests, however, that drug-abusive mothers tend to present late in pregnancy and already at risk (14).

5.3.8 There is also some evidence that IVDAs may not fit readily into existing provision for the HIV infected. They are said to be difficult patients and hard to assimilate into support groups or residential facilities with other risk categories (15). However, there are also some positive elements. There is some evidence that counselling can facilitate change of habits (16), and some observers discern more potential capacity for self-provisioning than has been realised. Bringing the more incorrigible IVDAs into the reach of HIV counselling therefore justifies great effort, but it is clear that they present some distinctive needs.

5.4 HAEMOPHILIACS

5.4.1 More than 1000 known HIV positives are male haemophiliacs who were infected via treatment for their already severe condition, and this has coloured their emotional reactions, especially the projection of anger. In addition, having only recently acquired independence of hospital via home therapy developments, they feel resentment at no longer being self-sufficient. The group is unique in that little more testing will be required and new cases should be rare. This simplifies service planning, and haemophiliacs are anyway already known to, and familiar with, the care sytems in treatment centres. Treatment for haemophiliacs is often family-orientated, especially with younger patients, and through long-standing acquaintance care staff may be able to identify any particular vulnerability to stress. Families know of the haemophilia, so that potentially disruptive revelations concerning the source of HIV infection are not required. Self-help provision has long existed, and the Haemophilia Society actively provides information and advice on HIV and AIDS.

5.4.2 The haemophiliac population is not homogeneous, and several groups have been identified as potentially in need of distinctive advice, support and counselling (17). These include mothers of young patients, adolescent haemophiliacs, young couples, and mature men in stable relationships. Issues which occur include guilt over complicity in the infecting treatment; burgeoning sexuality in the context of HIV; having children; disturbances of sexual relationships; fears of harming the partner; concern for the future welfare of spouse and children; and breaking the news to young sufferers. We were told that there are signs of depressive mood, tension and anxiety amongst wives and mothers; not florid manifestations, but indications of people on the edge and in need of supportive help (18).

5.4.3 For haemophiliacs and their families HIV counselling facilities are based on Haemophilia Reference Centres, which (except in Scotland) have recently had additional funds to cope with the burden of HIV work. The Social Services Committee recommended that these centres should be funded to provide a fully-trained counselling service (19). If this recommendation is accepted the distinctiveness of the haemophiliac group in respect of HIV counselling will be maintained.

5.5 PAEDIATRIC CASES

5.5.1 Child haemophiliacs are catered for as described above, so that the paediatric category effectively consists of the babies of HIV positive mothers, most of whom are IVDAs. This small but growing category, currently mostly

located in Scotland, causes great concern to care agencies. The need for HIV counselling here is with the mother, and there is little experience on which to build. In Edinburgh the well-being of the children is looked after through a special clinic conducted by Dr. Jacqueline Mok, while mothers are counselled through the City Clinic. This was established as an HIV unit alternative to the GUM clinic, with IVDAs particularly in mind (see 7.5.1 below). For these mothers similar considerations apply as to IVDAs in general, although they are particularly likely to require practical assistance. In addition, they tend to lack parenting skills and they require advice and support concerning child care in relation to HIV. Domestic relationships are often unstable, but experience suggests that while often erratic in respect of their own case they are more conscientious, with appointments for example, in respect of their children. There is also some evidence of withdrawal from drug use out of maternal concern (20). Because some of the children die there is a need for grief counselling in the longer run.

5.5.2 Some infected children come into care, and it has been discovered that foster parents can be found for these. Here the need for HIV counselling lies with the foster parents. In Edinburgh this service comes not from clinic counsellors but from an AIDS adviser appointed by the Regional Council. This officer has designated responsibility for adoption and fostering and for co-ordinating the necessary provision. Foster parents need a great deal of information and support, some of which is provided by bringing the families themselves together. This need for vicarious HIV counselling does not fit readily into the framework described in Section 6 below, and is best regarded as unique. Some Social Services Departments are evidently engaged in anticipatory recruitment and preparation of foster parents willing to accommodate HIV positive children, and this is undoubtedly prudent (21).

5.6 PRISONERS

5.6.1 Prisoners are not strictly a separate risk category for HIV infection, but their situation is distinctive. The Social Services Committee was clearly sceptical of Home Office estimates of the extent of seropositivity, homosexual behaviour and drug abuse amongst inmates, and felt that the full implications of possible HIV spread in prisons had not been grasped. Testing is available in prison with individual consent, but the Director of the Prison Medical Service believes that prisoners are not presenting for the test because they fear the consequences of identification (22).

5.6.2 Prisoners are in a unique situation in respect of HIV counselling because they have no choice of test site and no free access to community or voluntary provisions of support. We learned (23) that all prison medical officers have been informed of the need for counselling, and that the Prison Department has earmarked funds for training 25 per cent of all operational staff (ie not only discipline staff) about AIDS and the counselling needs of HIV positive prisoners, including how local statutory and voluntary services might be involved. No particular occupational grouping is designated for the provision of HIV counselling. Some prison psychologists undertake it, as do some hospital staff and some chaplains; the main criteria are commitment, suitability, and attendance at a NACTU course. If such a person is not available on the staff a suitable person will be brought in from another establishment or the local community even if this implies a sustained commitment. These arrangements seem adequate to meet the needs of HIV counselling, but prisoners have unique needs and difficult access circumstances. Given the conditions in prisons they probably have a particularly strong need for confidentiality, which it may be difficult to meet under the policy of placing HIV positive inmates either in a separate cell or a communal cell shared with other HIV infected prisoners. The HIV + prisoner also has a need, to quote Dr. Kilgour, for "safeguarding from the people who don't understand the nature of the disease" (24).

5.7 OTHER RISK CATEGORIES

5.7.1 This residual group includes heterosexual contacts of recognised risk groups and recipients of blood (in both cases, either at home or abroad). Little can be said about distinctive needs, although clearly these cases diversify the clientele for HIV counselling. Currently the numbers here are small, but any significant spread of infection into the general heterosexual population would create a new clientele for HIV counselling, and possibly a numerically dominant one if there is an epidemic. This clientele would be very heterogeneous, and it is not clear how far existing experience would provide an adequte guide to their needs because there is some tendency for thinking about counselling provision to be over-determined by the nature of existing HIV populations.

5.7.2 Of existing categories it is haemophiliacs who provide the nearest model of a general heterosexual group, and it is certainly likely that the family dimension seen there would be of relevance. Before the advent of AIDS the Haemophilia Reference Centres were experienced in counselling, communication and the hospital and domiciliary management of life-threatening conditions. These skills facilitated a family rather than an

individual perspective on care, and this perspective was found appropriate when HIV appeared. It has been suggested that the haemophilia comprehensive care system might serve as a model in developing services for new categories of those infected by HIV and their families (25). It seems certain that valuable lessons could be drawn from this sphere, but as noted above the haemophiliac population has certain distinguishing characteristics, including existing firm connections to a care system. For this reason the haemophiliac experience may not provide a fully satisfactory predictive model.

5.8 The variations within and between groups which are noted above illustrate how case-mix is an important issue in planning. Because different groups and sub-groups have distinctive characteristics and needs, they may be responsive to different approaches and require differentiated provision of HIV counselling. Overall provision needs to be sufficiently flexible to cater for the diversity amongst existing and potential clienteles.

6. A FRAMEWORK FOR HIV COUNSELLING

6.1 Since October 1985 voluntary HIV antibody tests have been made available in the UK, with official advice that their use should be accompanied by "counselling". As we noted in Section 2, this term is subject to different understandings, and for this and other reasons detailed practice has varied. If client needs are to be met and counselling objectives achieved, a coherent structure of provision is required, together with means to assure its quality (and, desirably, to evaluate its effectiveness). With time and experience some clear principles and a firmer general conception have emerged of the process which in this report we call HIV counselling.

6.2 From existing practice and published sources (1) we have abstracted a framework for HIV counselling, and this is shown as Figure I. This is a maximal prescription but it indicates the rationale of the process and summarises the best obtainable view of good practice. Empirically, the framework can be implemented in various ways, and we provide some examples of actual systems in Section 7. The analytical usefulness of the framework is as a template to match against existing practice or planned provision in a variety of test sites.

6.3 THE ELEMENTS OF THE FRAMEWORK

6.3.1 Box A. This is not part of the formal framework but is shown in outline to indicate that some clients may have received telephone counselling or other preliminary advice. However, the consensus is that it is unsafe to make assumptions about client preparedness, and all who present should receive pre-test counselling.

6.3.2 Box B. If counselling is available at presentation the client moves directly to pre-test counselling (Box D). If counselling is not immediately available an appointment is made (Box C).

6.3.3 Box D. Pre-test counselling may be differentiated for sound reasons, but good practice requires coverage of standard topics (see Table 3 of Appendix 2), and the client's risk category should be established. An estimate of waiting time for the result should be given or a firm appointment made if this is possible. Literature should be issued.

6.3.4 Box E. Some clients decline the test after pre-test counselling.

6.3.5 Box F. Sometimes a period for reflection is wanted by the client or seems desirable. The client may then decline the test or re-present.

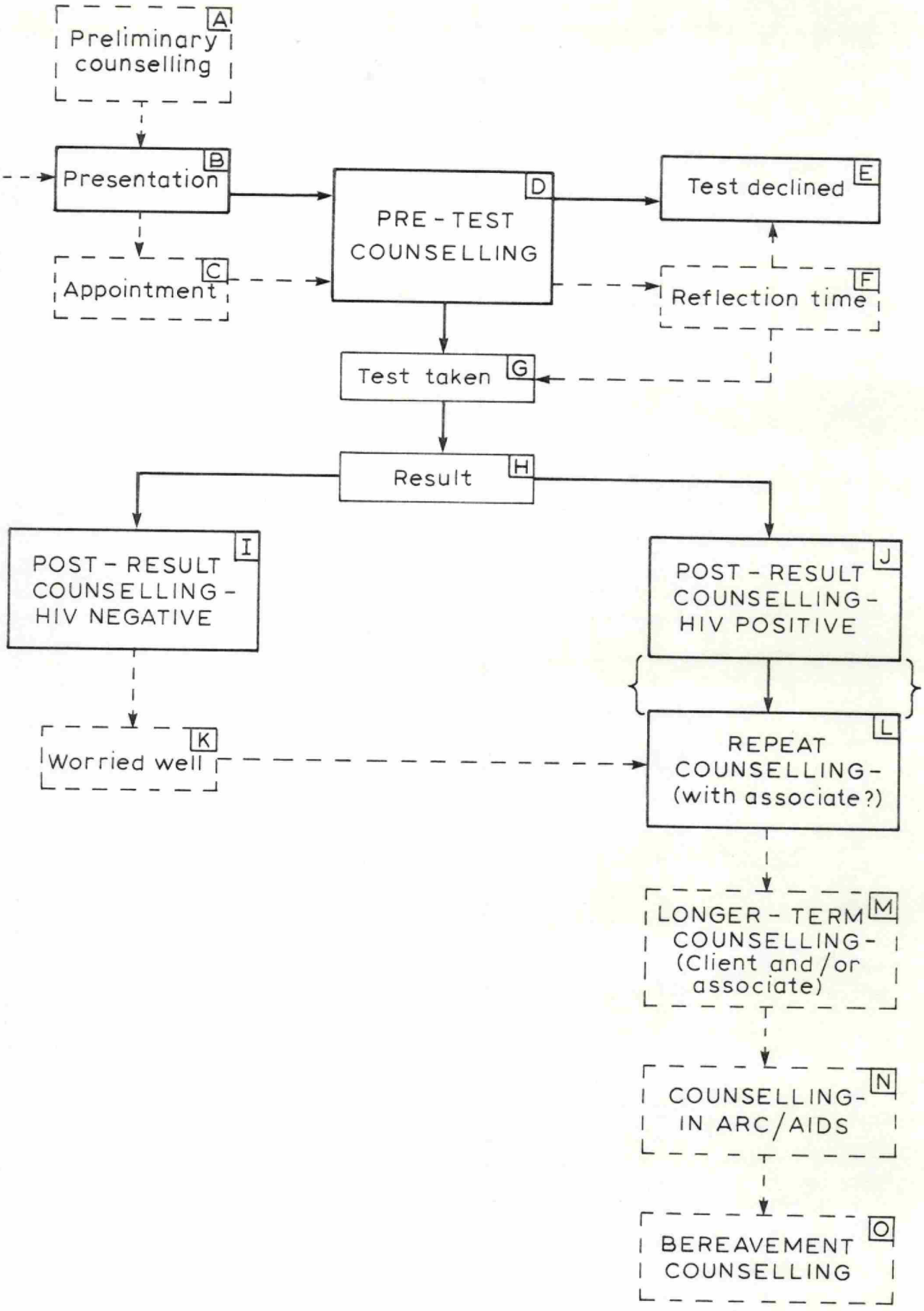

Figure 1 : A framework for HIV counselling

6.3.6 Box G. Blood is taken

6.3.7 Box H. A clear understanding on who will present the test result is required, and the result should be given only if counselling is available. Some practitioners advise not giving out positive results on Fridays.

6.3.8 Box I. HIV negative: the post-result counselling covers risk-reduction and possible re-testing, plus reassurance as appropriate. Literature is issued.

6.3.9 Box J. HIV positive: effective management requires allowing time to deal with shock reactions. Counselling deals with risk-reduction (regarding self and others), health maintenance and , as appropriate any of the issues described in 4.4.3 above. A repeat appointment is offered for within a few days, either routinely or if business is unfinished or if the client is too distracted for full attention. In some arrangements the immediate post-result interview is intentionally kept short to allow the client to recuperate, and to formulate questions for the repeat appointment. If a repeat appointment is made the client may be invited to consider bringing a partner, spouse or relative. Discretion is advised in revealing the news. If no repeat interview is fixed, an offer of continuing access at need is made, with the option of bringing an associate. In all cases literature is issued and the patient is given a "lifeline" telephone number for contacting the counsellor, together with details of support agencies.

6.3.10 Box K. The worried well may re-enter the system for further counselling.

6.3.11 Box L. The completion of immediate post-test counselling begun in Box J. Continuing access at need is offered. Discreet watch is kept for possible needs for referral for specialised therapy (and this applies to Box J if no repeat appointment is made).

6.3.12 Box M. The client or an associate may require further or continuing advice, support or counselling in respect of persisting or new issues.

6.3.13 Boxes N/O. HIV counselling after progression to ARC or AIDS and bereavement counselling are not strictly within our remit. However, we include them for completeness and because:

(i) in some systems the initial counsellor retains responsibilities throughout progression to illness and death;
(ii) if this is not the case, the need for clarity concerning transfer arrangements is shown; and
(iii) a reminder is provided that a full "continuum of

care" runs not from diagnosis to death but from pre-presentation to post-death.

6.4 It is necessary to repeat that the framework is an abstraction which depicts the elements of an HIV counselling system. It also represents a counsel of perfection which may not always be achievable or seem to be justified. The framework does, however, distill the views of experienced workers in the field, and it might be regarded as a specification which allows practice or plans to be scrutinised against criteria of good practice. The specification obviously carries resource implications, but it may facilitate consideration of the intended scope of a system, the division of labour in HIV counselling, the effective deployment of existing resources, and the search for economical modes of implementation. Selected issues in implementation are take up in Section 8.

7. HIV COUNSELLING IN PRACTICE

7.1 With Figure I as background, we now present vignettes of actual HIV counselling arrangements in a number of settings. The cases are chosen to illustrate how the abstract framework may be differently implemented in practice while still preserving its inner logic.

7.2 TWO LONDON GUM CLINICS.

7.2.1 St. Mary's Hospital, Paddington. Clients presenting for test at the Praed Street Clinic are assessed for risk category by a doctor. Those in low-risk categories receive pre-test counselling in brief form from the doctor. High-risk clients are transferrd to a Health Adviser for a more extended interview. As a time-saver and a supplement to counselling, the pre-test counselling centres round a purpose-written fact sheet. The test consent form incorporates a detailed certification that the client has understood the implications of the counselling. The immediate post-result counselling is conducted by the Health Adviser, with variations appropriate to the result. HIV positive clients receive an early repeat appointment and a further purpose-written guide. Further interviews and longer-term counselling are available, but Health Advisers do not make specific appointments or conduct home visits, so that continued service is at client initiative. Where necessary, seropositive clients or the worried well are referred to designated clinical pyschologists, one of whom specialises in the drug-dependent. Clients who become symptomatic are dealt with via a ward team which includes an AIDS co-ordinator and a designated social worker, and clinical psychologists become more involved here. The clinic Health Advisers maintain ordinary reponsibilities with other GUM clients, and are thus not solely engaged in HIV-related work.

7.2.2 The Middlesex Hospital. At James Pringle House there is particular emphasis on the desirability of continuity of relationship in HIV counselling. Pre-test counselling is conducted by Health Advisers, and is sufficiently elaborated in respect of safer sex and risk-reduction techniques to make post-test counselling unnecessary following a negative result. The immediate post-result and repeat counselling of seropositive clients is provided by the initial counsellor, and a purpose-written document to supplement this is in preparation. Longer-term counselling is available at client initiative, again from the initial counsellor, but home visits are not undertaken. The clinic has a designated clinical psychologist, and Health Advisers are being internally trained in psychological assessment to enable them to recognise need for specialised referral. For patients who become symptomatic it is proposed to develop

a home care team which would include a designated social worker (1). As at St. Mary's, Health advisers also undertake work which is not HIV-related.

7.3 A PROVINCIAL GUM CLINIC

7.3.1 Bradford. At the GUM clinic of St. Luke's Hospital the HIV counselling is conducted by an attached member of the Bradford Royal Infirmary social work team. Available for five of the clinic's nine weekly sessions, the counsellor undertakes pre-test and immediate post-result counselling with all clients. Thereafter, the counsellor is intended to provide a full service of counselling and support to the HIV positive and their families which will continue through full progression to AIDS and specifically includes bereavement counselling. In providing a social work service the counsellor is expected to liaise with other agencies and to marshall material help from both statutory and voluntary sources. Further responsibilities include the support of voluntary initiatives, the promotion of health education, and the provision of a specialised information resource to the local social services and health authorities. At least initially the counsellor is also expected to provide counselling and support for patients with certain other blood disorders, such as sickle-cell anaemia and leukaemia. This arrangement began in June 1987, and in the first two months 63 clients were tested, of whom six were HIV positive. It is therefore too early to know how the pattern of service will crystallise and develop.

7.4 A GUM OUTPOST

7.4.1 Bolton Royal Infirmary. The GUM clinic conducts its HIV antibody testing via sessional use of rooms in a Health Centre located away from the hospital. An advertised answerphone service directs callers to times when a direct line is available, and clients are seen mainly through appointments (30 minute intervals). Pre-test counselling is conducted by an AIDS Co-ordinator (from a nursing background), and the doctor screens clients for other sexually transmitted diseases apart from HIV. The AIDS Co-ordinator also provides the immediate post-result counselling, and a repeat interview is routinely arranged for seropositives. Seropositive clients are subject to quarterly medical recall, and longer term HIV counselling is associated with this, although clients are encouraged to make contact at need. The AIDS Co-ordinator's responsibilities extend through ARC and AIDS, and include making the necessary contacts with statutory and voluntary agencies. A dedicated half session weekly is available from a clinical pysychologist. Because the numbers of HIV positive and symptomatic patients are still relatively small,the longer term HIV counselling is provided on an informal basis which might

not suffice with a greater caseload. Provision will shortly be supplemented through appointment of an AIDS Counsellor who will service two GUM clinics. The AIDS Co-ordinator also has responsibilities in respect of the National AIDS Counselling Training Unit (North.

7.5 AN INDEPENDENT CLINIC

7.5.1 The City Hospital, Edinburgh. A self-referral HIV counselling and screening unit was established here both to pre-empt use of the blood transfusion service by IVDAs wishing for the antibody test and to offer an alternative to the GUM clinic at the Edinburgh Royal Infirmary (2). Four central sessions per week are provided, with a fifth at an outpost. At each session a doctor plus one of two part-time nurse/counsellors are available to counsel clients, not all of whom are IVDAs. Appointments are scheduled for 30 minutes, but the default rate is 40 per cent, and this creates leeway. Clients are allocated to the doctor or nurse/counsellors on no particular principle other than that the doctor deals with medical referrals. Post-result counselling is provided by the initial counsellor, and is differentiated by test result. Seropositive clients are offered a repeat interview and a purpose-written guide, plus the possibility of a medical examination. Home visits are possible, and the clinic offers longer-term counselling, although this is not often taken up. One third of seropositive clients are women, and where pregnancies and children are affected by HIV the clinic liaises closely with co-ordinated care arrangements designed to overcome the problems of haphazard life styles. Contraceptive advice and supplies are also offered. In principle, counselling is available through progression to AIDS, but few clients have yet made this transition and so procedures have not crystallised.

7.6 A HAEMOPHILIA CENTRE

7.6.1 The Royal Victoria Infirmary, Newcastle upon Tyne. The Haemophilia Reference Centre had a known clientele who had been exposed via blood products to HIV infection. When the antibody test became available it was offered to all patients, with almost universal take-up. Pre-test counselling was thus conducted in a context of existing relationships, and was shared amongst the doctor, nursing sister and attached social worker, partly on the basis of client preference. All test results were revealed by the doctor, but again patients could exercise preference regarding post-result counselling. In practice, over time, almost all patients have come into relationship with the social worker. This team member already provides a full social work service to haemophiliacs and their families, and longer-term HIV counselling has been absorbed into this. The service extends through full progression to AIDS and includes bereavement counselling

(3). Help is marshalled as appropriate from statutory and voluntary sources, a relatives support group is conducted and a group for older men is under consideration. Service planning is simplified because the full likely clientele is known.

7.6.2 The Centre is not a general test site, and telephone enquirers are given information but referred elsewhere. However, a few direct medical referrals are received, often in respect of clients with a blood-related at-risk experience overseas. The current practice is for the doctor to provide pre-test and post-result counselling, and while numbers remain small the full longer-term clinic service is made available.

7.7 AN ANTENATAL SERVICE

7.7.1 Riverside Health Authority. Since March 1987 all ante-natal clients of the St. Stephen's and Westminster hospitals have been offered screening for HIV infection. The offer, and pre-test counselling, are incorporated into the routine booking-in interview conducted by midwives trained for this task. The take-up rate is over 90 per cent, and women in high-risk categories who decline are treated as though positive for infection control purposes. The test is taken at the twelfth week of pregnancy, and is repeated at 30 weeks for high-risk categories. Positive test results are conveyed by the obstetrician, but post-result counselling in these cases is taken up by Health Advisers from the GUM clinic. HIV positive clients who opt to continue the pregnancy are also assigned to a special AIDS Research Clinic mounted by paediatricians to monitor the well-being of the babies. Only a small number of HIV positive results have appeared in the first six months of the scheme, all amongst women in high-risk categories. The arrangements will be reviewed after one year.

7.8 These vignettes indicate considerable variation in practical arrangements for HIV counselling, even although these are based on common principles. Furthermore, no universally best arrangement can be specified, because of inevitable differences in the nature of test sites and amongst the potential clientele. However, by reference to the framework outlined in Figure I it is possible to see how requirements of good practice are dealt with in different places, and what the overall scope of planned provision may be. Some service delivery considerations which arise here are considered in the next sections.

8. SELECTED ISSUES IN IMPLEMENTATION

8.1 THE LOCATION OF TEST SITES

8.1.1 The Social Services Committee saw it as generally accepted that HIV screening and counselling should lie within the GUM system (1). The justifications commonly advanced for this are that HIV infection is sexually transmitted, that a network of 213 clinics already exists, and that these clinics have a tradition of confidential one-to-one health advisory work. GUM consultants collectively have made strong bids for additional resources, and are against the establishment of independent HIV clinics (2). However, the significance and desirability of other sites also require consideration. GUM clinics generally lack familiarity with the life styles of IVDAs, and the Committee itself noted a need for alternative sites for drugs misusers (3). Alternative provision has been made in Edinburgh, and such arrangements may be appropriate in other places. Furthermore, experience has led others elsewhere to see benefits in separating HIV work from the GUM setting, as will happen when the purpose-built Kobler Centre at St. Stephen's Hospital in London comes into operation in early 1988.

8.1.2 Other considerations which we encountered are that GUM clinics tend to lack experience with chronicity, with life-threatening conditions, and with the family dimensions of illness (which may become relevant in the event of heterosexual spread). Some clinics open only for short periods, and it is noted that a quarter lack Health Advisers altogether, while half the remainder have only part-timers (4). In addition there are reports of variable and inadequate standards of HIV counselling (5), and we learned informally that advice may circulate within risk groups to avoid or prefer particular GUM clinics.

8.1.3 Hints of professional territoriality are detectable in some discussions of location (6). In practice, little is known of why test applicants present where they do, and data on the overall distribution of testing have not been collated. Evidence shows, however, that GUM clinics were the source of only half the blood samples analysed by the PHLS over a period (7). Non-GUM hospital settings accounted for a fifth of requests, and it is also clear that general practice surgeries are more significant test sites than some may have supposed. Over a quarter of samples came though GPs, with almost 10 per cent of the positives coming from this source. Doctors have been circularised on the need for HIV counselling with the antibody test, but it is uncertain how far general practitioners may have the time, temperament or training to provide this. We could find no information on the nature and quality of provision in general practice, or on arrangements in the other hospital settings. Beyond this,

it is known that some testing is conducted in private clinics, but detailed information on counselling arrangements is not available (8).

8.1.4 It is uncertain how far PHLS experience can be generalised (9), but it is evident that GUM clinics already have no monopoly of HIV testing and counselling, and diversification of test sites seems likely to increase. The need for HIV counselling therefore arises in a variety of settings, and this is why we have paid as much attention to principles of provision as to particular packages of delivery. With present policies on testing it is necessary for these principles to be adapted to particular conditions to ensure adequacy of provision. If the volume of testing to be undertaken escalates greatly it may perhaps become questionable whether elaborated HIV counselling can be sustained, and it may then be necessary to conceive of minimum acceptable standards rather than of best practice.

8.2 CONTINUITY AND SPAN OF HIV COUNSELLING

8.2.1 By continuity we mean the extent to which the same person is intended to conduct the various stages of HIV counselling provided for within any particular system. Span refers to how much of the framework shown in Figure I the arrangements are intended to cover. Continuity and span are therefore relevant to task allocation amongst various grades of personnel, because different balances of skills and time are called for by different stages of HIV counselling.

8.2.2 If the principle of continuity is applied, then those who conduct pre-test counselling must have the skills and the mandate to undertake later stages within the span of provision, whereas otherwise different elements may be undertaken by different personnel. Because greater flexibility is possible where continuity is not insisted upon the principle of continuity requires justification. This is usually offered in terms of clients who transpire to be HIV positive. It is said that even in pre-test counselling material emerges which is of later consequence, that the foundations of a relationship are then laid, and that clients dislike transferred relationships and the need to cover old ground. These points are valid but they must be set against the considerations that only a small minority of those receiving pre-test counselling are found to be seropositive, and that costs are involved. Not only is flexibility foregone, but over-qualification for the particular task may be demanded. Similar considerations apply to the post-result counselling of test candidates found to be antibody negative (who constitute the great majority). Only those found HIV positive (plus the "worried well") seem likely to make significant demands

upon skills in personal counselling and the mobilisation of community resources, and it may not be cost effective for those with such skills to be deployed for the full span of provision.

8.2.3 The designed span of provision is a policy matter which requires clarity on purposes and on the balance which is sought between individual and public welfare. There may be general background purposes behind counselling and screening, such as protection of the blood transfusion service or epidemiological benefit, but the immediate basic purposes are:

(a) to provide the conditions for informed consent;

(b) To guide the client towards a safer life style and to sources of help; and

(c) To curtail the spread of infection by seeking compliance in risk-reduction behaviour. Securing this compliance may require continued counselling beyond the immediate post-result period, but this is distinguishable from the further potential purpose of supplying a range of direct supportive care to seropositive clients throughout the asymptomatic phase. Beyond this is the further possible aim of distinguishing the HIV positive as a particular needs group meriting a designated supportive framework which is continuous from pre-test through full progression to AIDS and includes bereavement counselling. Some of these purposes are readily achievable through the conventional staffing of, for example, GUM clinics, but others may require additional provision.

8.3 TASK ALLOCATION

8.3.1. Personnel from many disciplines are currently involved in pre-test counselling (10). Variations in conditions make this inevitable, but ad hoc arrangements are likely to produce unfortunate consequences. Clarity regarding counselling resonsibilities is therefore imperative, not only to ensure task performance but to avoid client confusion and to identify training needs. Cost factors are also involved because of differentiated salary structures, and appropriate task allocation is difficult to separate from issues of continuity and span.

8.3.2 Different considerations apply to each grade of personnel. The use of medical time for pre-test counselling is expensive, for instance, and doctors in busy clinics may be unable to offer the appropriate extended attention to high-risk clients. This seems to be recognised in the St. Mary's system. Doctors, moreover, could not be expected

to undertake extensive long-term counselling, and they have no direct connection to social service agencies. Nurses may be qualified to provide pre-test counselling and post-result counselling to the seronegative, but they could not be assumed to possess the time and skills for longer-term work with HIV positives, where personal counselling and the ability to mobilise other resources may be required. Health Advisers are particularly qualified for health education work, and therefore for pre-test and post-result counselling. They do not necessarily have personal counselling skills, however, or direct social services connections, and they could not usually provide care throughout full progression to death and bereavement (again the St. Mary's case is instructive). Social workers could be expected to possess personal counselling skills and they have direct connections to social services resources, but they lack health advisory skills.

8.3.3. All personnel require some HIV-specific training. Beyond this, gaps in skills and capacities could in principle be filled by additional training and modified conditions of work. It is important to consider, however, whether effective deployment might best be achieved by sacrificing continuity and splitting HIV counselling reponsibilities according to existing staff skills. Of the stages shown in Figure I, it is perhaps pre-test counselling and post-result counselling of the seronegatve which most easily lend themselves to splitting off. They are primarily 'one-off' encounters with a high informational content, are relatively easy to standardise, and require skills which are more readily available within GUM and other clinics than may be those required for personal counselling. They can also suitably be conducted by staff whose conditions do not favour the provision of longer-term service or who are only episodically available. A further consideration is that elaborated pre-test counselling by skilled health advisory staff may economise time overall by obviating the need for post-result conselling following negative results.

8.4 SOCIAL SERVICES INVOLVEMENT

8.4.1 Of the arrangements described in Section 7, only the Bradford and Newcastle examples directly engage social workers in HIV counselling with clients who are seropositive but asymptomatic. Without a survey we do not know the national pattern, but we suspect that currently direct social worker involvement may be uncommon. This may appear anomalous when it is widely accepted that SSDs will be centrally concerned in the care of people with AIDS, but it reflects a general absence of discussion of the relationship of the social services to those who are HIV positive. The ADSS memorandum to the Social Services

committee dealt entirely with AIDS and had no mention of the prior stage (11). The Directors do refer to individual counselling and group support in the context of AIDS, but their greater preoccupation seems to be with practical support (12). More generally, we detected some tendency for medical and health care workers to view social workers primarily as gatekeeprs to practical community services.

8.4.2 We believe that the absence of discussion of social services involvement in provision for the HIV positive creates two possibilities for concern. One is that some aspects of the situation of seropositives are not unique, but that there may be failure to consider relevant areas of experience which SSDs have accumulated with other client groups. The second is that elements of social worker expertise may be ignored which are of particular relevance to (especially longer-term) HIV counselling. Amongst these elements we would include: substantial personal counselling skills; experience in co-ordinating care services at a specific client level; capacities for instigating client self-help activities; and skills in group-work and other methods of working alternative to one-to-one activity. Although social worker participation may not necessarily be entailed, we believe that planning for HIV counselling provision should always take these consideration into account.

8.5 DESIGNATED VERSUS GENERALIST STAFF

8.5.1 Whether those involved in HIV counselling should also have responsibilities not related to HIV is a matter not simply of personnel deployment but possibly of staff welfare. Dr. Pinching has observed that exclusive concern with AIDS-related work may become emotionally overwhelming, and he favours mixed work-loads (13). Some unpublished research by Mr. David Miller has found that staff who work more than 60 per cent of their time on AIDS-related matters are more vulnerable to stress (14). Three quarters of such staff in his study experienced significant stress or morbidity, including suicidal thoughts. He believes that it is the intensity of work which causes problems and that all staff should have some non-AIDS work. Health Advisers confirmed to us that HIV counselling can be stressful, especially if compounded with long hours and overload, and they suggested the desirability of restrictions on the amount of HIV-related work performed by individuals (15).

8.5.2 Observations of this kind have implications for task allocation which are especially acute in the case of

designated HIV units, where mixed work loads may be difficult to achieve. If experience continues to confirm the hazards of exclusive work with HIV and AIDS this would not invalidate the case for such units, but it would suggest the need for careful attention to staff welfare and to possible ways of providing a mix of responsibilities.

8.6 WORK FLOW

8.6.1 Rational staffing arrangements depend not only on the overall demand for HIV counselling (discussed in Section 3) but also on the predictability of the flow of work. Gross fluctuations in the rate of presentation for testing have serious consequences for the quality of service. At St. Mary's Hospital and the Middlesex Hospital the large increass in attendance following "AIDS WEEK" included greater numbers from high-risk as well as low-risk categories, and this was seen as a bonus from the campaign. However the HIV counselling facilities were evidently saturated, so that only attenuated service could be provided. In such conditions, clients do not receive full benefit and the wider benefits of promoting risk-reduction behaviour are not fully achieved. Since risk-reduction is one of the justifications of the cost of counselling it is clear that episodic flooding of test sites is self-defeating. Staff concerned evidently feel that they will be better prepared on a future occasion, but possibilities of short-term augmentation of services may be limited by financial considerations, accommodation difficulties and problems in finding suitable temporary HIV counsellors. Nevertheless, clinics would clearly benefit from maximum specific notice of intended media campaigns, and issues of flexibility and contingency provision in HIV counselling arrangements will repay attention.

8.6.2 In respect of post-result and longer term counselling with the HIV positive, the numbers of clients are smaller and less volative. However, the demand on staff resources depends on the nature and extend of expressed demand by clients, and it is necessary to repeat that little is known of what this is (or might be under differing conditions of encouragement). Where the fullest span of provision is intended, the flow of presentation cumulates into caseloads which include the care of people with AIDS. In the case of centres such as Bradford experience does not yet show how many cases covering the full spectrum of HIV and AIDS might suitably be carried. It is therefore necessary that case load issues should be carefully monitored.

8.6.3 In some sites difficulties may arise not from episodic flooding of demand but from insufficiency of flow. Where presentations are few the counselling effort is likely to

lose momentum and precision. Counsellors who see few clients lack the opportunity to develop diagnostic thinking and pattern recognition and can accumulate expertise only slowly. This hampers professional development and may impair quality of service. The report HIV infection in Scotland recognised this, and recommended that such counsellors might be linked with a busier centre, in the form either of rotation or allocated sessions (16). However, apart from any travelling problems, this solution assumes similarity of HIV counselling arrangements and would raise issues of accountability if different employing authorities were involved. Peripatetic arrangements would also carry implications for continuity and span of provision, since longer-term counselling would be difficult in conditions of only episodic attachment.

8.7 FINANCIAL COSTS

8.7.1 Most HIV counselling to date has been carried within the general workload and budget of clinics, and so there is little guidance on overall or per capita costs. Where, as in the Riverside ante-natal service, pre-test counselling is incorporated into a routinely-provided session, this may impose little or no additional cost. This is mostly not the case, however, and we can trace only one discrete estimate of counselling costs, at the City Clinic in Edinburgh. In the first year of operation the cost was £61.22 per client, with no reckoning for capital costs of premises (17). However, the clinic then operated below full capacity and the default rate on appointments was high. With changes here the cost might fall to about £20.00 per client. This calculation allows one hour for counselling each client; the clinic does offer longer-term counselling, but take-up so far has been low (18). The figures above include £8.00 for the cost of testing for HIV and hepatitis B, so that in optimum conditions the cost for counselling alone would be £12.00 per patient. Because circumstances vary so greatly across test sites it would be imprudent to rely uncritically on this estimate, and we understand that work in hand elsewhere may provide wider information (19) on the costs of various kinds of care for the HIV positive and people with AIDS.

9. EXTERNAL RESOURCES

9.1 Sections 6 to 8 above deal with formal structures of provision for test-associated counselling, but there are numerous other helping sources which provide both a context and a resource for HIV counselling. These external agencies provide a context because clients may make independent use of them before, during and after any relationship with the formal system, and also because some of them have helped to set the agenda for formal HIV counselling systems. They provide a resource because the HIV counsellor may need to bring about a synthesis of help of various kinds for the benefit of clients. External resources, which may be either statutory or voluntary, can be broadly divided here into those of a generalist kind and those with a specific HIV remit. The latter are particularly likely to be in the voluntary sector, and their significant role led the Social Services Committee to recommend enhanced support from public finances (1). This group prominently includes the agencies associated with gay enterprise, noted in 5.2 above, but the total field is broader, and it is helpful to note the range of external resources potentially relevant to HIV counselling.

9.2 GENERALIST AGENCIES

9.2.1 Important examples here are other health service facilities which provide either advice (eg on diet) or therapy, and prominent amongst these are departments of psychological medicine. In some cases clinical psychologists are specifically assigned to HIV-related work or provide dedicated sessions, but where this is not so good links are essential. Examples of other relevant generalist services are local authority departments; legal, welfare rights or housing advisory services; drugs agencies; lesbian and gay projects; marital or family counsellors or therapists; religious advisers and groups; the Samaritans; family planning agencies; and general practitioners and dentists if, as happens, clients have difficulty in finding these. It may also be noted that, while anxious to protect clients from quackery, leading authorities on HIV are not necessarily unsympathetic to practitioners of alternative or complementary medicine (2).

9.3 HIV-ORIENTATED RESOURCES

9.3.1 Literature. This is available in many varieties and from many sources, but with materials from the Terence Higgins Trust particularly prominent. Literature may contribute to time-saving, but experienced workers suggest that none

should be issued without careful prior vetting of contents.

9.3.2 Switchboards. At the national level are the Terence Higgins Trust Helpline (with priority numbers for the HIV positive and people with AIDS), The National AIDS Helpline (previously the National Advisory Service on AIDS), and the tape-recorded Healthline AIDS Information Service of the College of Health. At local level there are switchboards with names such as AIDSline or AIDSlink which offer an HIV-specific service to the general public, and others oriented towards a homosexual clientele which include HIV in their concerns. There are now some 50 AIDSlines and 70 lesbian and gay helplines (3). Interim evaluation of NASA indicates that callers want not simply information but to talk through issues concerning their sexuality and sexual practices, and some evidence suggests that switchboards may deflect business from HIV clinics and counselling facilities, thus lightening their load (4). AIDSline groups also commonly undertake a variety of related activities (5).

9.3.3 The Terence Higgins Trust. As well as its switchboard and literature service the Trust provides legal and health education services, counsellor training, support groups (including for wives and mothers), one-to-one counselling (including for IVDAs), "buddying" services, and sheltered accommodation. Direct services are available only in London. The Scottish AIDS Monitor has similar functions but is less well resourced and has less wide-ranging activities.

9.3.4 Body Positive. This is a nation-wide but not centrally organised cluster of peer support groups for those infected by HIV, and it offers sociability, solidarity and mutual help in maintaining health and risk-reduction guidelines. Body Positive believes that it may have been in touch with approaching half of all known seropositives, although it does not claim this number as members.

9.3.5 Drop-in Centres. Some areas have proposals for centres which are primarily conceived for people with ARC or AIDS but which incorporate drop-in social, informational and service facilities for the HIV positive. Examples from Manchester AIDSline and Lambeth AIDS Action are shown in Appendix 3. The London Lighthouse project intends a drop-in facility, as does the Kobler Centre at St. Stephen's Hospital. Detectable behind some voluntary sector proposals is a distinctive perspective which is antipathetic to the "medical model" of AIDS (6). We could trace no estimates of the effective demand a centre might expect, the area it would sensibly serve, or the size of clientele needed for viability.

9.3.6 Resource Centres. Proposals have been mounted by a group of local and health authorities for a Community Support Centre, located in Newcastle. This will have a Region-wide brief to: develop a model of home-based care for those with AIDS or who are HIV positive; provide advice and support to the primary health care team; advise care staff and provide training; support the work of voluntary bodies; and identify unmet needs amongst patients and their associates. The multidisciplinary staff will not primarily provide direct care, but will carry a small caseload to maintain "sharp end" experience. Although not directly accessible to clients, such a centre will clearly be a major resource for HIV counsellors.

9.3.7 The above listing is not exhaustive and new developments constantly appear, but it sufficiently indicates the diverse context of HIV counselling and the range of provisions with which counsellors need to be familiar. The extensive possibilities of collaboration and referral also raise the issue of confidentiality. Sometimes the client's antibody status may be irrelevant to referral, but where it is relevant the client's consent for disclosure is essential, even if refusal may preclude access to the resource. Experienced counsellors suggest that when referring it is prudent to have known contacts and some anticipation of likely response, so that there is a need to build up personal relationships across the spectrum of other resources.

9.4 A RESERVATION

9.4.1 Existing support groups and befriending schemes successfully provide for the needs of many, but a reservation must be made. Inevitably in the context of their origins many support schemes have what may be called a gay ambience, and indeed part of the rationale for Body Positive is the need for groups where gay life styles and language are appreciated. By the same token, this ambience may not be congenial to all categories of clients, and not even to all gay men. The opinion was expressed to us that there is a developing need for other groups to be encouraged and sponsored, and volunteer befrienders found, on the basis of relevant client differences. This was seen not as divisiveness but as a realistic recognition that common experience of HIV infection may not sufficiently over-ride other factors such as life style differences and group affiliation.

9.5 Finally in this section, it bears repeating that scant information is available on the use made by the HIV positive of these various resources, whether independently or by referral, or on how effectively they are helped. Similarly, no clear picture is available of the extent to

which proffered longer-term counselling is accepted, or by whom. Our impression is that the picture may be varied, with little actual uptake in at least some places. The extent to which this reflects the need and preferences of clients, the availability of resources, or agency style in provision and referral is unclear.

10. THE TRAINING AND SUPPORT NEEDS OF HIV COUNSELLORS

10.1 COUNSELLOR QUALIFICATIONS

10.1.1 To facilitate consideration of training needs we have identified a list of qualifications said to be desirable for effective HIC counselling (1). These include:

- a thorough working knowledge of HIV disease, its effects and its social and emotional implications;
- a working knowledge of the life styles and language of significant client groups;
- a working knowledge of helping services of the kind described in Section 9 above;
- skills in communication and professional liaison;
- skills in health advising and knowledge of risk-reduction techniques;
- basic skills in personal counselling;
- an ability to recognise indicators of need for specialised referral; and
- an understanding of the principles of confidentiality.

10.1.2 It was frequently emphasised to us that a thorough knowledge of HIV and AIDS is an absolute requirement for HIV counsellors, so that attention to this is likely to figure in all basic training. It was also widely insisted that training is more than a matter of imparting skills and knowledge, and that it must always engage people in coming to terms with the often deep-seated fears, emotions and attitudes which AIDS may arouse. Beyond this, staff come to HIV counselling differentially equipped by their disciplinary backgrounds, so that their training needs vary. The above specification of qualifications is a maximal one, indicating what may be called for to cover the fullest span of HIV counselling. In practice, not all arrangements are full span, and with division of labour the full specification may not be required of any one person. Thus the training needs of counsellors are differentiated not only by disciplinary backgrund but by the proposed span of duties and the pattern of task allocation.

10.2 TRAINING ON AIDS

10.2.1 The overall need for training on AIDS is far wider than that of HIV counsellors alone. Staff in the health and social services variously have responsibilities for planning, for education, for training or for direct delivery of care services of different kinds. The overall requirement is for training pvovision which is targetted towards the needs of particular work settings and staff groups and thus varies appropriately as to content, method, duration and level. Some authorities are clearly undertaking systematic and differentiated

programmes (2), but our impression is that overall there is little co-ordination in the total training effort.

10.2.2 Across the country there is occurring a welter of AIDS training activity. For example, many health and local authorities mount events for their staffs, and the London Borough's Training Committee co-sponsors training which crosses agency and sector boundaries. Typically such events include input from voluntary bodies which, in relation to resources, make heroic efforts in respect both of external contribution and their own programmes (3). Course number 934 of the ENB is mounted by several nursing schools and polytechnics, and independent agencies such as the Centre for the Advancement of Counselling offer a variety of courses. Numerous organisations organise conferences or seminars on an ad hoc basis, and a freelance training consultancy may soon be established (4). Mention must also be made of the two operational National AIDS Counselling Training Units (NACTUs) but these are discussed more extensively below.

10.2.3 The high activity levels undoubtedly respond to a huge demand for training, and events are typically over-subscribed. There is lacking, however, any means, for example, to chart the current pattern of activity; to identify and measure the specific training needs of particular groups; to guard against both duplication and omissions; and to compile a database of good practice, appropriate materials and model standards. These are general considerations in respect of AIDS training, but they also have force in respect of HIV counselling.

10.3 TRAINING AND HIV COUNSELLING

10.3.1 The spectrum of HIV counselling is very wide, because all who deal in any capacity with persons who are seropositive or have AIDS are likely to be drawn into counselling in some sense. Even amongst those with a specific HIV counselling mandate the range is from those providing voluntary switchboard shifts to those carrying major responsibilities for continuing face to face care. Although we recognise other counselling training needs, our focus here is upon those with professional responsibilities within a recognised test site.

10.3.2 An important dimension of the overall training provision is the extent to which it matches the differentiated needs of those assigned to HIV counselling. On this measure our impression is that what is available falls short of what is required. Much of what is available is not targetted towards specific audiences. Variety in the backgrounds of course participants may be productive in some ways, but unselective recruitment can bring together persons with such different needs and levels of knowledge and experience that the benefits of variety are not

achieved. Offerings tend to be pitched at basic or introductory levels and there is a shortage of advanced or specialised modules. Most courses are of block form and brief duration, with no preparatory work, project activities, follow-up or assessment. Typically courses offer a mixture of informational, attitudinal and experiential sessions, but time and other limitations make it likely that the result is to raise awareness and identify issues rather than to impart skills. These are generalised comments which misrepresent some cases, but we believe the overall picture of insufficient targetting and differentiation is valid.

10.3.4 Of particular relevance here are the National AIDS Counselling Training Units, at the Bolton Royal Infirmary and St. Mary's Hospital, Paddington (5). Originally these intended a "cascade" programme of training trainers, but were each overwhelmed by the volume of immediate demand and swept into the energetic provision of standard courses on an all-comers basis. Hitherto courses have been of two days duration, but the St. Mary's unit now proposes to change to three day and NACTU (North) is reviewing its pattern of provision. At both units courses include an experiential element and, significantly, participant feedback indicates a desire for more of this and for work on basic personal counselling skills. Both units have encountered difficulties in finding appropriate materials and appropriately qualified course contributors, especially regarding personal counselling skills. Because of their national remit both units have felt forced into brief block courses and have been unable effectively to select, assess or follow up their scattered clientele, although each essays course evaluation by questionnaire. Pressure of work has so far precluded extensive liaison or collaboration between the units.

10.3.4 We must establish clearly that these comments do not constitute an evaluation of the quality of work at these units. Rather, they are points of which those concerned are fully conscious. The pressures of urgent demand and operating constraints have, however, prevented the NACTUs from so far finding a distinctive or strategic role in the training of HIV counsellors. It is highly desirable that a means be found of bringing provision more into line with the differentiated needs and contingencies of counsellors, especially those outside London. The following issues would particularly repay attention.

(a) The identification of patterns of need for training modules of differing orientation, level and degree of specialism.

(b) The need to provide for the distinctive training requirements of those with responsibilities for

counselling training, who are at present inadequately provided for. (The British Association for Counselling is currently seeking support for a project related to this objective).

(c) The need for adequate training provision in respect of personal counselling skills. (It might be noted here that organisations such as the National Marriage Guidance Council are experienced in offering skills packages to outside agencies).

(d) The exploration of training methodology, including learning methods, course format, and possibilities of selection, preparatory work, project activity, follow-up and assessment.

(e) The development of high quality training materials, in package form and suitable for use away from major training centres. (We know of at least three packages in develoment (6) although not necessarily with counsellor training in mind).

(f) The development of ways to mount training opportunities on a geographically devolved basis which incorporates pre- and post-course liaison with local organisers.

10.3.5 A strategic approach to the training of HIV counsellors would help to meet the recommendation of the Social Services committees that the training issue should be resolved at once (7). The Committee also called for the training issue to be resolved in co-ordination with the voluntary bodies working in the field. We have not seen the training of volunteers as lying within our remit, but undoubtedly acknowledgement is required of the past contribution and continuing significance of these voluntary bodies to counsellor training. The facilities which they have developed merit support in their own right and, in addition, their special understanding has a particular contribution to make to the planning and provision of training. Nevertheless, the major provision of test-associated counselling lies increasingly within the statutory services, and it is here that the issues must principally be addressed.

10.4 OTHER NEEDS OF COUNSELLORS

10.4.1 Updating. Because reliable knowledge is imperative and the AIDS scene is fast-changing, HIV counsellors need not only training but the facilities to update their knowledge. Currently no suitable vehicle exists for this purpose. New information and developments are reported in diverse locations which are not readily accessible to a counsellor in post. The AIDS Newsletter is a useful source of information, but it is a digest of newspaper

and periodical items rather than a vehicle for updating knowledge. The new journal AIDS may serve to centralise publications of original papers, but it is likely to be primarily of medical and scientific interest. The requirement is for a regular authoritative evaluation of developments relevant to counsellors, presented in appropriate format and language. One possibility here is the development of a computer-aided expert system for use by counsellors of the kind described by Dr. Brittain to the Social Services Committee (8).

10.4.2 Professional association. Regular association with professional peers provides an important mechanism for the informal exchange of experience and discussion of professional issues. HIV counsellors in London are able to be in ready contact, and meetings are periodically organised. In the provinces however, access to other counsellors is not easily arranged, and counsellors speak of feelings of professional isolation. The idea has been canvassed of a national association of HIV counsellors, based initially upon past participants in NACTU courses (9). This idea has not been effectively pursued, but a national association if it existed might publish an informative newsletter which could serve updating purposes and provide a vehicle for discussion of professional issues.

10.4.3 Supervision. In social work and within counselling organisations the importance of supervision and access to consultation is generally recognised. Skilled supervision and case discussion are important to the consolidation and development of practice skills and professional confidence. Their absence can lead to the attrition of sound principles acquired in training, or to their too rigid or inappropriate application. Supervision also has a protective function against anxieties and depression which may be engendered by exposure to the confusion and distress of clients. Emotional support can perhaps be found by alternative means, but the challenge of supervision as a stimulus to professional development is not readily replaced .

10.4.4 Support. We noted in 8.4 above that working with HIV and AIDS can be stressful to staff, and this will be expecially so for those dealing with the dying and the bereaved. In these circumstances it is helpful to have available trusted confidantes or a support group within which emotions and frustrations can be constructively and safely ventilated. Supportive facilities have been formed within the major centres of AIDS experience, often on a multi-disciplinary basis. It may be more difficult to arrange support groups in smaller units elsewhere, but resources might conceivably be found in outside bodies such as local hospices or the kind of centre described in 9.3.6 above.

10.5 These issues of updating, professional association, supervision and support are inter-related. Problems stemming from inadequacies here are exacerbated if in addition a low work flow hampers accumulation of experience and exercise of skills, or if training opportunities are felt to have been inadequate. One counsellor forlornly described his training as "sitting next to Nellie", and another had been left to find her own training. Feelings of isolation and of being unsupported readily develop in such situations and we heard expression of these feelings (10). Inevitably the circumstances and experience of counsellors will be different as between the busy major centres and elsewhere, but sufficient regard has perhaps not always been given towards training, support and the other issues discussed here. Inadequate preparation and support are inimical to the professional development and morale of counsellors, and adversly affect the quality of service they can deliver. It is important therefore that service planning should attend adequately to the needs of counsellors as well as those of clients.

11. INDICATORS OF CLIENT VULNERABILITY

11.1 Experience suggests that most of those who are found to be HIV positive are subject to some degree of adjustment stress, but that some are especially vulnerable and in need of greater care. As an aid to client management it would clearly be helpful if staff involved in HIV screening and counselling could make early identification of special psychosocial vulnerability. A secondary part of our brief was to seek for known indicators of need for 'more intensive provision', which we understood to refer to need for personal counselling, possibly on a protracted basis, and beyond this possibly for specialised psychological or psychiatric referral. It is disappointing to report that our enquiries here did not yield substantial results, although our work was not entirely barren.

11.2 We noted earlier that, because of long acquaintance with the patient and his family and the availability of detailed records, staff in haemophilia clinics are often able to identify those with special vulnerability to stress and to ensure that supportive provision is particularly offered in these cases. Assessment is based on factors such as basic personality, social integration, family structure and the quality of relationships, present life arrangemens, coping skills and degree of past success in overcoming problems, including life-threatening situations (1). However, the advantage of ability to anticipate need for more intensive provision on the basis of long-standing acquaintance with clients is not widely shared in other test settings. General practitioners may sometimes have deep knowledge of applicants for the test but this will rarely be the case for staff in GUM clinics and other HIV centres. They in particular would benefit from readily identifiable indicators of client vulnerability.

11.3 We did hear suggestions that risk category for HIV infection might have a predictive value in respect of stress. One hypothesis, for example, was that homosexual men are often better informed about HIV than heterosexuals, and more realistic in approaching the test because their high-risk status has caused them to consider the prospect of infection more profoundly. Another was that bisexual men may be the most fearful and disturbed because of the secretive nature of their sexual activity and the implication of HIV concerning women partners. Of IVDAs it was suggested that infection could seem merely one more hazard in an already hazardous life, so that responses might be more blase. In respect of older haemophiliacs it was observed that many would have faced their mortality before, so that a life-threatening experience would not be so shockingly new. Ideas of this kind have a certain surface plausibility, but they are highly speculative and not grounded in documented experience. Furthermore, we would recall here our earlier observation that members of

particular risk categories are not homogeneous either socially or psychologically. Our conclusion is that risk category in itself is not shown to be predictive of client vulnerability.

11.4 The only systematic consideration of indicators of vulnerability which we can trace in UK published sources lies in various writings of Mr. David Miller. In one paper he briefly lists some client features through which vulnerability to anxiety and other psychological or psychiatric phenomena are mediated, and he concludes:

"Where patients are socially isolated, have occupational inflexibility or are unemployed, have insufficient financial support and poor coping skills and are of a depressive or inflexible temperament, their response to AIDS-related anxieties is frequently more catastrophic" (2).

11.5 In two other papers Miller has listed certain characteristics of the worried well which, he observes, are also servicable as good indicators of psychological vulnerability in all patient groups (3). From these three sources the following checklist can be derived.

- poor post-adolescent sexual adjustment
- social isolation, with poor social networking or support
- dependence in close relationships (if any)
- multiple misinterpreted somatic features, frequently associated with undiagnosed viral or postviral states (not HIV) or anxiety or depression
- a psychiatric history or high levels of physician attendance
- high levels of anxiety or depression
- low or non-existent family awareness of client sexuality, and relative lack of family support
- exposure to traumatic life events
- conspicuous guilt over sexual or life style activities
- expressed or covert suicidal indication, sometimes with a history of unsuccessful attempts
- obsessive rumination on HIV infection disease and decay, and/or compulsive features involving body checking, washing, and repeated questions of physicians.

11.6 This list carries authority because it is based upon systematic study of a sample of the worried well together with extensive clinical experience in two major HIV centres. The features described could undoubtedly furnish clues to an HIV counsellor of clients' response to infection and needs for care. However, it is not a list of simple indicators, and the predictive value of its components are not ranked or quantified. Some of the items

are not so much warning indicators as florid expressions of a need for care. Few of the items would reveal themselves in pre-test counselling unless this were very elaborated, and many would become evident later only if extended personal counselling was anyway being undertaken. Some of the items confirm the necessity for HIV counsellors to be capable of identifying psychological morbidity - for example, the somatic, cognitive and behavioural signs of anxiety, depression and obsessive states (4). Because the list has reference to all stages of the HIV/AIDS spectrum (plus the worried well) it confirms more generally that an unknown proportion of the HIV counselling clientele is indeed in need of skilled and intensive attention.

11.7 Miller provides a clue to one further possible type of indicator of vulnerability. This is his observation, based on American research, that higher levels of expressed psychological disturbance may be found in those who have progressed to ARC but not yet to AIDS. These higher levels he interprets as reflecting the greater uncertainty experienced in this condition, since "those with AIDS at least finally know what the enemy is " (5). This finding has not been confirmed for UK patients, but it could possibly be a special case of the more general proposition that significant life transitions may be traumatic. If so, client transition to any new stage in the AIDS progression may indicate a necessity for alertness by HIV counsellors to more intensive needs.

11.8 In summary on this part of our brief, we were not able to identify a shortlist of readily-accessible indicators of client need for more intensive provision, but we did find confirmation that such a need exists in some cases, and some material relevant to this. This need will certainly be encountered in systems where longer-term HIV counselling for the seropositive is provided, and especially in full-span systems. We see this as indicating the potential depth of the HIV counsellor's role, with clear implications for personnel specifications and training. We also see it as suggestive concerning the role which social workers might play with the HIV team.

12. CONCLUSION: SUMMARY OF SERVICE DELIVERY ISSUES

12.1 This report has presented an analysis and commentary on the following matters:

- some conceptual distinctions in respect of helping provision
- an increasing and diversely composed clientele
- a client career with three primary reference points
- client needs for advice, support and counselling
- a range of packages of provision and an abstraction of their common elements
- a context of resources external to clinic HIV counselling provision
- a variety of potential providers, and their needs
- some issues of location and co-ordination.

Our commentary raises at various points some particular issues of service delivery which concern the nature of the HIV counselling package, the clientele and the counselling staff. We conclude by summarising these and identifying their location in the text.

12.2 THE PACKAGE

12.2.1 A key decision concerns what we have called the span of the package (8.2.3). There are three basic possibilities:

(i) Pre-test and immediate post-result counselling as covered by boxes B - L of Figure I. This is the minimum provision consistent with current official advice on screening and counselling; it covers facilitating informed consent, educating clients in risk reduction, dealing with the immediate impact of positive results, and informing clients of other sources of help.

(ii) Extension of the package to include longer-term counselling up to the point of becoming symptomatic (box M). This requires consideration of how the package relates to provision for persons with ARC or AIDS (1.6; 4.2).

(iii) Further extension to include full supportive service for symptomatic clients (box N) and the bereaved (box O). This is unlikley to be achievable via the conventional staffing of GUM clinics or through GP's surgeries (8.1.1 - 8.1.3; 8.2.3).

12.2.2 Clarity is needed on whether the service is intended to include personal counselling as we have defined it (2.2); if so, the staffing and/or training implications of this must be catered for (8.3.2; 10.3.4c).

12.2.3 Decision is required on whether service is to be available to intimate associates of the client (4.5).

12.2.4 Consideration is required of the desirability of screening and counselling packages located other than in GUM clinics (5.3.8; 8.1).

12.2.5 Package design may necessitate a choice of priorities between HIV objectives of harm-reduction and other policy aims in dealing with IVDAs (5.3.5).

12.2.6 Clarification of policy is desirable on the promotion of screening and counselling packages, and on contact tracing (3.10).

12.2.7 Package design should take note of, and relate adequately to, the context of external resources (9.1 - 9.4)

12.3 THE CLIENTELE

12.3.1 Service planning requires adequate quantitative data on aspects of the demand for HIV counselling. These include: the volume of presentations for the test (3.6 - 3.8); the numbers and geographical distribution of the HIV positive (3.1 - 3.3); and the rate of transition between different AIDS-related conditions (3.5).

12.3.2 Data are required on the flow of clients as well as numbers and distribution. Episodic peaks saturate the service (8.6.1), and insufficiency of flow hampers service development (8.6.3).

12.3.4 Information is required on "case-mix" (3.4), because differences between and within client groups carry implications for service provision (5.2 - 5.7).

12.4 COUNSELLING STAFF

12.4.1 The principle of continuity in counselling relationships has merits but creates inflexibility and possibly inappropriate staff deployment (8.2.2).

12.4.2 Staff of differing disciplines are differentially equipped for the various elements in HIV counselling (8.3.2; 4.4). Appropriate job specifications depend upon the intended continuity and span of the provision (10.1.1; 10.1.2), and effective deployment may be facilitated by division of labour (8.3.3).

12.4.3 Consideration needs to be given to the utilisation of Social Services experience and social worker expertise in arrangements for HIV counselling.

12.4.4 Staff engaged exclusively in HIV-related work may be more at risk of stress than those with mixed responsibilities. (8.5).

12.4.5 Training needs of counselling staff are differentiated by disciplinary background and task allocation (10.1.2). Training opportunities should be varied to reflect this (10.2.1) but are not always so (10.3.2).

12.4.6 To be adequate, training programmes need to ensure self-scrutiny by counselling staff in respect of attitudes and fears (10.1.2).

12.4.7 Attention is required to the needs of counselling staff for updating opportunities (10.4.1), professional association (10.4.2), supervision (10.4.3) and emotional support (10.4.4).

APPENDIX 1

LIST OF PERSONS CONTACTED

(N.B. Asterisk indicates persons met on visits).

ALLDRITT, Lindsey. The Monitoring Research Group, Department of Sociology, Goldsmiths' College.

ASHWORTH, G.J.. Manager, Medical Social Work Department, Doncaster Royal Infirmary.

BATH, Dr. George. Specialist in Community Medicine, Lothian Health Board. *

BISSETT, Dr. Kate. The City Clinic, City Hospital, Edinburgh. *

CHAPMAN, Gavin. Humberside Friend.

CHARLES-EDWARDS, David. Executive Officer, British Association for Counselling. *.

COOPER, Alison. Senior clinical psychologist, London Borough of Newham SSD; member of East London Community Action Service. *

COSGROVE, John. Health Visitor/counsellor, Edinburgh Royal Infirmary GUM clinic.

COTTON, Terry. Principal Development Officer (AIDS), London Borough of Hammersmith and Fulham SSD.

COYLE, Robert. Health and Welfare Department, Trades Union Congress.

CURLESS, Dr. Eric. Consultants in GUM, Bolton Royal Infirmary; National AIDS Counselling Training Unit (North) *

CURRAN, Len. Principal psychologist, Long Lartin Prison.

DEES, Jeff. Humberside Friend.

DUFF, Dr. Celia. Specialist in Community Medicine, East Anglian RHA.

EARLIE, William. S/W-AIDS Co-ordinator, London Borough of Tower Hamlets SSD; member of East London Community Action Service. *

FARRAR, Nicholas. Area Social Services Officer, Bradford Royal Infirmary.

FREEBURNE, Vera. Assistant Director of Midwifery Services, Westminster Hospital.

FURLONG, Rod. Principal Social Worker, Devon County Council.

GAITLEY, Roger. Acting Principal Officer (AIDS and Drug Abuse), Grampian Regional Council Department of Social Work; convenor of BASW HIV/AIDS Project Group.

GALBRAITH, Dr. Spencer. PHLS Communicable Diseases Surveillance Centre.

GARBUTT, Sister S. John Hunter Clinic, St. Stephen's Hospital, London. *

GODSELL, Moira. Social Services Inspectorate, DHSS. *

GOODMAN, Christopher. Specialist Social Worker (Addictions), London Borough of Richmond-on-Thames.

GOODSIR, Jane. Director of Release.

GOODSON, Charles. Director of Park Lodge, Hackney; member of East London Community Action Service. *

GRAY, Ian. Environmental Health Officer, London Borough of Hackney.

GREEN, Janet. Counselling Administrator, Terence Higgins Trust.

GREEN, John. District Clinical Psychologist, Department of Psychology, St. Mary's Hospital, Paddington. *

GREY, Anthony. Convenor of British Association for Counselling AIDS Panel; Chairman of the Albany Society.

GRIMSHAW, Jonathan. National AIDS Counselling Training Unit at St. Mary's Hospital, Paddington; Body Positive.

HALLIDAY, Moira. Social Worker (HIV-Related Infection), Bradford Royal Infirmary.

HILLIARD, Nichola. Information Officer, National Children's Bureau.

JOHNSON, Rev. Malcolm. Member of East London Community Action Service. *.

JONES, Dr. Peter. Consultant, Haemophilia Reference Centre, Royal Victoria Infirmary, Newcastle upon Tyne. *.

KENNEDY, Jane. AIDS Worker, Standing Conference on Drug Abuse.

LIEVERS, Steve. Assistant Director of Nursing Services, St. Stephen's Hospital, London. *

LOVIE, Jean. Social Worker, Haemophilia Reference Centre, Royal Victoria Infirmary, Newcastle upon Tyne. *.

MALLINSON, Will. National Co-ordinator, Scottish AIDS Monitor. *

McCARTHY, Mike. Assistant Secretary (Policy Development), British Association of Social workers.

MILLER, David. Senior Clinical Psychologist, James Pringle House, the Middlesex Hospital, London. *

MILLER, Dr. Elizabeth. PHLS Communicable Diseases Surveillance Centre.

MITCHELL-CHRISTIE, Adam. Bradford and Airedale Health promotion Unit; Pennine AIDS Link.

MOK, Dr. Jacqueline. Community Child Health Consultant, Edinburgh City Hospital.

MORGAN, Shirley. Social Worker, Haemophilia Reference Centre, Royal victoria Infirmary, Newcastle upon Tyne. *.

MOSS, Dr. Veronica. Medical Director, Mildmay Mission Hospital. Hackney.

MOSS, Vincent. Manager Health Adviser, Praed Street Clinic, St. Mary's Hospital, Paddington.

NICHOLAS, Heledd. Health Adviser, James Pringle House, the Middlesex Hospital, London. *.

ROWLEY, Steve. Thomas McCauley Ward, St. Stephen's Hospital, London. *.

SKINNER, Kate. Regional AIDS Adviser, Lothian Regional Council. *.

TAYLOR, David. AIDS Co-ordinator, Lothian Regional Council. *.

THOM, Deborah. Social and Statistical Information Officer, Family Planning Information Service.

STONE, Yvonne. Senior Midwife, Westminster Hospital.

UNELL, Ira. Senior Social Worker, Regional DDU Nottingham.

WATTERS, David. Co-ordinator of the Haemophilia Society.

WESTLAND, Peter. Under-Secretary for Social Services, Association of Municipal Authorities.

WHELAN, Vicki. Co-ordinator, Manchester AIDSline. *.

WHITMORE, Robert. clinical psychologist, Bolton Royal Infirmary.

WILKINS, Pamela. AIDS Co-ordinator, Bolton Royal Infirmary and National AIDS Counselling Training Unit (North). *

WILLIAMS, Gwynne. Training Officer (AIDS), Lothian Regional Council Department of Social Work. *.

WILSON, Janie. AIDS Community Care Organiser, Royal Borough of Kensington and Chelsea. *.

APPENDIX 2

TABLE 1. Psychological and emotional reactions of patients with HIV infection and disease.

Fear and anxiety of:

Physical decline and disability
Disfigurement
Death
Abandonment and social/sexual rejection
Infecting others and being infected by them
Lover's health decline
Inability to manage the situation

Anger and frustration over:

Uncertainty of illness and effectiveness of treatments
Lack of, or confusing information from staff
Inability to change the circumstances and being "caught out"

Guilt Over:

Association of the illness with sexuality
Being identified as homosexual or a drug user
Having possibly passed the infection to others
Past "misdemeanours" resulting in illness as punishment

Depression Over:

The "inevitability" of physical decline
Helplessness to win over the disease in the absence of a cure
Physical, social and occupational limits imposed by the infection and disease
Social, occupational, emotional and sexual rejection

Shock Over:

Loss of hopes for good news

Source: David Miller, "HIV Counselling: some practical problems and issues", J. Royal Society of Medicine, vol. 80, May 1987, p.279.

TABLE 2. Common AIDS-related patient anxieties

Prognosis in the short and long term
Infection risk to and from other people
Social, occupational, domestic and sexual hostility and rejection
Abandonment, isolation and physical pain
Inability to alter circumstances
How to maximise future health
Appearance of new or repeated infections
Ability of lover/family/partner to cope
Availability of appropriate medical/dental treatment
Being identified as homosexual/drug abuser
Loss of privacy/confidentiality
Future social and sexual acceptability
Declining ability to cope
Loss of physical and financial independence

Source: David Miller, "HIV Counselling: some practical problems and issues", J. Royal Society of Medicine, vol. 80, May 1987, p.279.

TABLE 3. Counselling before HIV testing

The Test

Is not a test for AIDS
Necessitates sufficient time elapsed for seroconversion to have occurred
Indicates only previous exposure to HIV
Gives no indication of prognosis, severity of infection, or infectiousness

Practical consequences of being identified seropositive

Ineligible for future life insurance or some mortgages
Possible difficulties obtaining dental and medical treatment
Precluded from some types of employment and employers
Dismissal by some employers with resulting financial burdens

Potential psychological consequences of being seropositive

Unresolvable uncertainty
High level anxiety, depression, guilt, and obsessive disorders
Relationship implications

Other Issues

All persons potentially at risk should adopt safer sex and risk reduction guidelines.

Source: David Miller "Counselling", British Medical Journal, vol. 294, 27 June 1987, p. 1672.

APPENDIX 3

DROP-IN CENTRES

Paragraph 9.3.5 of our report refers to ideas for drop-in centres. To illustrate these ideas we summarise below proposals being developed by Manchester AIDSline and Lambeth AIDS Action. (NB These summaries are derived from working documents which do not necessarily represent the final thinking of those concerned).

Lambeth AIDS Action. The aim is to establish an HIV Centre run on multi-disciplinary lines with a high degree of user involvement. The Centre would be open day and evenings, with a coffee bar, to act as a drop-in social centre for people with AIDS or the virus. In addition to this social facility there would be provision for sessional advice on welfare rights, housing, legal matters and Social Services facilities. Health advice and personal counselling would also be available. Lambeth AIDS Action would base its own administration and other activities on the Centre. These other activities would include a 24 hour switchboard; health promotion work, particularly amongst at-risk groups; outreach work, particularly with drugs misusers; and research. The centre would be located in health authority accommodation surplus to needs.

Manchester AIDSline. The emphasis here is on combining a training centre with a drop-in resource for people with AIDS. The drop-in facility would provide welfare rights, legal and housing advisory services, personal counselling and a personal support group. In addition there would be provision for alternative and complementary medicine, visualisation therapy, advice on diet and cosmetic camouflage, an aerobics or keep fit group, and a "buddying service". The Centre would form an administrative base for AIDSline and Body Positive, and would house the switchboard service. The training centre element would be run in conjunction with Manchester Polytechnic (which mounts an ENB course), and would house a cuttings and educational materials collection. Courses would be offered to a wide range of professional and voluntary workers, and the Centre would host conferences and seminars. The aim is to house the Centre in surplus health authority premises.

NOTES AND REFERENCES

Section 1

1. Third Report from the Social Services Committee of the House of Commons, Session 1986-87, Problems Associated with AIDS, 182 - I, para. 132. (N.B. In further references below this source is referred to as the Report of the Social Services Committee).

Section 2

1. A medical definition of counselling is offered in the Memorandum submitted to the Social Services Committee by the Royal College of General Practitioners (Report, 182 - xii, p. 130, para. 31). This states:

> "Counselling consists of listening carefully and professionally to the patient and responding courteously, clearly and systematically. It includes the provision of advice and the clarification of options available to the patient and an explanation of investigation and treatment".

The British Association for Counselling defines the task of counselling as:

> "To give the client an opportunity to explore, discover and clarify ways of living more resourcefully and toward greater well-being."

See the Memorandum of the Albany Society to the Social Services Committee (Report, 182 - iv, pp. 116 - 130), which also states that counselling in this sense is specifically not a matter of giving advice or prescribing behaviour. This memorandum contains a helpful summary of the conditions, skills and conceptualisations relevant to what we have called "personal counselling" in the text.

2. An example of this over-inclusive approach is provided in David Miller, "HIV Counselling: some practical problems and issues", Journal of the Royal Society of Medicine, vol. 80, May 1987, p. 278. This runs:

> "Counselling means facilitating understanding: (1) by individual support, discussion and health education of patients, lovers, families and carers; (2) by health education for society as a whole and all its subgroups, on routes of human immunodeficiency virus (HIV) transmission, methods of risk-reduction and infection control; and (3) by the training and support of staff working with HIV-infected patients".

Section 3

1. The major risk groups are currently recognised to be homosexual/bisexual men and intravenous drug abusers (IVDAs).

2. For a discussion see Nicholas Wells, The AIDS Virus: Forecasting its Impact, Office of Health Economics, 1986, pp. 24 - 30

3. DHSS press release, 6 July 1987, Quarterly Figures on AIDS.

4. This is because the geographical locations of the reporting laboratory, the test site of origin and the normal residence of the patient may all be different. Work is in hand at the CDSC to improve the data on geographical distribution.

5. HIV Infection in Scotland. Report of the Scottish Committee on HIV Infection and Intravenous Drug Misuse. Scottish Home and Health Department, September 1986 (mimeo).

6. See, for example, HIV Infection in Scotland (as in reference 5 above); Report by the Director of Social Services of the Royal Borough of Kensington and Chelsea, The Impact of AIDS in Kensington and Chelsea: Implications of Care in the Community, June 1987; Denise Platt, "The community care challenge for local authorities" in AIDS: Planning Local Services. King's Fund Centre, 1987, pp. 25 - 6

7. The ratio of 5:1 is based on 6349 known cases against the estimated 30 - 40,000 total cases. The ratio is then applied to the CDSC figures for the Regional distribution of known cases.

8. In Scotland, 60% of HIV positives are IVDAs and 26% are homosexual/bisexual, against comparable figures for the rest of the UK of 7% and 78%. Women represent 27% of Scottish cases against 5% elsewhere.

9. Michael W. Adler, "Care for patients with HIV infection and AIDS", British Medical Journal, volume 295, 4 July 1987, pp. 27 - 30.

10. Anthony J. Pinching, Memorandum to the Social Services Committee, Report, 182 - v, p.147.

11. E. J. Beck et al., "HIV testing: changing trends at a clinic for sexually transmitted diseases in London", British Medical Journal, vol. 295, 18 July 1987, pp. 191 - 3.

12. R. Anderson et al., "AIDS publicity campaigns", Lancet, 20 June 1987, pp. 1429 - 30. C. Sonnex et al., "HIV infection: increase in public awareness and anxiety", British Medical Journal, vol. 295, 18 July 1987, pp. 193 - 5. P.D. Woolley and G.R. Kinghorn, "AIDS publicity campaigns", Lancet,

1 August 1987, p. 284.

13. The apparently higher strike rate at St. Mary's Hospital comes from averaging over a longer period which combines high positivity rates found amongst earlier and high-risk attenders and much lower rates found when the test population was diluted by low-risk individuals motivated by the media campaigns. At November 1986 the seropositivity rate was 6%, almost identical to the 5.7% at the Middlesex Hospital.

14. David Miller, "Counselling", British Medical Journal, vol. 294, 27 June 1987, pp. 1671 - 4.

15. David Miller, John Green and Alana McCreaner, "Organising a counselling service for problems related to the acquired immune deficiency syndrome (AIDS)", Genitourinary Medicine, vol. 62, 1986, pp. 116 - 22.

16. A.G. Lawrence and A.E Singaratnam, "Changes in sexual behaviour and incidence of gonorrhoea", Lancet, 25 April 1987, pp. 982 - 3.

17. Social Services Committee, Report, 182 - i, p.24, q.78.

18. Memorandum from the East Anglian RHA to the Social Services committee, Report, 182 - xii, pp. 37 - 9, para. A4.

19. Memorandum from Dr. Graham Bird to the Social Services Committee, Report, 182 - xii, pp. 8 - 10.

Section 4

1. Michael W. Adler, as in reference 9 of Section 3 above.

2. It seems probable that in some cases at least AIDS co-ordinators do act informally in this capacity, even although specific direct care involvement may be strictly speaking outside their remit. Such arrangements are dependent upon numbers remaining small.

3. Policies here vary even in respect of AIDS. Some local authorities accept AIDS as by definition constituting vulnerability for the purposes of the Act, whereas others would seek to establish this by medical examination. These differences are a potential source of friction between housing authorities.

4. There is some variability in the use of the term "worried well". In some usages the term includes all those who are anxious about AIDS, but the tendency now is to reserve the term for a more specific group who are deeply affected psychologically. See 11.5 and 11.6 below, and David Miller as in reference 14 of Section 3.

5. David Miller, "Taking the anxiety out of AIDS", Stress Medicine, vol. 2, 1986, pp. 259 - 65. In 4.4.3 we have also drawn more generally on David Miller, Jonathan Weber and John Green, The Management of AIDS Patients, McMillan: London, 1986.

6. David Miller, as in reference 14 of Section 3. p. 273.

Section 5

1. Memorandum of the Terence Higgins Trust to the Social Services Committee, Report, 182 - iv, pp. 101 - 3.

2. For a discussion see Colin Clews, "AIDS: the limits to self-help". Social Work Today, 25 August 1986, p.23.

3. This paragraph draws upon observations made by David Miller in pp. 133 - 8 of The Management of AIDS Patients, cited in reference 5 of Section 4.

4. Social Services Committee, Report, 182 - I, paragraph 80.

5. One calculation is that the spread of infection by needles is at 5 to 7 times the rate by sexual intercourse. See R.P. Brettle et al., "Human immunodeficiency virus and drug misuse: the Edinburgh experience", British Medical Journal, vol. 295, 15 August 1987, pp. 421 - 4.

6. Of 191 IVDAs studied, 44 (23%) had shared needles in 48 other locations, and of these IVDAs 52% were HIV positive.

7. HIV infection in Scotland, as in reference 5 of Section 3.

8. Social Services Inspectorate Project on Drug Misuse, Report, December 1986, DHSS (mimeo).

9. For Amsterdam see E.C. Buning et al., "Preventing AIDS in Amsterdam", Druglink, vol. 1 (3), p. 9. For Sydney see P. Turbitt, "The nurses' role in the prevention of transmission of the Human Immunodeficiency virus in a new-risk nation", poster presentation at the international Conference on AIDS in Washington 1987 (mimeo).

10. Personal communication from Lindsey Alldritt of the Monitoring Research Group, Department of Sociology, Goldsmiths' College.

11. For a vigorous presentation of this viewpoint see Christopher Goodman, "Why AIDS prevention must now be the only response to drug users", Social Work Today, 17 August 1987, pp. 10 - 11.

12. Guardian, 6 July 1987 and personal communication from Jane

Goodsir, Director of Release.

13. One purpose of the proposed AIDS nursing home at Torpichen in West Lothian was to enable IVDAs to build up physical strength. The enforced cancellation of his project was a demonstration of the negative perceptions of IVDAs held by the general public.

14. Dr. Jacqueline Mok, reported in AIDS in Childhood and Adolescence, proceedings of a Seminar at the National Children's Bureau, 3 February 1987 (mimeo).

15. These observations are derived from: the memorandum from Dr. J. T. McManus et al. to the Social Services Committee (Report, 182 - xii, p.156); Social Services Committee, Report, 182 - I, para. 152; personal communication from Janet Green, counselling Administrator with the Terence Higgins Trust.

16. Memorandum from Druglink to the Social Services Committee (Report, 182 - xii, pp. 122 - 3.

17. BASW Haemophilia and Related Haemostatic Disorders Special Interest Group, AIDS and Haemophilia, Discussion Paper, August 1985 (mimeo); also personal communication from Jean Lovie.

18. Personal communication from Jean Lovie.

19. Social Services Committee, Report, 182 - I, recommendation 80.

20. Personal Communication from Dr. Jacqueline Mok.

21. Devon County Council is an example - personal communication from Rod Furlong.

22. NACRO News Digest, no. 45, July 1987, p. 10. The Home Office training film for prison officers seems to suggest that medical officers have pressed antibody tests on prisoners. Dr. Kilgour stated that this was a fault in the film and that the need for consent would be pointed out by a trained presenter every time the film was shown.

23. Personal communication from Len Curran.

24. As reference 22 above.

25. Memorandum from the Northern Regional Haemophilia Service to the Social Services committee (Report, 182 - xii, pp. 32 - 3).

Section 6

1. The principles embodied in the framework are based upon observations made during visits to St. Mary's Hospital, Paddington; the Middlesex Hospital; St. Steven's Hospital, London; the Bolton Royal Infirmary; the City Hospital, Edinburgh; and the Royal Victoria Infirmary, Newcastle upon Tyne. Material is drawn also from the following published sources: David Miller, Jonathan Weber and John Green, "The Management of AIDS Patients, MacMillan: London, 1986; David Miller, "Counselling", British Medical Journal,, vol. 294, 27 June 1987, pp. 1671 - 4; David Miller, John Green and Alana McCreaner, "Organising a counselling service for problems related to the acquired immune deficiency syndrome (AIDS)," Genitourinary Medicine, vol. 62, 1986, pp. 116 - 22.

Section 7

1. Michael W. Adler, cited in reference 9 of Section 3.

2. For a fuller account see R. P. Brettle et al., cited in reference 5 of Section 5.

3. For some details see Jean Lovie and Shirley Morgan, "Living to the end", Community Care, 23 April 1987, pp. 18 - 19.

Section 8

1. Social Services Committee, Report, 182 - I, para. 110.

2. Memorandum submitted to the Social Services Committee on behalf of the Council of the Medical Society for the Study of Venereal Diseases (Report, 182 - xii, pp. 44 - 6).

3. Social Services Committee, Report, 182 - I, para. 110.

4. Memorandum submitted to the Social Services Committee by the Health Visitors Association (Report, 182 - xii, pp. 95 - 7).

5. Social Services Committee, Report, 182 - xii, Memoranda nos. 8; 19, para. 4; 28; 56; 67, para 2b; and 72

6. Evidence of professional territoriality may be seen in the "concern" felt by GUM consultants that "voluntary organisations and individuals with little knowledge of venereology have become intimately involved in Health Authority decision making" (see Memorandum cited in reference 2 above, p.46). Note also the complaint from GUM medical staff at Newcastle General Hospital concerning thepreferential funding of haemophiliac clinics in respect of HIV work (Memorandum no. 72 cited in reference 4 above).

More generally, the Memoranda and evidence submitted to the Social Services Committee contained numerous bids for various medical specialisms to be considered. Denise Platt (cited in reference 6 of Section 3 above) observes that "vested professional interests about who owns the problem are also apparent" (p. 27).

7. Personal communication from Dr. Elizabeth Miller. In January - March 1987, ten PHLS laboratories processed 14,228 samples. Of these, 49% were from GUM clinics, 28% from GPs and almost 20% from "other hospital sources". It is not known how far this distribution can be generalised to other laboratory services.

8. A survey of six private clinics revealed that the cost of a consultation starts at £85.00 with an additional £10 - £30 for the test itself; some clinics charge for counselling and testing together. Some private clinics are said to offer tests without proper counselling, and the Health Minister, Mr. Tony Newton, has announced that the Government is considering whether steps are necessary to regulate or monitor private screening clinics and the laboratores they use. See AIDS Newsletter, 18 July 1987, item 448 and 11 August 1987, item 537. It seems unlikely that private clinics offer HIV counselling on a long-term basis.

9. The proportion of total antibody testing which is processed by the PHLS is not known, but only about one third of seropositive results are being reported from PHLS laboratories.

10. These include doctors, clinical psychologists, Health Advisers, social workers, Health visitors, clinic nurses, midwives and "AIDS counsellors" of diverse backgrounds.

11. Memorandum submitted to the Social Services Committee by the Association of Directors of Social Services (Report, 182 - viii, pp. 238 - 40).

12. The nature of the ADSS memorandum drew a critical rejoinder from a hospital social work manager who believed it to understate the potential contribution of social workers. See letter from G. J. Ashworth, Community Care, 2 July 1987 p. 10. The British Association of Social Workers has established a working party (Chaired by Roger Gaitley) to consider HIV issues in relation to social work.

13. Social Services Committee, Report, 182 - v, q. 59, p. 168

14. Personal communication from David Miller.

15. Personal communications from Heledd Nicholas and Vincent Moss.

16. HIV Infection in Scotland, cited in reference 5 of Section 3 above, para 4.6.7.

17. R.P. Brettle et al., cited in reference 5 of Section 5 above. This is a robust calculation which divides certain direct costs by the number of patients actually attending. The costs allowed for were: salaries, £18,500; initial equipent, £3,000; consumables, £2,500; HIV and hepatitis B testing, £3,000. The premises were regarded as being available without cost.

18. Personal communication from Dr. K. Bissett.

19. DHSS research brief, Social Services Provision for AIDS Sufferers, para, 4a, and Social Services Insight, 18 September 1987, p.10.

Section 9

1. Social Services Committee, Report, 182 - I, recommendations 27, 29, 35 and 75.

2. Social Services Committee, Report, 182 - v, q. 600, pp. 170 - 1.

3. Personal communication from Adam Mitchell-Christie. Mr. Mitchell-Christie has compiled a register of HIV-related switchboards.

4. See H. Slavin and K. Smith, "People's need for information - the work of the National Advisory Service on AIDS", Health Education Journal, vol. 46 (2), 1987, pp. 60 - 61.

5. As an example, the activities of Manchester AIDSline include public education, training, fund-raising, providing a "buddying" service, running a Body Positive suport group and convening a Women and AIDS group. An interesting example of a different kind of AIDS action group which is not linked to a switchboard wervice is provided by the East London Community Action Service. ELCAS was established in June 1986 by a group of professionals who were concerned about the paucity of resources for people with AIDS in East London. This group offers a training and educational programme to organisations, acts as a co-ordinating forum for local voluntary bodies, is developing residential accommodation for people with AIDS, and has now established a "Professional Befriending Service".

6. Some indication of this is given by preferences in language use; for example, the term "people with AIDS" is preferred to "AIDS sufferers" or "AIDS victims".

Section 10

1. We rely here on a combination of published writings, (particularly those of David Miller), memoranda submitted to the Social Services Committee, and personal communications.

2. An example of a systematic and differentiated approach to training is provided by the Islington Health Authority. See D. Panter, "Training about AIDS: reaping the benefits", Health Education Journal, vol. 46 (2),1987, pp. 74 - 6.

3. The Terence Higgins Trust is prominent here, but training is also undertaken by London Lighthouse, many AIDSline organisations, special interest groups such as ELCAS and other voluntary bodies.

4. The formation of a freelance consultancy service is reported in the AIDS Newsletter, 21 August 1987, item 564.

5. The third unit, at Birmingham, was not fully operational during our work.

6. These are: the British Association for Counselling: the AIDS Virus Education and Research Trust in association with Bristol Polytechnic; and the London Borough's Training Committee in association with the Project for Advice, Counselling and Education and the Terence Higgins Trust. Of these, only the BAC seems specifically directed towards counsellor training.

7. Social Services Committee, Report, 182 - I, recommendation 51.

8. Social Services committee, Report, 182 - I, para. 70.

9. Jonathan Grimshaw told us that this has been discussed within the NACTU at St. Mary's Hospital

10. Some aspects of feelings of isolation are discussed in the edited proceedings of a round table discussion, "Beyond hope and hopelessness", Community Care, 10 September 1987, pp. 15 - 18.

Section 11

1. BASW Special interest Group discussion paper cited in reference 17 of Section 5, plus personal communication from Jean Lovie.

2. David Miller, "Taking the anxiety out of AIDS", Stress Medecine, vol. 2, 1986, p. 261

3. David Miller, "Counselling", British Medical Journal, vol. 294, 27 June 1987, pp. 1671 - 4; and "Predictors of chronic psychosocial disturbance arising from the threat of HIV infection: Lessons from heterosexual, bisexual and homosexual worried well patients", paper prepared for the world conference on AIDS held in Washington, 1987 (mimeo).

4. One irony here is that anxiety may provoke symptoms which mimic some of those of ARC, thus producing a kind of psuedo-AIDS condition. See S. Miller et al., "A pseudo-AIDS syndrome following from a fear of AIDS", British Journal of Psychiatry, vol. 146, 1985, pp. 550 - 51.

5. David Miller, "HIV counselling: some practical problems and issues", Journal of the Royal Society of Medicine, vol. 80, May 1987, p.279.