

Proceeding with care

*Phase 3 of an on-going study of
the impact of combination therapies
on the needs of people with HIV*

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Preface

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Contents

Summary	2
Recommendations	3
1. Introduction and methods	4
1.1 Methods	4
1.2 Sample characteristics	5
1.3 Problems with the self-report of need	6
2. What is a need?	8
2.1 The concept of need in theory and policy	8
2.2 The limitations of service-based definitions of HIV need	9
2.3 A subjective approach: needs shaped by the possibilities of life	9
3. Needs	11
3.1 The right to remain	11
3.2 Shelter and security	12
3.3 Sustaining the routines of daily life	13
3.4 Mental health: coping with adversity	14
3.5 Economic security and independence	15
3.6 Gaining employment	17
3.7 Human contact and communication	18
3.8 Sustaining partner and family relationships	20
3.9 Sex	22
3.10 Managing dependency	24
3.11 The demands of medicine	25
4. Meeting needs: making choices	28
4.1 Acknowledging need and the value of personal autonomy	28
4.2 The availability of familiar and reliable support	29
4.3 The obstacles to accessing unfamiliar support	30
4.4 The quality of the response	31
5. Meeting needs: choices made	34
5.1 Self: meeting your own needs	34
5.2 Partners, family and friends	35
5.3 Services	36
5.4 Other sources of support	39
6. Using services	40
6.1 Exploring services	40
6.2 Exploring needs	42
6.3 Changing needs and changing service use	43
7. Conclusion	44
References	46

Summary

The impact of anti-HIV combination therapy on the needs of people with HIV has been shaped both by changes in health and changes in prospects. A gradual shift has taken place, away from short-term needs and the possibilities of illness, to needs defined by the long-term and the possibilities of health. But needs remain highly individual – although important for some, to others this pattern of change is minor or even irrelevant.

The clinical benefits of treatment vary considerably. Many of those who have seen major improvements in their health are now able to meet their daily needs by themselves. But for those coping with chronic disability or side effects, sustaining daily routines remains difficult.

The wider impact of combination therapy has been on perceptions of the possibilities of life. Almost everyone living with HIV now contends with an increasing range of possible futures. As horizons expand, needs almost always increase. Those who risk change face many needs, such as needs for confidence, understanding, resources, mobility, skills and friendship.

But combination therapy is only one of many things which have shaped the needs of people with HIV. Overall, patterns of need have not changed radically, because individual needs continue to be defined by the many other demands of life. People with HIV are still coping with uncertainty, discrimination, anxiety, violence, loss and displacement. People with HIV are still looking after children, seeking and sustaining relationships, searching for trust in friendships and satisfaction in sex. People with HIV are still holding down jobs, fighting for basic rights and welfare, coping with inadequate living conditions, and managing dependency on drugs. Above all, people with HIV are still coping with the reality of living with infection, with doubt, and with the legacy of the past. For any individual, need is highly subjective, rooted in personal circumstances and always open to change.

Changes in need have not always been reflected in changes in demand for services. People with HIV meet their needs by drawing on many sources of support – formal, informal and (above all) internal. Hence it is not always services which feel the impact of changes in need, especially when they play a relatively minor role in any individual's life.

Furthermore, demand for services is not simply a reflection of need. People with HIV do not rationally select services to fulfil identified needs. Different people gain very different things from the same service, regardless of what the provider is aiming to achieve. For any individual, service use is a process of exploration, of working out what works best in dealing with the reality of life. Changes in need have affected service use in different ways, depending on the role of service use in any individual's life.

People with HIV recognise that services cannot do everything for them and turn to many other sources of support to deal with changes in their lives. What matters to them is that services respect them, understand them for who they are, and attempt, as far as possible, to respond to the individuality of their needs.

Recommendations

- ▶ Providers should respect the individuality of their users' needs and be sensitive to their beliefs, interests and doubts. Responsiveness to individual need is more important than delivering the 'right' services to everyone.
- ▶ Providers and commissioners should not focus on combination therapy as the key to understanding the needs of their users, but attend to all the things which shape individual lives. Treatment taking is part of life – not the other way round.
- ▶ Providers and commissioners should not make simple distinctions between the needs of those who are taking combination therapy and the needs of those who are not doing so (or those who have had to stop taking therapy).
- ▶ Providers should not confuse their users' needs with their demands for services, even though this may be the way many users have learnt to express and understand their needs. This is crucial to any review or development of service provision.
- ▶ Many people with HIV still struggle to meet basic needs. Commissioners must ensure that appropriate support is available for those whose basic needs are least well met.
- ▶ Psychological support services for people with HIV should not be reduced. The uncertainties of treatment and the difficulties of rebuilding lives have added to the complex mental health needs of many people with HIV.
- ▶ Commissioners and providers should consider how to deliver individualised information, advice and support services which meet the highly personal needs related to thinking through the possibilities and obstacles of new life, including the potential impact on current security.
- ▶ The value of self-help groups and similar support services for many people with HIV should be recognised. Their strengths lie in their individual responsiveness, flexibility and focus on mutual understanding as the basis for identifying and meeting mutual need.
- ▶ In developing adherence-support services, providers should focus on people's lives first and treatment second. People with HIV are told that they must adhere to treatment, but adherence is a clinical requirement not a personal need. What they need is support in bringing order and routine planning to individual lives.
- ▶ Asylum seekers with HIV should not be subject to the new national system of dispersal. The vast range of specific services and support mechanisms available in London are crucial to many Africans with HIV in meeting their most basic needs.

1 Introduction and methods

The advent of anti-HIV combination therapies has irrevocably changed the lives of people with HIV in the UK. The rapid changes in HIV treatment options over the last four years have raised hopes and expectations about the impact of treatment on the lives of most people with HIV. Even those who are not taking treatment must now assess the new possibilities which it offers, however qualified these may be.

This study is the third part of an on-going project exploring the social impact of anti-HIV combination therapies on the lives of people with HIV. The first study, a qualitative exploration of the impact of therapy, drew attention to the differences between clinical change and social change: improvements in health did not always lead to change in other aspects of people's lives (Anderson and Weatherburn, 1998). Although health is an important part of anyone's life, it is far from all-defining. The second study, a national survey of people with HIV in the UK, focussed on key aspects of the treatment-related experience of people with HIV (Anderson and Weatherburn, 1999). The results were mainly encouraging: treatment was widely available, adherence rates were high and the great majority of people with HIV were satisfied with their clinical services.

This third study builds on the earlier findings to explore the changing needs and service use of people with HIV. Considerable efforts are currently being put into the re-configuration of HIV services, a response both to the perceived impact of combination therapies on needs and to their cost. This report offers a critical perspective on the changing needs of the users, or potential users, of these services.

Any development of services relies to some degree on a 'broad brush' approach to understanding change. But the danger inherent in such an approach is that certain stories of change are overstated. This report acknowledges the need of service providers to identify change at a population level, but draws attention to the multiplicity of stories which this can obscure.

The study included people who were taking combination therapy, those who had not started therapy despite being advised to do so, and those who had stopped taking therapy. The approach was qualitative, so there is no measure here of the changes taking place. But the results offer an opportunity to reflect on the assumptions we make about what these needs are and how they have been affected by combination therapy.

1.1 METHODS

Forty-seven people living with HIV took part in the study. To be eligible participants had to be living in London and to have experience of taking combination therapy (currently or in the past) or to have decided not to take therapy despite having been advised to do so. They were recruited through four HIV clinics across London and through advertisements placed in the HIV press. In order to increase the number of participants with experience of injecting drug use, flyers were also given out by three drugs agencies. The Positively Women African support group also promoted recruitment

Prospective participants were invited to phone a confidential telephone line to find out more about the study. They were able to choose between a male and female interviewer and were offered a £20 contribution towards expenses. Interviews took place in the Sigma Research offices in South London unless participants had mobility problems – then interviews were conducted in participants' own homes. Four interviews also took place in the offices of the Healthy Options Team, Mile End. Interviews took place from May to July 1999.

The interview schedule was designed to provide a semi-structured framework in which points of particular interest and relevance to the individual participant could be explored in greater depth. Although a clear distinction between the themes of need and service use was hard to sustain, participants were not asked specifically about their use of services until after they had reflected at length on their experience of living with HIV, their needs and how they had addressed their needs. Interviews were tape recorded, with the consent of the participants, and transcribed. All data from the interviews was kept confidential and secure.

There were several steps to the analysis. Initially, every case was considered on its own terms, in order to identify the issues and problems specific to each participant. On the basis of this analysis, a broad thematic framework was developed. This was then used as the outline for a cross-case content analysis which fleshed out, challenged and modified the individual themes within the framework. During the report-writing phase, searches across the whole data set were used to check and test the content of each section.

1.2 SAMPLE CHARACTERISTICS

Twenty-five of the 47 participants were taking combination therapy at the time of interview. Of the 22 who were not taking therapy, four had done so in the past but had stopped and 18 had chosen not to start despite being advised to do so. The following is a summary of the demographic characteristics of the participants:

Sex:	29 men and 18 women.
Age:	average (mean) of 37 with no differences between men and women. The youngest participant was 25, the oldest 58.
Ethnicity:	32 White including 5 White Irish (5 women, 27 men); 14 Black African (13 women, one man); one mixed race man.
Sexuality:	25 heterosexuals (18 women, 7 men), 19 gay men and 3 bisexual men.
Employment status:	40 not in paid employment, 7 in paid employment (3 women, 4 men).
Experience of injecting drug use:	13 had injected drugs at some time in their lives (3 women, 10 men); 6 had injected drugs in the six months prior to interview (2 women, 4 men).
Time since diagnosis:	average (mean) of 6 years and 6 months (men, 7 years and 4 months; women 5 years and 4 months).

All but four of the participants regularly used an HIV clinic, that is, at least once every 3 months. Of the four who did not, two went only once a year and two went even less often.

1.3 PROBLEMS WITH THE SELF-REPORT OF NEED

Asking people to describe their needs is not a straightforward process. The acknowledgement of personal need may at times be difficult or even painful. For any individual, understanding personal need takes time and is often achieved through interaction with people who can provide some kind of mirror to personal experience.

At the Mildmay I felt nobody could come and see me so I had complete sanctuary which was important to me at the time and I praise that place enormously because in six weeks it completely turned my whole life and it looked at it from every possible angle. Seeing in the hospital people dying. Speaking to counsellors in the hospital. Seeing the terrible illnesses associated with AIDS because it was essentially a hospice and people were dying there. It was like a shovel went through my system and it made me think, 'Well I've got to think about where I am and what I'm doing and how I relate to other people'. That was the immediate impact. I was right underneath, on the face and I saw what it was like and I thought, 'I can't hide my head in the sand for ever'. There was a part of me, a voice inside saying, 'You need help, you need help', which is not easy for me to listen to but it was overwhelming and there was that part of me which was crying out for some guidance, some support, somebody to listen or somebody that I could talk to. It was quite overwhelming, I couldn't ignore it.

– White gay men, taking combination therapy

For this participant, acknowledgement of dependence and vulnerability is both challenging and transforming. Not everyone was willing to confront their needs in this way, especially if doing so meant accepting personal weakness. Similarly, participants had different perceptions of what 'counted' as a need. Several felt that need only related to physical problems and that emotional or other psychological matters were not real needs.

My needs have basically stayed the same because I haven't had major illnesses and that. But maybe there are needs out there that I'm not addressing like things... I don't know, I think I'm stuck in limbo... I don't think I have any needs. Maybe I do but that's my answer. I suppose I really look on my needs as physical. If someone said to me, 'When do you think you will need services?' It would be, 'Well when I'm lying on my back'. So I suppose that's the needs in services. I don't look at the other...

Maybe talking to someone as a need and that kind of stuff.

– White heterosexual man (current IDU), not taking combination therapy

This illustrates the reflexivity of need – some needs inhibit their own recognition and expression. Although deficits in physical health are usually acknowledged, deficits in psychological well-being are not. If you have considerable psychological needs, you may *in consequence* find it hard to express and address these. All the investigative techniques of psychology and related disciplines are necessary for this reason.

Needs are also always changing. Asking someone about their needs at a particular time may not be a very reliable way of identifying their ongoing needs. The question 'What are your needs?' may be confusing because, at a particular time, need may not seem very great. Few people go through a conscious process of identifying their needs and then deciding how to meet them. Many do not think about need at all and find discussion of need difficult because it requires that they abstract something from their daily lives in a way which is unfamiliar.

These problems cannot be ignored in the reporting of need. Most professionals deal with them by imposing a framework for identifying need, but researchers have a commitment to making sense of the experience of participants on their own terms, trying to understand their point of view without predetermined ideas of what counts as a need. However, it is also the business of research to make sense of what people say and creating order from such data involves making lots of choices.

This report is ultimately only one interpretation of the accounts of our participants. In order to try and keep this interpretation true to those accounts, we have placed considerable emphasis on how the participants perceived their own needs, paying particular attention to how such perceptions were shaped and how they changed over time. Above all, an *a priori* model of what is and is not a need has not been used (see next chapter). The framework for discussing need (used in chapter 4) has grown out of the participants' own perceptions of need and is designed to give insight into their experiences rather than function as a working model of need. It is a quirky, sometimes repetitive, interpretative perspective on need, not a finely tuned model for assessing need. The framework avoids terminology which is not used by the participants. As no attempt is made to assess psychological need beyond what people report, some readers may feel that this area of need is under-reported.

2 What is a need?

Need is not a straightforward concept. In everyday language, 'need' is used in lots of different ways with many meanings and nuances. This chapter reviews how the concept of need has been used in recent health and social care debates and describes our approach to understanding need.

2.1 THE CONCEPT OF NEED IN THEORY AND POLICY

An early attempt to define need (Bradshaw, 1972) set out four different types of need: needs which individuals feel, needs which individuals express, needs which professionals identify (normative needs) and needs revealed by the differences across populations (comparative needs). This classification draws attention to the multiple perspectives from which need can be defined, all of which may conflict: individuals experience and express their needs in the immediate reality of their lives; professionals make judgements about the needs of their clients based on their professional priorities; and the state makes judgements about needs based on statistics, economics and political priorities. In practice, these different perspectives are not easily kept apart.

A more recent model suggests that need is best understood in terms of three overlapping areas of interest: need, demand and supply (Stevens & Raferty, 1994). Whatever an individual's need may be, this becomes a demand when it is expressed in terms of a service: 'I need home care'. However, it is up to professionals and the state to decide what services are actually supplied, so there is always a limit to what individuals can demand, based on professional decisions about which demands are legitimate and affordable.

The provision of services is increasingly concerned with responding to individual needs. Over the last decade, government policy has sought to make health and social care 'needs-led'. This policy shift began with the publication of the 1990 NHS and Community Care Act which stated that 'social services authorities will be expected to set out their assessment of the needs of the population they serve' (Department of Health, 1990). Population needs assessment was combined with individual needs assessments to create a new framework of needs-based planning. Henceforth, the provision of welfare services was to begin from the needs of the individual citizen rather than from the pronouncements of bureaucrats and public sector professionals (Langan, 1998). This was part of a shift in public policy away from state responsibility for providing comprehensive welfare, regardless of need, to a focus on the specific needs (and responsibilities) of individuals and communities.

In the event, the professionals kept their grip on need. Although service providers took a greater interest in assessing needs, they continued to be defined in terms of services. In the guidance issued by the Department of Health, need was defined as 'the ability of an individual or collection of individuals to benefit from care' (Price Waterhouse, 1993). This definition is now usually described in terms of an individual's 'capacity to benefit' from services (Wright *et al.*, 1998). For individuals with HIV, this approach to understanding need may seem limiting. But for service providers and commissioners, it is both practical and efficient. After all, why should a service be interested in assessing needs which it can do nothing to address?

2.2 THE LIMITATIONS OF SERVICE-BASED DEFINITIONS OF HIV NEED

Service-based definitions of need have dominated HIV research as much as any other area of health and social care. For example, in one study of the needs of people with HIV in London, 'a need was taken to mean one individual's expression of need for a single service' (Petrou *et al.*, 1996). Needs assessments which are undertaken by professional providers focus on the potential of their services to benefit users (e.g. Oman *et al.*, 1999); and even those which make a point of seeking 'service user views' are still primarily interested in the service users' views on services, rather than need (e.g. Warren *et al.*, 1994). Such studies are still useful – each contributes to the service's capacity to be of benefit to its clients. However, the dominance of service interests can be cause problems.

The most immediate problem with this approach is that people with HIV do not express or understand their needs solely in terms of demand for services, not least because services may play a very small part in how they meet their needs. However useful a focus on demand may be for HIV service providers, this is always likely to distort their understanding of the needs of people with HIV.

Second, a focus on demand for services can limit providers' own understanding of what needs the services are actually meeting. For example, if someone has a 'need for counselling', what are they actually hoping the service will deliver for them? Diverse experiences – isolation, rejection, trauma, violence, shame – will create equally diverse needs, all of which counselling may provide for, including needs for human contact, reassurance, self-worth, confidence, peace of mind and clarity of purpose. A specific service may meet a wide range of needs, but may not meet any need in its entirety. It may also meet needs which it does not aim to meet.

Third, a focus on demand for existing services may fail to discover significant changes in individuals' overall patterns of need – changes which may undermine the usefulness of established services. Arguably, this is the current concern in the HIV sector because of the impact of combination therapy: service providers are being forced to look beyond their usual service profile and grasp broader changes in the needs of individuals with HIV. There is, however, a danger in this process. If demand for services only reflects a small part of the needs of people with HIV (and how these needs are met), changes in individuals' needs may have little impact on this demand.

Service providers must remember that, however important their services may be, the demands made by their users will only ever reflect part of their needs. It is a mistake to assume that any change in the needs of people with HIV will inevitably impact on the contribution of a service to meeting them.

2.3 A SUBJECTIVE APPROACH: NEEDS SHAPED BY THE POSSIBILITIES OF LIFE

In this study, we sought to describe individuals' perceptions of their needs, as far as possible independently from their service use. However, individuals' perceptions of need are often radically different, not simply because some people are short of more things than others, but because different people have very different ideas about what matters to them in life and what life can offer. For some, there were very few things which were perceived as needs – perhaps just shelter, sustenance, security and peace of mind. For others, there were many, such as work, intellectual or physical challenges, sex, freedom to travel, fitness, companionship, ambition, political engagement, or freedom of expression. Much depended on how individuals perceived the possibilities of their lives – a simple, quiet life with little ambition would define far fewer needs than a life filled with hope and potential.

Individual perceptions of need are therefore shaped by the circumstances, constraints and opportunities of life, and by attitudes and beliefs about life and its purposes. Although there is a handful of things which we are essential in everyone's life, most needs are *not* universal. One person's need may be irrelevant to another, but this does not diminish the personal importance of the need. Hierarchies of needs and 'wants' obscure the individuality and subjectivity of need.

Personal needs can increase in a straightforward way if something in life is lost, such as health. But needs also change when perceptions of what is possible in life changes. For example, an HIV diagnosis may create immediate losses, defining new needs for support or healthcare, but needs related to career development and long-term planning may in time be relinquished. The hope offered by therapy has made it possible for some to reverse such changes, but in choosing to imagine a new life, a range of needs related to personal development emerge. Changes can also be gradual: for someone who has been chronically ill, improvements in health may lead to a slow awakening of the possibilities of a more active life, defining new needs for fitness, transport, friendship and money.

Beyond these changes in perceptions of need, new needs can be created by new demands placed upon people. The dominant example in this study is the clinical requirement for strict adherence to combination therapy. Although therapy can improve health, new needs are created by the demands of the regimen: for the understanding, skills and orderliness to take the medications as prescribed.

This model of need, bringing together individual perceptions about life's possibilities with the reality of current difficulties and losses, is both individualistic and dynamic. Every participant in the study had a unique perception of need and a unique story of need. These needs are described in chapter 3. Every participant had also found their own way of meeting their needs, drawing on a range of sources of support (chapters 4 and 5). Although services were important in meeting needs, this was not the only role they played in people's lives. Chapter 6 explores in more detail the complex relationship between needs and service use.

3 Needs

The principal impact of combination therapy has been to bring better health and better prospects to many people with HIV. These changes provide the starting point for this study and for current debate about changing needs. But better health and better prospects do not translate into a common picture of changing need, for a number of reasons.

First, the individuality of experience of HIV and combination therapy is inescapable. The impact of health and hope on any individual's life is always shaped by personal circumstances. Even substantial changes in health may have little impact on other aspects of life, depending on individual opportunities, resources and the obstacles to personal change.

Second, combination therapy has not always delivered better health and the future of therapy remains uncertain. Poor health, serious illness and side effects all feature in the stories told by participants. The change in prospects has been profound, but worries about treatment failure continue to affect individual choices.

Third, even positive change does not have a consistent impact on need. Although improving health is likely to be experienced as a reduction in need, better prospects often increase need: a reduction in a health deficit goes hand-in-hand with an increase in the possibilities of life (as horizons expand, needs increase). The combined effect of these changes on need is, therefore, unpredictable.

No-one saw their future possibilities solely in terms of decline (although for a few participants, who had been seriously ill or disabled, this was a very real prospect). In many different ways, participants were rethinking the possibilities of their lives. In doing so, they were always going forward, never going back: HIV had changed everyone irrevocably. What came between these new possibilities and current reality was not just the uncertainties of therapies, but the damage inflicted by the past. Participants in this study had coped with their fair share of illness, impoverishment, isolation, displacement, bereavement, unemployment and violence. The individual needs described in this chapter are shaped by the tension between this inheritance and the expanding future which combination therapy has made possible.

The needs described in this chapter are divided into categories which are inter-related and overlapping. Although the first two or three of these categories concern very basic needs, there is otherwise no particular order. Different individuals have different perceptions of what needs are important.

3.1 THE RIGHT TO REMAIN

Most people in the UK can be confident in their right to remain and their right to medical treatment. But there is a minority among people with HIV (predominantly people from sub-Saharan Africa) who cannot share in this confidence. Rights are not needs, but because the right to remain is intimately bound up with access to treatment for those who have no access in their countries of origin, this right becomes a central need for anyone who risks losing it. For the Africans in this study who were waiting for news from the Home Office, this need dominated their lives and all their other needs.

Although participants in this situation usually had almost nothing, they did not necessarily perceive themselves as being needy. They could not envisage anything other than a very simple existence as nothing greater could be risked when the future was so uncertain. Within the bounds of such an existence, needs were very simple – principally they were for shelter, food and money. If these needs were met, the limited circumstances of life could be sustained and, to some degree, accepted.

There is no treatment in Zimbabwe; nothing, nothing at all. Anyway I wait patiently because as long as they have the passport there I know they are not saying, 'Go'. But the minute the passport comes up they say 'Oh what have we here?' ... I like my life quiet, you know, no fussing around, you know, just peace and things and waiting patient.... My needs? I don't have any needs!
– *Black African heterosexual woman, taking combination therapy*

One participant described how her life had been transformed by profound dependency. Her shift from a demanding working life in Uganda to a state of utter dependence is an extreme illustration of how perceptions of need change. Although she moved from having everything to having almost nothing, her needs were now far simpler. Nonetheless, this was not a pay-off she was always happy with.

I get depressed, once in a while. When I think about my salary I had back home and I had all this stuff. I had a driver taking me to work, picking me up and all that kind of thing, I had a servant in my house. But now I'm almost like a baby because I don't have any money. But then I think I chose this, I chose to come and do this.
– *Black African heterosexual woman, not taking combination therapy*

Whatever benefits therapy brings, it cannot transform a life dominated by the deliberations of the Home Office.

3.2 SHELTER AND SECURITY

Shelter is a fundamental need which, if not met, reduces life to an existence without even the most basic forms of security. The impact of homelessness on people with HIV can be particularly devastating, given the health problems which can ensue. Several participants described how their lives had been severely constrained by inadequate housing. Those who had experienced temporary accommodation knew well what life could be like in such circumstances.

The second time in hospital they didn't discharge me until they had found me a place to go. So they placed me with a family for six to seven months. Then I was moved into a bed and breakfast. You know how these things are, you just survive.
– *Black African heterosexual woman, taking combination therapy*

When I went into temporary accommodation there was nothing in the house, nothing at all. I cried, I cried, I wanted to go back to my husband and I was saying to myself, 'I wish I had the means and then I would go back home'. But I don't know, I managed to cope somehow because I was getting £40 from social services every week... so it was really difficult for me and the kids. Yes but the kids they were happy that I was not with their dad any more.
– *Black African heterosexual woman, taking combination therapy*

In the latter example, the participant was fleeing from a husband who had started beating her after her diagnosis. So although her new accommodation was appalling, it fulfilled her primary need for security for herself and her children.

People who live in poor housing are usually in considerable need precisely because housing is so central to almost all aspects of daily activity. There is a limit to how much anyone can come to terms with poor living conditions when such conditions sustain patterns of stress, ill health, isolation, discrimination, insecurity and poor nutrition. Improvements in housing transformed participants' lives.

I think the biggest need I had at that time was to find a stable place to live, I think what was causing me the greatest anxiety at that time because I was in a sort of flat share situation. I eventually did get a flat with this tenants housing group and that was done through a social worker at the hospital. It was a need I felt to have a stable, secure, safe home. So that was incredibly important to me. At home I was fine. That was where I felt safe so I was fine there. I could manage everything inside. I didn't need to be aware of what other people were thinking, it was only me, so that was perfect.

– White gay man, taking combination therapy

Housing remains a fundamental need, whatever your health status. None of the participants felt that changes brought about by therapy had decreased their housing needs.

3.3 SUSTAINING THE ROUTINES OF DAILY LIFE

The impact of combination therapy on personal need is most pronounced when illness has undermined personal ability to manage the basic routines of daily life: getting around, eating, washing, staying awake (or sleeping), facing the morning, going to the shops, cooking, cleaning, getting through the day. These are the daily needs which are most closely dependent on health and which also underpin quality of life – so improvements in health can be transforming.

Loss of health can have multiple effects on need: not only making daily needs much harder to meet, but creating new needs for pain control and symptom management and *diminishing* the needs defined by an active, healthy life.

The trouble is when you are poorly it sort of invades the whole of your life. Your life becomes very small.... You live your life in this sort of microcosmos. And just going to the shops is a major expedition, you know, and I'd spend the whole day watching daytime television because I wasn't well enough to do anything else. And a friend coming round for a cup of tea was the event of the day, you know, sort of thing. Because life becomes so much smaller, my needs... would seem very trivial now looking back but were important to me at the time, like maybe somebody helping with the shopping or going on a little walk, you know, going out in the car for a little drive or something like that.

– White gay man, taking combination therapy

When combination therapy brings escape from this 'microcosmos' of need, where illness interferes with almost every aspect of daily life, the experience is always liberating. One woman who had been through very serious illness described her contentment at being able to lead 'a normal life', even though this life involved little more than coping with everyday needs and ensuring that there was food on the table for her children. For many of those who experienced this change, needs shifted: from the needs of getting through the day to the more individual needs of making the best use (and sense) of the time available. The need for something to do with new-found health was common; a number of participants described the boredom of living from day-to-day, caught between health problems and anxiety about the future.

There were some participants who still struggled to sustain their daily routines and whose lives remained profoundly limited by their difficulty in coping with the basic demands of life. Some had been seriously ill and remained fragile or disabled despite recovery, others were coping with chronic side effects and some continued to struggle with long-term health problems.

All my veins had been used up over the years and I had been using both sides of my groin for about 10 years. I just get knackered, I can't walk very far anyway. As I say, we just cope day to day. You know, you just take one day at a time and see how it is. Like some days I'm in bed all day and some days X [partner's name] is in bed all day. I mean because of night sweats and stuff we can't even sleep together in the night. We sleep separately because I'm up and down three or four times in the night changing sheets and then I've got a kidney problem and I go to the toilet about eight times during the night so I'm up and down constantly every half hour, every hour. So a lot has changed, everything has changed.

– White heterosexual man (past IDU), not taking combination therapy

Taking therapy brings the extra demands of daily pill-taking. Perceptions of the problems created by the pills varied enormously, but they undoubtedly had an impact on the daily life. Lots of adjustments had to be made and in some cases these were frustrating – special dietary requirements and interruptions in sleeping patterns for doses were intrusive. But eating, sleeping and getting through the day never became serious difficulties because of the demands of pill-taking (as they easily could through illness). The difficulty was in meeting the requirement for adherence adequately, rather than in meeting the needs of daily life.

3.4 MENTAL HEALTH: COPING WITH ADVERSITY

Participants' accounts of how they coped with their HIV diagnosis typically contained elements of both crisis and containment, experienced in very different ways.

Straight after diagnosis I didn't feel particularly distraught or under a hell of a lot of pressure. It was like, 'Okay I can deal with this', but that's as far as it went. 'I can deal with it': it was enough just to say it. The three months later I thought, 'Well maybe I'm not dealing with it', and I just broke down and cried and I'd not really cried about it before.

– White gay man, taking combination therapy

Those who tried not to let their life be disrupted by HIV usually found that some kind of confrontation with their diagnosis was inevitable, sometimes for seemingly arbitrary reasons, at other times because of the onset of illness or because of mental collapse. Everyone had, in some way or other, found their lives changed by HIV. And everyone had been forced to work out ways of coping with their infection. Everyone had achieved some degree of acceptance, but the mortal reality of HIV inevitably meant a sense of crisis could easily return. Depression and anxiety were common.

Beyond the immediate impact of HIV, all the participants had coped with other forms of adversity. The three main sub-samples in this study – gay men, African women and people with experience of injecting drug use – all had stories to tell.

My children are in Africa, Rwanda, and I've been trying to get them here but it's not easy because I can't raise the money for their transport and all that. Because I tend to think that maybe I had them when I was already HIV positive so they might be sick. They might die without care, without medication. I have three boys and the eldest one is about 14 now. They don't have a father, their dad died. So it all depresses me. And even

our people back home, you know, relatives, you hear them dying because they don't have any access to even a [drug] trial of their own so you wonder how well life is going or what we are up to.

– *Black African heterosexual woman, taking combination therapy*

I left school at an early age. I got raped when I was 16 when I was squatting at the time and somebody broke in, two people broke in. And I managed to get out of the situation and the way I was treated by officials, by police and that, wasn't good right at that moment. I was just messed up, you know. I'd been doing drugs since I was 11. I had my first mushroom trip when I was 8 so I've been quite a messed up kid. I can't see no way out. Do you know what I mean?

– *White heterosexual man (current IDU), taking combination therapy*

Despair comes and goes and all of a sudden with the bomb being here and the bomb being in Soho – I was there the day before. I used to pop in at lunch time for a quick half during my lunch break and that blew my mind. I just lost it completely. It brought back all the rest of it and I thought, 'Well I'm not safe to go anywhere now'. Plus there was just a passer by saying 'you poof bastard', which I suppose happens. I mean I've heard of people being spat on and all sorts of things but that freaked me out even more.

– *White gay man, not taking combination therapy*

These examples illustrate how the demands placed on inner resources can be multiple and profound: discrimination, violence, displacement, bereavement, addiction and marginalisation all adding to the demands of living with HIV. These three individuals had particularly harsh stories, but everyone had been forced to cope with the other adversities in their lives.

Two particularly common experiences were bereavement and displacement. Some participants had experienced multiple bereavements, others had been overwhelmed by the loss of the person who mattered most to them. One way or another, they had coped, but the effects were usually permanent. For some of the African women, displacement was experienced as a different kind of loss – leaving their homes, families and lives in Africa with no knowledge of when (or if) they would return to them. Leaving children behind was a loss that was particularly hard to bear.

Given the complexity of the causes and the experience of adversity, the impact of therapies on participants' needs was highly individual. Improvements in physical health did lead to improvements in mental health, but better physical health did not mean that the damage done by HIV was undone. Furthermore, side effects could be emotionally debilitating, especially if they were chronic, and the daily grind of pill-taking could also be depressing – although usually less so than anticipated.

New hope and new possibilities diminished fears of illness and mortality, but brought new risks and anxieties. Most participants wanted to exploit the better prospects delivered by combination therapy, but this created needs for confidence and inner strength. Getting to grips with life again could seem a daunting task, especially when the future remained uncertain.

3.5 ECONOMIC SECURITY AND INDEPENDENCE

Economic security, however basic, is a universal need. The need for economic independence, on the other hand, is far from universal – although essential for some people, it is irrelevant to others. Economic security was usually achieved, albeit provisionally, either through paid employment or through welfare benefits. There were some participants who had neither –

predominantly Africans without entitlement to either work or benefits. In these circumstances, charitable or social services handouts were all that could be relied on – a basic dependency which had to be sustained in spite of a willingness to work.

I wasn't getting any benefits, any like Income Support, and I just used to get money from the social services so it was really difficult for me. So Positively Women again they applied for money for me from CRUSAID and the children's charity CWAC. So from there I started picking up although the financial side was still difficult. I used to look forward going to the groups every Mondays and Thursdays. I need extra money every week. I am scared because even to get a job is difficult because I went to this agency and they want to know if I'm entitled to work so they need to see my passport so that has put me off.
– *Black African heterosexual woman, taking combination therapy*

Those who received welfare benefits usually had more freedom to pursue their lives. Although they did not have to face the demands associated with work, they also had to live without economic independence. There was rarely any alternative for someone on long-term sick benefit but to give up any desire for such independence and find a way of living within the limits which benefits impose. The acceptance of such economic dependence was rarely easy, because of the loss of control which accompanied it.

Just before I was diagnosed I decided to get off drugs. I would get off drugs and get a normal 9 to 5 job which I did. But then I got my positive diagnosis so that sort of stopped me in my tracks a bit. Anyway, my mental attitude had been to support myself, get on with my life, fight the virus etc., but I just feel the benefits.... I just feel they maybe stopped me going out there and doing stuff.
– *White heterosexual man (current IDU), not taking combination therapy*

Work fulfils many more needs than those of economic security and independence. Giving up work often meant giving up a way of life, a set of ambitions or goals, or simply a way of filling the day. These could be felt as far greater losses than the loss of economic independence.

The better health and prospects offered by combination therapy have made the option of working more real for many people (Weatherburn, Clarkson & Kumari, 1999). But this does not change the need for economic security – it simply increases the available ways in which the need can be addressed. Everyone sought economic security as much as they had done before and, for many welfare benefits remained a better way of achieving this security (despite the risks of loss of benefits) than going back to work, because of the risks of relapse, side effects and treatment failure. Working for a wage, although now more possible, was widely perceived to be a less secure way of getting a regular income.

Improved health and prospects had a greater impact on the need for economic independence. The constraints of being dependent on long-term sickness benefits were borne more easily by those who lived for the present than by those who wanted to plan for the future. Those who perceived therapy as offering a new lease of life were more likely to feel a need for economic independence. As the possibilities of life expanded, the limitations imposed by dependence on benefits became less tolerable. It was people in this situation who were likely to perceive the greater security offered by benefits as being a 'trap', preventing them from achieving economic independence.

I feel like I can go back into society again as a useful person, maybe start work again and being independent again rather than relying on the social system. Although I do have an income from the social system I find that you are tighter and you do have a limitation and your life is dictated by them which is really quite depressing sometimes. You think, 'Well people have a holiday here and there and I need to be careful and a bit more frugal with money'. So I thought well the treatment is working at the moment and if everything goes okay in the next few months I would like to start back at work but also make sure that I'm still getting the help from my clinic and I'll also (fingers crossed) find a job where they are okay about HIV or they are okay if I have to visit the clinic every fortnight or whatever.

– *White gay man, taking combination therapy*

These examples demonstrate that although therapy has brought about changes in the need for economic independence, most people who have an interest in working have many other reasons (and needs) prominent in their minds.

3.6 GAINING EMPLOYMENT

Combination therapy has had a profound impact on many people's attitudes towards work, not necessarily because it is suddenly possible to work again but because it might be. Interest in working is one expression of a broader re-orientation of life goals. This change of perspective is profound, but remains qualified by the risks of change and the uncertainties of therapy itself. This section explores the needs *created* by a renewed interest in work.

Those who had thought about working had many things to consider. Above all, they had to assess the risks of change against the potential benefits of employment. The former tended to seem more concrete than the latter: if the benefits of employment were purpose, direction and self-worth, then these could easily be overwhelmed by the more immediate risk of *losing* economic security. Without confidence that illness would not intervene and undermine any attempt at working, or that benefits would be recoverable if this happened, many felt that their interest in working would have to remain on hold (Weatherburn, Clarkson & Kumari, 1999).

A very clear need, articulated by many participants, was for guidance about how they could personally start along a path towards employment whilst minimising the risks to current security. This was allied to a need for individualised advice about building or rebuilding careers. Everyone had very different employment histories but all been affected by HIV. Many participants had found it difficult to turn the rhetoric of going 'back to work' into something meaningful to them.

You are trying to find out what happens to your income and okay, what if you get sick again and your income has been reduced or whatever. Is it going to come back to the same? But I haven't been able to really get the full information. I've been thinking maybe I will try and get hold of the people that can give a one-to-one talk if that is possible.

– *Black African heterosexual woman, taking combination therapy*

I mean there is a lot of talk in some of the papers about going back to work and things like that. I think there is a definite need on my part to assess where I am now in terms of state benefits. If this physical improvement is to be sustained then as I approach 40, to what extent is there something else out there for me to do? For the life of me I can't see it. It looks incredibly complicated and difficult and every time I try to approach that subject, in terms of either thinking about going back to university or thinking about

doing something, it gets incredibly complicated and I get these red warning lights that say, 'Hold on'. I think I have very definite need at the moment for some guidance or advice or support in relation to that. Even the counselling aspects of it are going into that in terms of assessing your value and where you are going. Very, very complicated and difficult.

– White gay man, taking combination therapy

This participant had pursued a very successful professional career but had been forced to give it up through a combination of illness and discrimination and so now felt that any return to work would have to be in a completely new capacity. He was highly skilled, but no longer felt able or willing to use the skills he had. This sense of changed lives and changed priorities was common: if the experience of HIV changed someone's outlook on life, this was likely to be reflected in their ideas about what employment they could pursue.

I think I would find it hard getting back into a full-time job again. I worked buying and selling computers for companies and stuff like that. That side I've just realised over the past few weeks that things have moved on so much I feel totally lost, totally lost. You can do free courses like at [named local] College so I'm sort of thinking along the lines of doing something like that but I am very fearful of going back into work for a number of reasons. One, because my health is so on and off all the time at the moment I couldn't see myself working, even holding down a proper 9 to 5 job in the near future. And also lack of skills from not working over the past few years. And also the feeling that if I do a job I don't just want to go out and work to make money to survive. It's got to be something that's got to be special or something fulfilling.

– White gay man, taking combination therapy

This man articulates three very different needs: a need for skills and knowledge, a need for confidence in his health and a need for fulfilment in any work he takes on. These variety of needs are typical and illustrate why many participants were finding it difficult to turn a genuine interest in work into concrete progress towards employment. Many were addressing (or thinking of addressing) their needs for skills and experience in different ways, such as volunteering for HIV organisations, going on skills-building courses and studying. However, employability could still seemed elusive – because of their HIV status, the potential for illness, the demands of treatment-taking and the gaps in their employment history.

Lots of participants wanted to work, but they did not want to be forced to work. Even when needs for skills or experience are met, the need for confidence in the future may still be great. Imagining a new future always involves risk-taking, but if the system which encourages risk-taking does not respect the potential consequences if things do not work out, this confidence can easily fail. Overt pressure to return to work, the inflexibility of the benefits system and anxiety about benefit changes all contributed to anxiety rather than confidence.

3.7 HUMAN CONTACT AND COMMUNICATION

The need for human contact and communication was widely felt, but was also very idiosyncratic. For some participants, they were fundamental needs, whilst others lived in relative isolation quite happily. Such differences were a matter not only of personal temperament, but also of how individuals adapted to changed personal circumstances.

The experience of diagnosis typically had an immediate impact on participants' needs to talk to others, and finding people who would understand living with HIV became a priority. Many of

the African women described finding themselves in need of support precisely because their established pattern of human contact had broken down irretrievably following disclosure. Their need to talk about having HIV was directly in conflict with their need to sustain relationships with their existing networks.

Yes, I had to cope by myself. But deep down it was hurting so much, it was hurting. In the end I had to tell my friends because I couldn't cope just laughing when I didn't mean it. I told one friend and she was just shocked but didn't say anything. Another aunt of mine, she just cried. It was more like silence, you know, you don't say anything anyway. Maybe afterwards they must have thought, 'Why is she even saying it?' But to me it was like relief bringing it out. Later on I started to wish that maybe if we could talk more about it. But this maybe was because nobody had any knowledge about anything else to say. They just waited for you to die.

– Black African heterosexual woman, taking combination therapy

Feelings of isolation and loneliness were expressed across all the sub-samples in the study. They were caused by a wide variety of problems: leaving work, having limited financial resources, living with illness and disability, caring for others (including children), lack of personal confidence, anxiety about discrimination and refusal to accept professional and community views about HIV. In the following example, poor housing, illness, displacement and fear all contribute to (and are compounded by) the experience of loneliness.

Yes it was hard because when I was in the hostel I was lonely. I was lonely, I had that problem, I found myself sick. I had no pain or illness that was bothering me, I was just okay, you know, but just being alone and thinking about it affected me. Maybe it was loneliness that affected me even more than the HIV itself. I was lonely because I had come in this country without knowing anybody. I left my children in Africa so I was just imagining myself, 'I'm going to die here. My children are not here, my people...' It was like running from danger and you are getting into a more dangerous situation by knowing the state of me so it was more scary. I don't know, I managed to cope you know. [laugh]

– Black African heterosexual woman, taking combination therapy

Those who came to lead more isolated lives typically had a sense of what they had given up, but differed in their sense of regret for these losses. For some, isolation meant loneliness and the need for human contact remained acute. For others, isolation was accepted, in some cases even welcomed, as personal perceptions of the value of relationships and the need for human contact changed.

The impact of combination therapy on the need for human contact and communication has been to fulfil some immediate needs, but also to generate new ones. For some participants, being healthier made it easier to meet people but so created new needs among those who had previously lived quieter lives. As the opportunities to get out, socialise and make fuller use of time increased, the need for a social network became more pressing. Those without such a network could find the prospect of rebuilding one quite daunting.

I've been thinking about going out on to the club/pub scene but I'm very 'iffy' about that because I've been off it for a long time and I know what it's like and it's not always the best place to meet people. I am starting because of feeling physically fit, much stronger and fitter, wanting to start to play some sports again and thinking that if I can get involved in maybe a badminton club or tennis club or something I might start to meet people that way. But it's a strange thing and there's an age factor because I've

turned 40 since and that's turning me against going back on to the gay scene because it's very age discriminatory. It's difficult at this stage in life to think about meeting people. I've thought about HIV support groups or Body Positive support groups and maybe that might be an answer in one way but again, it's quite difficult to make the first step of going to place like that. It's quite difficult to walk into a crowded room of people on your own to be maybe left alone. There is nothing quite as lonely as that. [laugh] Like going to a disco every night. If I've felt extreme feelings of loneliness it's been mostly in places like Heaven or large night clubs where you are on your own.
– *White gay man, taking combination therapy*

This pattern of increasing need with increased health was reflected in different ways by several participants. Several of those who had established regular contact with self-help groups felt that these links were even more important to them at a time when the future held both more promise and more risk.

3.8 SUSTAINING PARTNER AND FAMILY RELATIONSHIPS

Families are traditionally considered to be central to the way individuals pursue their lives, defining and meeting a wide range of needs and providing security and stability. Those who have a high level of personal investment in partner and family relationships can find that these relationships dominate their needs, particularly at times of crisis. Of course, many of those living with HIV in the UK do not live in traditional family units or have seen their families disintegrate. Understandings of 'family' were radically different across the participants in the study – and many did not choose to use the term for their immediate relationships.

Intimate relationships are often fragile and the strength of feeling that sustains them can all too easily be corrupted: affection, care and love being displaced by equally strong feelings of resentment, anger or jealousy. The experience of disclosure to partners after diagnosis was usually met either by immense support or by a reversal of support – there were stories of denial, rejection, violence and loss. Those who struggled to sustain relationships under such circumstances were shouldered with substantial extra needs at a time of personal crisis. In most of these cases, relationships had to end.

It affected my relationship with my partner quite significantly. Not just on the safe sex side of things. He couldn't deal with it really. He kept saying things like, 'It's okay for you – you are not going to be left on your own'. He couldn't deal with it more than me and two years later we ended up splitting up because of that. I was quite resentful because it sort of held me back again with dealing with it because all I kept hearing was, 'It's alright for you'. Those actual words came out of his mouth.
– *White gay man, taking combination therapy*

Some participants had been living with HIV for very many years and so had had time to re-evaluate their relationships and build new ones if necessary (and where possible). Although everyone talked about the role of partners in their past, only a minority had partners at the time of interview. Relationships still created ongoing needs, but these were not usually dominated by HIV. However, two women had partners who did not know about their status, for whom the risks of disclosure from treatment-taking or through illness or side effects caused problems.

Unlike relationships, families can rarely be built anew from scratch. Consequently, the impact of an individual's diagnosis on their family was usually permanent. Family relationships were rarely ideal prior to diagnosis. Most of the gay men were displaced from their parents and siblings and

had relatively little contact with them (if any). Although some still valued the family contacts they had, family life was not experienced or sought as the dominant framework for daily living. However, precisely because of this distance from family, these participants were protected from the impact of disclosure to them. In general, the gay men who talked about current relationships with other family members described their role in positive terms.

Family life was much more of a concern for the Black African women. Most had experienced multiple challenges to their family relationships: not only from diagnosis but also from displacement and bereavement. Following diagnosis, some had experienced rejection or silence, others tremendous support. But families were, or became, scattered – most women had close relations living in Africa and few could turn for support to parents or siblings in London. For some of the African women, fear of the disintegration of family relationships profoundly inhibited their willingness to disclose their HIV status even when it was necessary in order to access services.

The participants with a history of injecting drug use rarely had much contact with their families. Once again, displacement from family was a common feature of the stories told: most had come to London – often from Scotland, Ireland and Italy – either to escape the problems where they lived or to seek help. Those who continued to sustain their family relationships encountered the same struggles and surprises as anyone else.

I talked to my sister, of course, being herself positive she was also very supportive with my daughter. But I waited a couple of years to say to my mum but she took it very well. Surprisingly, also to be a person without any study, without any degree. She's been very supportive. She's never, never make me feel uncomfortable in her home.... She was very, very good. With my mother no problem at all. My brother, when he knew that I was positive.... I waited three years before to say to him. When I say to him this from that time he don't speak to me any more, absolutely.

– White heterosexual woman (current IDU), not taking combination therapy

Those participants who were looking after children had a whole set of further ongoing needs which could easily come to dominate all aspects of life. Child-care needs were greatest when they were compounded by personal health needs – looking after children when also coping with illness or the side effects of treatment could be overwhelming. But children were always the priority.

Maybe if I am not well, because sometimes you can have really severe diarrhoea, the only place now that I can run to that I know I can get help is Mildmay if they have a space. So what I normally do is I just phone my social worker and say, 'Please, I am feeling run down could you book me in for Mildmay. I need to go and have a rest', because they will take care of [son's name]. That's the only place left but sometimes when they are full it's really hard. I know I have been sick on various occasions and they can't get any help for my son. And lately if I have to go to hospital my son has to go to foster care and they can't even find a foster home, you know, like in an emergency, they can't find anyone and they ask me, 'Don't you have any friends?' They ask me to just phone around and ask. I've ended up not going to hospital and I say, 'Let me stay at home because I can't get anyone to look after my son. I'm not well at all! So there have been situations where I have been really desperate and can't get help.

– Black African heterosexual woman, taking combination therapy

Most of the women in the study had chosen not to disclose their HIV status to their children or had only done so when their children were considered old enough to understand. The avoidance of disclosure inevitably created further needs: the daily practical difficulties of hiding

evidence of HIV contributing to the strain of worrying about when and how children would eventually find out and what impact this would have on them. The demands of childcare could also be isolating, increasing needs for contact and communication with others.

Children could also define needs through their absence: the women who were displaced from their children in Africa had to bear a daily burden of loss, sometimes exacerbated by lack of knowledge about their children's health. Those who sent money back for their support were reduced to living on very little indeed.

Combination therapy had, for some, reduced worries about the future of their children. Children became the focus of interest in the future rather than the source of anxiety about it. Nonetheless, for those who were not so hopeful or who still struggled with illness, planning for their children in the event of their own death was a perennial concern.

I hope when I be sick or die to find someone to care for my daughter. This is all that I wish for because my husband is not a person that I can count on. All my effort now with Body and Soul is try to build up a relation with someone that can be there for my daughter. My hope for now is try to find the way to leave behind me a daughter that has got someone that can help her through the life. I don't count nationality, sexuality, job or nothing but good people that really care about her. This is what I want go through now.

– White heterosexual woman (current IDU), not taking combination therapy

3.9 SEX

Sex is not a universal need. Several participants were not sexually active and had no desire to be so, for diverse reasons: the death of a partner; the indifference of age; the effects of heroin or Methadone; the complications of intimacy; the expectations of prospective partners.

Among the those for whom sex still mattered, meeting the need for sex could be anything from the simplest of tasks to a series of considerable hurdles.

If I want sex I just go out and get laid.

– White bisexual man, not taking combination therapy

I didn't have a boyfriend when I was diagnosed and then I decided not to even have one. I just wasn't interested in anyone else. But now I think I am going to get one boyfriend now. What was worrying me was that if I get a boyfriend who is negative should I tell the person or not? Because the thing is with African men, let's say I get an African boyfriend, it's very difficult to explain because they don't trust using condoms. You have to convince them somehow unless you get someone who is really like understands that there is HIV or there is diseases that can be transmitted and people should use condoms. But then life has to go on so I decided that I am going to look for a boyfriend [laugh]. So it only depends whether I want who is positive or negative so I don't know. I would prefer who is positive because he would understand. If I start treatment then I don't have to hide it. Because if you start treatment and then you have to hide the tablets because people want to know, 'Why are you drinking so many tablets?' So I think I would prefer someone who is positive.

– Black African heterosexual woman, not taking combination therapy

Participants in all the sub-samples experienced the problems identified by this African woman: loss of interest in sex following diagnosis, loss of confidence, the difficulties of disclosure to

prospective partners (complicated by pill-taking) and negotiating the use of condoms. For some, diagnosis had brought feelings of worthlessness, contamination or undesirability and the prospect of having to negotiate sex in circumstances where rejection was both more likely and more damaging. Those who recovered their interest in sex usually did so through a broader process of accepting life with HIV (Keogh & Beardsell, 1997). Those who experienced a loss of sexual activity for physical reasons did not always perceive this as a decrease in need, especially if the problem was impotence. Three participants had used Viagra to deal with this problem (with mixed results).

Poor physical health was closely linked to sexual health: changes in body weight or appearance could profoundly affect sexual confidence. If combination therapy delivered increased health and energy (and no debilitating side effects), interest in sex and strength to fulfil the need could all be recovered.

My sex life has always been very high and I'm very promiscuous which is why I got AIDS in the first place and I've always been in open relationships, I've never been faithful. So my sex life went down when I was sick obviously. It went up high again very, very quickly after I started combination therapy and it's been high ever since.
– *White gay man (past IDU), not taking combination therapy*

Unlike this man, most participants found a renewed need for sex could not be easily fulfilled. For some participants, finding a willing partner was a major hurdle in itself, complicated by decisions about disclosure that dominated many participants' concerns about sex. Every possible strategy was described: telling no-one; telling everyone; telling people only when the time was right.

Positively Women were great for that because it was just a place to go and express my fears and my doubts and hear other women doing the same. If you sat in one of our groups, if you were a fly on the wall in one of our groups after about two minutes we would be talking about sex like most groups of women. And it brings it's own problems – How do you tell them? When do you tell them? What do you tell them? Do you tell them? Huge issues that had never really been an issue before.
– *White heterosexual woman (past IDU), taking combination therapy*

Disclosure was always more of a problem for those who pursued sex in the context of potential or existing relationships – including most of the women for whom finding an HIV-positive sexual partner was a common ideal. However, many of the gay men also expressed concern about the impact of disclosure on relationships in which they had a personal investment.

Once the willing partner had been found, negotiation of sex could present its own problems – not least the use (or non-use) of condoms. Those who chose not to disclose but to use condoms had to face the potential difficulty of persuading their partners to use them. Although everyone who adopted this strategy wanted to use condoms, a few acknowledged that condoms were not always used if the other person was not willing. For a few, pressure not to use condoms had been felt even when disclosure had taken place. Two participants described difficulties with the practicalities of using condoms.

Although treatment had increased a few participants' interest in (and need for) sex, its impact was minor in comparison to the ongoing impact of HIV itself. Other than one man who did not accept that HIV was a sexually transmitted virus, everyone recognised the seriousness of HIV transmission and therefore faced the ongoing challenge of getting the balance between disclosure and protection right.

3.10 MANAGING DEPENDENCY

Drug use meets needs and creates needs. Those participants who had experience of drug dependency knew that there was always a trade-off between their need for drugs and their need to control the impact of drug use on their lives. Everyone achieved this trade-off in different ways, some more successfully than others.

The experience of those who became dependent on drugs was very diverse: one man had unwittingly become dependent on Valium through careless prescribing; another felt that the likelihood of early mortality was an incentive to move from occasional ecstasy use to 'trying it all'. Others had long histories of injecting going back to the families and communities in which they had grown up.

Many participants had used drugs as one of the ways of coping with HIV. As drug use is often sustained by social networks, the experience of isolation led several respondents back into drug use. In the following woman's case, the loss of intimacy imposed by diagnosis was resolved at the cost of a return to injecting drug use:

I realised that in reality I was feeling very lonely, that I was scared to be in a relation[ship], also in an adventure, also about the sexual needs. If I go maybe in a clubbing one boy maybe try to know me and many time I have to find excuse. So I found this boy that we was friend from long time – positive. We be together and after 6 months we was together. Because he was fixing I begin to fix myself. Was like, okay you are positive, you cannot stay with nobody that is not positive. And positive was most of the time in the drug environment. It was like without choice. You cannot think you are someone and to have you or choose you or someone that is not in drugs can accept you with this sickness.

– White heterosexual woman (current IDU), not taking combination therapy

Those who had overcome dependency were clear that the break with drug use had been important to their confidence and prospects. But such clean breaks with the past were unusual and reflected substantial achievements. Those who were still dependent on drugs typically wanted to achieve some kind of balance – they did not want their lives to be dominated by the demands and effects of drug use, but nor did they want to live with the pain of total abstinence.

I believe it [Methadone] gets into your every bone. I've tried to come off it and I'm afraid that if I did stop taking it that I would begin falling away and that it is kind of holding me together, you know.

– White heterosexual woman (current IDU), taking combination therapy

The difficulty of managing dependence lay in the fragility of any balance between the need for drugs and the need to cope with their impact. The costs and benefits of drug use could shift with changes in personal circumstances, tolerance of the drugs and the availability and quality of the drugs. It was particularly difficult to sustain a pattern of drug use which was markedly different from that of partners and friends.

Much also depended on the willingness of services to understand and respond to individual needs. The limitations of what services offered could easily exacerbate rather than fulfil the need to manage dependency.

My doctor knew, and I went to her one day and said, 'This is intolerable. I can't go on like this. I need to come off heroin', and I'd actually started using crack cocaine. 'I really need to come off this and I need you to give me a decent substitute'. And she said, 'I'll give you Methadone'. I said, 'I don't want Methadone. I hate Methadone. Methadone is really bad for you. Just give me DF 118s and I can wean myself off, I know how to do it'. She said, 'No you will have to have 60 mls of Methadone a day'. So I went back the next week and she said, 'How are you getting on?' I said, 'Well it's terrible because I don't like Methadone and I'm still using crack'. She said, 'If you do that again I'll take you off your Methadone'. So I went back the next time and said I was fine. And I know that it appears that addicts are liars but I've found that I had to lie. I found that I wasn't allowed to be honest about my problem. They are really not interested in addiction and I find that's just been the way of it.

– White heterosexual woman (past IDU), taking combination therapy

Although drug use did create specific problems for those thinking about starting combination therapy (such as concern about potential interactions), anxieties were in general no different from those of others – distrust in the claims of medicine, worries about side effects, expectations of having to sustain a highly disciplined daily routine. The four participants who had started and sustained combination therapy whilst also continuing to take heroin or Methadone had all clinically done well, but because their drug use was bound up with so much of their lives, changing health had little or no impact on their use of drugs. The need to manage their dependency remained key – it was made easier, but not diminished, by improvements in their health and mobility.

3.11 THE DEMANDS OF MEDICINE

Medicine seeks to meet the needs of those who turn to it, but it also creates needs. Being a patient means interacting with professionals and with the body of knowledge that defines their expertise and power. This requires confidence, communication skills and understanding. Also, the prescription of medical treatment makes very explicit demands – creating an immediate set of needs related to taking treatment correctly and a secondary set related to coping with the (side) effects of treatment.

Not everyone accepts what medicine has to offer – some participants refused to accept the claims of clinical medicine and had little contact with such services. Their lack of confidence in combination therapy was linked to an interest in thinking about health more holistically and appreciating the role of alternative therapies and lifestyle in maintaining health.

However, most were happy to be patients, at least sometimes. The most immediate need created by being a patient was for the time and resources to go to an HIV clinic. For a few, this could not be taken for granted. One man, changed his career because he was not confident that his employer would give him the necessary support. Some of those not in work were also concerned that this might be an obstacle to getting back into employment.

Sustaining a good relationship with a doctor was also seen as crucial. But in engaging with doctors, they had to engage with the language of medicine. Everybody wanted some degree of understanding about their condition and the options available to them. However, very few participants wanted to keep up with HIV treatment information in very great detail. Some also expressed reservations about their own abilities to make critical judgements about treatment choices. But those who were happy to leave things to their doctor were out-numbered by those who felt a need for some control over treatment decisions.

In different ways, everyone was working out how to cope with the uncertainties of HIV medicine. Those who were most critical of the information available were often the most needy because they felt there was nowhere reliable they could turn. Increased exposure to (sometimes contradictory) information could increase need if the main outcome was a loss of confidence in what was being read. Most people had come to some kind of acceptance of these ambiguities, recognising that everything they needed to know could not be known.

THT they have told me I can get into the Internet in their library. I get information. Africare has got quite a lot and the hospital a lot of it also. I don't know, I still think there is something missing... They just try the side effects of most of these medications on us. You either volunteer or you start medication and then they see what happens to you. I think it's a bit hit and miss.

– Black African heterosexual woman, not taking combination therapy

Needs for knowledge about treatment were also defined by circumstances. Those who were taking combination therapy successfully often did not feel any pressure to find out more about their treatment options, although most recognised the likelihood of future changes in regimen. Those who were having problems with their combination were faced with making sense of complex choices but the time of greatest need was the point of first starting combination therapy. Several participants reflected on their lack of knowledge, and the inadequacy of clinical services, at the time when it was most crucial.

The day I came home with that carrier bag full of drugs, I put it away and there is a phone line called the AIDS Treatment Project and I phoned them and they understood completely. And it was great because the doctors were acting as if it was nothing, 'Here are two carrier bags full of drugs, take them'. But the guy on the phone line said, 'Yes it's a huge step'. He asked me what drugs I had and I sat there trying to read a few and he said it wasn't a protease inhibitor, it was one of the more mild combinations and it was fairly manageable. It was four of these very large pills in the morning which I had to dissolve in water and very, very difficult to swallow, bitter taste. By the time you'd had that you didn't really feel like breakfast anyway. But the rest of it wasn't too difficult. I think it was 12 pills during the day but 4 of them were in the morning when you got up.

– White gay man, stopped taking combination therapy

This example illustrates the second major area of need created by medicine: the requirement to adhere to treatments. The personal needs which are created by this requirement are for discipline and organisation in everyday life, fulfilled primarily through processes of planning and remembering. Another man who had no help from his hospital when he was starting therapy described how these needs were met through the simplest of interventions.

I was given all the medicines and came away from the hospital with suitcases of tablets. It's very daunting actually. I would have welcomed if there was a pharmacist there who could have spoken to me. Because I wasn't coping, you know, I wasn't coping with when to take and what to do. I went to my local high street pharmacist and not saying what the problem was just spoke to a pharmacist there and she directed me on the case of the little pill box which I hadn't even thought of and wasn't aware of and I bought one off her for £10 or something and that is the only way I cope with all these tablets. It was perfect – dividing them up into each compartment for the day.

– White gay man, taking combination therapy

The participants who were taking combination therapy had mixed feelings about taking the medications: some found it intrusive and frustrating, others found it quite easy to fit pill-taking into their other daily routines. However, personal feelings about adherence do not necessarily reflect unmet needs. One of the men who expressed the greatest dislike of the regimen was the least needy – he had never missed a dose and organised his life very carefully to ensure that this remained true.

Yes, every day, every day you have to take them. But I think particularly... I think the only thing that it erodes on is my social life. I'm not free to go around doing what I like the way I used to. Like I said earlier on, some people chose to carry the drugs with them. I just can't contemplate doing that. Not for fear that people will see them and put 2 and 2 together. It's just bloody inconvenient. You can't go around carrying pills. Once or twice I have taken them to the gym with me, the evening dose which is just one pill and that hasn't been too bad but it's still something I would prefer not to do. So I think that's the only thing that has changed, the fact that I'm now controlled, my movements are controlled.

– Black African gay man, taking combination therapy

This man had lost some of the flexibility to enjoy the social life he was used to. This was common, especially among those whose regimens had special requirements such as the refrigeration of medications. Although the effect of such changes may initially have been to reduce quality of life, almost everyone accepted their necessity. Realism about the need to take the pills was far greater than regret over the loss of personal freedom to do anything at anytime. Even when the routine of pill-taking became the dominant routine of life, personal perceptions of the possibilities of life were marginally, not radically, changed (although there were some worries about how pill-taking might restrict opportunities for work).

Those who had gained better health were likely to see the inconvenience of pill-taking as a reasonable price to pay. However, for a few, pill-taking became an oppressive requirement which undermined confidence and could lead to anxiety and depression.

4 Meeting needs: making choices

Every individual finds their own personal solution to their needs. There is extraordinary variety in these solutions, reflecting the complexity of the lives in which choices are made. The next two chapters explore the factors which shape these choices and the range of choices made by the participants in this study.

In this chapter, participants' varying approaches to meeting their needs are analysed in terms of four shared concerns. These are best understood as the ways in which participants answered, for themselves, the following questions:

- ▶ Am I willing to turn to others for support?
- ▶ Who do I know whom I can rely on?
- ▶ Is it worth seeking support from people I don't know?
- ▶ Is anyone actually able to understand me and help me?

Although participants asked many other questions, the wide variations in responses to these four go a long way to accounting for the diversity in how they met their needs – over and above the differences in what their needs were.

4.1 ACKNOWLEDGING NEED AND THE VALUE OF PERSONAL AUTONOMY

Willingness to turn to others for support requires both that need is acknowledged and that personal autonomy is not undermined. These issues are usually closely related: those who place great value on their own autonomy may be unwilling to think of themselves as being 'in need', although this depends on how the role of support is perceived.

In recounting their stories of living with HIV, some participants identified occasions in the past when they felt they had not faced their own needs. These retrospective assessments demonstrated the difficulty of acknowledging personal needs. In the following example, lack of clarity about personal need is expressed as anxiety about personal entitlement to support.

I think looking back, in retrospect I had more need than I was prepared to admit or acknowledge and I wish... I wish in a sense that I'd linked into the support, the services, more and I did to some degree. I went to George House [Trust] and places like that to have lunch and... I felt a bit of a fraud. I know that sounds very strange because there were people there who were very poorly and people who'd been in hospital and people who'd lost their partners and things and I hadn't done any of that. All I'd done was been told I'd got this condition and I felt perfectly okay. So in a way I didn't feel I was... I mean I knew I was technically but I didn't feel very confident about asking for help because I didn't think I was in any particular need.
– *White gay man, taking combination therapy*

A similar tension between perception of need and service use is expressed in the following example, although here the tension is less to do with sense of entitlement and more to do with sense of personal autonomy.

Someone comes in and they will wash up or... I don't know, whatever, it's a bit weird especially on a day like this it's like I find it really weird someone coming into my house and saying, 'Okay I'll wash up for you'. But then there are other days when I really can't do anything. It's quite weird. It's almost like an narcoleptic tiredness and I just sleep all day. So I'm kind of more accepting that maybe I do need this assistance at this point but it kind of feels odd. I mean I'm an independent person, always have been, but I think by them coming in will allow me to maintain that independence and keep my energy directed elsewhere other than the menial side of life like dusting and whatever.
– *White gay man, not taking combination therapy*

Those who placed a high value on personal autonomy were not necessarily people who resisted turning to others for help. Willingness to accept support depended on whether doing so was perceived as increasing dependency or as a means of maintaining independence. In practice, getting support from other people, particularly services, requires some acceptance of dependence, even if this is rationalised in terms of maintaining independence. A shift between these two ways of understanding need and autonomy could have a major effect on how someone went about meeting their needs.

4.2 THE AVAILABILITY OF FAMILIAR AND RELIABLE SUPPORT

Familiarity, reliability and accessibility are always important to people seeking help. When in need, most people turn first to those whom they know and can trust, those with whom they have some history of mutual care. Partners, family and friendship networks can offer immediate support post-diagnosis, but the experience of living with chronic illness creates different support needs. Services which initially seem hard to access may in time be perceived as the best places to turn, particularly if their reliability has been demonstrated. Many participants knew nobody else with HIV at the time of their diagnosis and had little or no contact with services. However, both services and other people with HIV come to feature prominently in most accounts of support received.

The accessibility of even the most valued sources of support may always remain a problem. Serious illness at home was the most common context of this: a time when access to almost all forms of support decreased. Partners and close family were often the people who offered most at such times.

Well a lot of the services are very difficult to use if you couldn't go to them, you know, like FACTS is in Crouch End and when I was well enough to drive up there I would go up there but often I would just sit on my own and struggle through a morning and I couldn't cope with it because it was very noisy and there were lots of people gossiping and chatting which is fair enough. I relied a lot on my mother who would drop everything and come down and stay. I really, really missed not having a partner then. When I was poorly I wanted a partner very much just to be around and make the cups of tea and talk and watch television with. I hadn't built a very strong friendship network in London and some of my friends lived a long way away geographically and were also still working all the time and busy so I did feel a bit isolated really.
– *White gay man, taking combination therapy*

Similarly, those who experienced severe side effects from treatment sometimes found that their familiar network of support – both informal and formal – was not as accessible (and sometimes not as reliable) as they had hoped.

4.3 THE OBSTACLES TO ACCESSING UNFAMILIAR SUPPORT

Most participants had, at some point, looked beyond their immediate and familiar sources of support to people and places they did not know. Some did this straight after diagnosis, either because they had no-one to turn to or because they were confident they would get help elsewhere. Others only faced the obstacles of accessing unfamiliar support when their circumstances forced them to do so. These obstacles could be considerable, and those who perceived them as such usually tried to cope for as long as possible with the support which they knew they could rely on. One of the African participants gave a graphic account of why this had made sense to her, until her circumstances changed dramatically.

I came to be diagnosed after I just had my baby. We are both very sick and we were also in hospital. At that time I was alone, just me and my baby. It was very difficult. Then my mum came over as well from Africa for support. I was very ill and she was taking care of my baby... So it took a lot of time for me to access all the support groups because I was relying basically on my mum. She was all I wanted. When they were trying to tell me, 'Oh there is places you can go', but I didn't want to go then. I have a sister as well but she wasn't my main support but my mum stayed with me all the time... She gave me a lot of support at that time. I really didn't feel I wanted to go anywhere else. I didn't want to see people so I really just wanted to be at home.

Unfortunately, I lost my mother on the same year. It was really hard because I was so much depending on her and she just collapsed and died. Then I started getting help from.... You know, so many people got involved because she was well known in the hospital, that she was always my supporter. That time was when I started accessing the groups. At the hospital they said, 'You can't cope, you have to have help for you and the child and family', and that's when I started getting support.

– Black African heterosexual woman, taking combination therapy

Of the many obstacles to accessing unfamiliar support, lack of knowledge was the most basic. All participants had been diagnosed with HIV in a clinic where most had been given some basic information about other services. Many of the gay men had also benefited from the coverage of services in the gay press and the more established knowledge about HIV among their peers. Those who had experienced the greatest isolation had not known of the existence of the most basic forms of formal support available to them.

I left my job, lost my home. I didn't know anything about services and benefits at the time so as far as I was concerned I couldn't work. I left my job so there was no way I could pay my rent so I moved into a squat. It was terrible, terrible. It was all burned out. There was one socket in the whole place, no fridge and no stove. All I had was a mattress on the floor and that was it. It was one of the worst years of my life.

– Mixed race gay man, taking combination therapy

Despite such experiences, worries about the outcome of seeking support from unfamiliar people or services was almost always a bigger problem than lack of knowledge of where to find support. Never knowing how a new friend, a prospective partner or a service would deal with disclosure about HIV limited the opportunities to build new networks of support. Finding new friends who understood about HIV was perceived to be an almost impossible task within African communities – hence the popularity of peer support groups where mutual need secured mutual understanding. Building new relationships was perceived by almost everyone to be fraught with difficulty, principally because of the problem of disclosure, but also because of the longer term strains of coping with HIV in a relationship.

In making contact with services, the problem of disclosure was essentially a problem of confidentiality. Once again, it was the African women who were most concerned about the possible negative consequences of an ever wider range of people, both service providers and service users, finding out. They were not only worried that people would talk, but that they would encounter people they knew, including members of extended families.

Like there is the group which is just up the road and I find that extremely difficult to access because it is down the road from my daughter's school. That's a very practical problem I've got there and I would be absolutely terrified that one of her friends would see me walking in there and I think that is a big problem for women that they don't want to go there in case somebody sees them. I didn't want to go to any of the local services in case somebody was working there that knew me. It took me a long time to find a doctor because I was really scared that the receptionist might be my neighbour's cousin or something because although London is a big city it's quite a wee village around here and people live and work locally and that really terrified me. Finding a dentist scared the shit out of me.

– White heterosexual woman (past IDU), taking combination therapy

A number of women described the important role that peripatetic workers had played in overcoming their fears about going to self-help groups. Talking to someone in hospital or at home had been crucial to gaining the confidence to enter the unfamiliar world of self-help and voluntary services.

When I went for my results and they gave me my results I had a bit of counselling and the lady told me about Positively Women but I didn't go there immediately. It took me time. I used to think, 'If I go I might meet somebody I knew'. But the lady told me that only people go there that's positive. But still it took me about 6 months because I called them once, spoke to them on the phone and they asked me to come but I didn't go. So they visited me twice at home just to encourage me to come to the group.

– Black African heterosexual woman, taking combination therapy

One-to-one advocacy of this kind was valuable not only in securing confidence in the services, but also in improving self-confidence. Many participants had suffered losses of self-confidence following diagnosis, through illness, isolation, rejection, violence or through loss of direction and certainty in life. For several participants, self-help groups had played a key role in building personal confidence, leading to increasing service use. Similarly, improvements in health could enhance self-confidence as well as mobility, and thereby increase use of services.

4.4 THE QUALITY OF THE RESPONSE

Judgements about the quality and effectiveness of individuals and services in meeting needs inevitably affected the choices participants made. These judgements encompassed a wide variety of concerns but were dominated by two closely related issues: sensitivity to personal need and the demands made by others.

Sensitivity to need, characterised by attention to the individuality of need, was a quality which was highly prized in all who experienced it. When someone took the time to genuinely listen and understand personal needs, the rewards were great. Partners and other close relations were both the best and the worst at this. The interdependence of close relationships could mean that changes in individual need were not properly acknowledged by the other – sometimes resulting in these needs being exacerbated rather than alleviated.

Failure to attend to the individuality of need was often perceived as a fault of service providers. The promotion of a particular view of the world by providers, and above all a particular view of the importance of combination therapy, could have a severe impact on perceptions of the value of the service and confidence in it. Those whose experience and attitudes matched the expectations of the service providers fared well, but there were many divergences from these expectations, large and small.

**So I phoned the National AIDS line and said, 'I've been given an AIDS diagnosis', and they went, 'You mean an HIV diagnosis.' 'No, I've been given an AIDS diagnosis today', and they were going, 'An AIDS diagnosis?' And it was like, 'Yes! That's what you are there for – to understand me – shut up! Yes I've got an AIDS diagnosis'. And all they could do was like, 'Well combination therapy then'. No that's not... I just needed to be able to talk through the pros and the cons of taking combination therapy because I'm so confused, I'm so lost now. I've been confused by the hospital. So everywhere I went to access some information – I contacted Body Positive, I wrote and got the National AIDS Manual, Treatment Updates and stuff but again it was all very... I was just more confused by then. I don't know what to do. The medical team who is looking after me is saying, 'take it'. I'm not sure if that's the right thing for me at this point. I think what would help me would be for someone to understand where the fuck I'm coming from and actually say, 'Yes I understand why you are not taking combination therapy and that's okay. However, maybe later we will have to look at it again'. I just want someone to say, 'Yes we understand why you are not taking combination therapy'.
– *White gay man, not taking combination therapy***

For some, the demands made by services were explicit and discriminatory. A woman with a history of injecting drug use expressed the impact of such demands on her attitudes to services.

**I had to see a probation officer and she had to write a probationary report for me and all she said was, 'If you refuse to go to drug rehab then I will suggest that you get five years in prison'. Oh well that's really helpful, 'Okay I'll go to a drug rehab'. That's not how you help people. That is not how you help people. So she was absolutely no good. I said to this social worker at St. Thomas, 'I really need a pair of shoes for my daughter'. And you'd think she was giving it to me out of her own money, out of her own pocket, and she was like, 'You are not going to go and buy drugs with this are you?' 'For fuck's sake no! I can get my money for drugs somewhere else. I need this for shoes'. And that kind of help is no help.
– *White heterosexual woman (past IDU), taking combination therapy***

What mattered to most participants was not that a service provided exactly what they needed – they recognised that any service could only do so much. What was important was that providers respected them as individuals, did not make assumptions about who they were, took the time to listen and understand, and were patient and flexible. Experience of an environment where no demands were made came as a shock to a gay man, who had plenty of experience of service use, when he started attending meetings of the Society of Friends:

Somebody who is there fairly often said, 'The thing I like about you is you are always smiling', and I thought 'my God'. And in some ways it's true because it's a group of people that make one feel incredibly relaxed but I think the shock was that I didn't realise it showed [laugh]. I mean part of it is no demands are made on you and there are actually very few groups you could actually join in this life where there are absolutely no demands. It's one of the few bits of my life I've never had demands made on me and I was terribly reassured. You see you make demands on yourself and other people make demands on you and so there my experience is fairly unusual.

– *White gay man, taking combination therapy*

Those services which provided opportunities for peer support, and so let people get on with meeting their own needs, were more likely than more formal services to be perceived in positive terms. However, there were lots of examples of professional-client interactions succeeding because of the sensitivity of the professional and the ensuing sense of shared power in the relationship.

They can give you the best service when they do their job with their heart, with their mind, with the proper attitude that don't make you feel small. I've found many good people really and they make a difference in my life.

– *White heterosexual woman (current IDU), not taking combination therapy*

This chapter has highlighted the practical and personal challenges involved in seeking and asking for help. Even those participants who had no difficulty making new friends and accessing services still had to consider what it meant to them to get support from others. It is therefore not surprising that all participants valued responses which respected their individuality and made few demands of them.

5 Meeting needs: the choices made

This chapter describes who and what was important to the participants in meeting their needs. Given the different ways in which participants answered the four questions explored in the last chapter, their choices were inevitably very diverse, ranging from total self-reliance to routine service use.

5.1 SELF: MEETING YOUR OWN NEEDS

People living with HIV meet most of their needs on their own, most of the time. Exceptional circumstances include acute or respite care away from home when 24 hour support is available for most daily needs. Admission to hospital, in particular, involves giving up personal autonomy and control over the routines of daily life – an experience which can make people aware of how important this control is to them.

Those who were economically independent were typically more focussed on meeting their own needs than those who were dependent on welfare benefits. Those in paid employment had the greatest resources with which to manage their lives and meet their needs, but financial resources were seen as only one of the benefits of employment – it was the sense of autonomy which mattered most. At the other end of the economic spectrum, there were some participants who did not receive benefits and had to struggle to get money wherever they could. They usually had an acute sense of the importance of self-reliance.

The doctor I was seeing at the time was a real bastard actually. He said to me, 'Well if we are going to finance this combination thing they can't afford to give benefits as well; which is a bit of a dubious thing to say [laugh]. He happened to mention that a lot of people were thinking about going back to work and I said, 'Yes that sounds okay'. So I lost the benefits outright and I had to re-apply with a burden because I'd already had them taken away from me. That took about 11 months but I did eventually get them back. Luckily enough I had about £1,200 saved and I started getting into things like the gym so I paid for the gym for a year and I went to the gym every day. I lived on £64 a week, gave up drinking, gave up smoking, gave up going out, socialising, living almost, and went on a very strict regime, very strict diet. And I just thought, 'Throw yourself into the gym! I got very, very big and all that and it was just like a religion. I thought if you could hold on and get the money back it would be okay so I just got very self disciplined.
– *White gay man, stopped taking combination therapy*

Many other participants described how they had been forced to draw on inner resources in adverse and often unexpected circumstances. If there was no-one to turn to, or those to whom they turned to failed them, they had no options other than to find strength within. For some, this was empowering, but for others, experience of rejection or ineffectual services lead inexorably to a self-reliance which was isolating.

I tried a couple of different groups but quite often it was me, three gay men and that was it. I learned I could do without the groups. The thing is you just wake up every morning. I think you have an idea when you are younger that if you really give up in life then you just quietly die but you don't, you just wake up and wake up and wake up and that's it. It was then that I realised that I had wasted 10 years waiting to die. But the longer it went on the more pathetic it was.

– *White heterosexual woman, not taking combination therapy*

Everyone living with HIV must draw on internal resources to meet the particular demands of coping with the disease on a daily basis. Whatever the other circumstances of life, everyone had to rely on their own motivation to get up every day and get on with life.

All the rest can help but with a big gun at the back it's me that has to be with it, it's me that's got to trigger this thing and this body. Those other things can help but at the end of the day it's up to me and if I don't.... I mean the doctors can give me all those tablets but if I don't take them then they are not going to help me so everything comes back to me and that's the way I see it.

– *White gay man, taking combination therapy*

The importance of self-motivation to take the tablets was widely expressed. Everyone taking combination therapy was well aware that it was down to them to get on with the daily business of pill-taking. Adherence to medications had to become as integral as all the other routines of daily life.

5.2 PARTNERS, FAMILY AND FRIENDS

A minority of participants had a partner at the time of interview, and only a few of these described their current relationships as being central to how they met their needs. Those who had sustained relationships through diagnosis and the multiple adjustments of living with HIV were most likely to turn to their partners for support.

Who has been most important to you?

My partner because... I don't know how to put it without it sounding silly or over romantic. Well he's my reason for living really so that's the most important thing. I sometimes think if it weren't for him I would have been tempted to think, 'Well, what's the point?'

– *White gay man, taking combination therapy*

For most participants, such a relationship was something to dream of. Most had experienced the failure of relationships, often because of the impact of HIV, so wariness was common. When opportunities arose, and new relationships offered the possibility of real fulfilment, they were treated with considerable care.

I'm happy, very happy, he's very nice. I met him through a magazine – Positive Nation. Very nice, I've met his children, he's very keen on us living together but I'm taking everything slow, a day at a time. He's very nice, loving, very kind.

– *Black African heterosexual woman, not taking combination therapy*

The impact of HIV diagnosis on family relationships varied considerably. However, the passage of time had usually seen some resolution of the impact of diagnosis and disclosure. Most participants knew where which family members they could turn to for support. For some, family members had no role to play in meeting their needs or created more needs than they resolved. But for others, family members who were supportive after diagnosis – and who remained

accessible – often proved to be very important, particularly in times of great need. Although their contributions to meeting need were often intermittent, it was the reliability of their support which mattered.

Many participants identified friends as having been, and continuing to be, important sources of support. Given the extent of displacement from family, friends were sometimes perceived to fulfil the role that family members would traditionally play in responding to crisis. Friends were also be crucial where services failed.

I told these other people, my brother and I've got a good group of friends. I've got very, very loving friends in Uganda and here. I told them, you know, friends you can confide in and trust. You don't want to tell many people. But you see, in the final analysis eventually it will be known. Suppose I get spots and I get rashes, your friends will know eventually, your family, your friends will get to know so I think it's best to tell people you trust early enough so that they are able to accept it. Very supportive, my friends are very supportive, they really are.

– Black African heterosexual woman, not taking combination therapy

Although friends often helped meet social and emotional needs they rarely became carers. This was a boundary which was typically only crossed by certain family members – particularly mothers and partners. Some participants also felt that there was a limit to the support that could be expected from friends and that care had to be taken not to make too many demands.

As with other relationships, the experience of diagnosis and learning to live with HIV had changed many participants' attitudes to their friendships. Almost all had built new friendships following their diagnosis, usually with other positive people. In many cases, friendships had begun with contact through services, such as drop-in centres or support groups, which could be seen as the only places where they were able to meet people in whom they could trust. Other positive people often played a crucial role in supporting the process of learning to live with HIV (see self-help groups, below).

5.3 SERVICES

AIDS service organisations and statutory HIV services are set up to meet the needs of people with HIV. But whatever needs an organisation sets out to meet, those who use it will make their own judgements about its function and value to them. The next chapter explores in more detail the ways in which individuals go about using services and their reasons for doing so.

A very wide variety of services were used by the participants including HIV (GUM) clinics, social services, advice and advocacy services, self-help groups, drop-in centres, newsletters, counselling, childcare, complementary therapies (of all kinds) and drugs and rehabilitation services. This section describes in brief only those types of organisations which a majority of participants had used and which were typically used on an on-going basis: clinical services, self-help groups and information resources.

5.3.1 Clinics

The only service that almost all participants used regularly was clinical care, and this was always principally through a specialist HIV clinic rather than through a GP. Very few participants were not in regular contact with a clinic, all of whom felt that Western medicine could not adequately meet their health care needs.

Those who did use clinical services had done so, in the first instance, for HIV testing or treatment of illness. Maintaining health remained the principle purpose of using clinical services, although other needs were also addressed in some clinic-based services. However, because illness and treatment could impact on many other needs, the sometimes limited horizons of some clinic staff came in for criticism.

I wasn't happy with the way that they dealt with it. The clinic at the time was really based on diagnosis rather than giving you information on basically how you would feel mentally, whatever, physically. I think at the time they were just geared to giving you the drugs and letting you get on with it.

– White gay man, taking combination therapy

Most participants felt their clinics did more than this, but the dominant focus on physical health did not always leave time to address the other needs which treatment could affect. Those participants who had used health advisors and counsellors in clinic settings all valued the role they had played in addressing their wider needs. However, there is always likely to be a tension between the breadth of the impact of clinical services and the extent (in terms of needs addressed) of the services they provide. In general, participants were happy with their clinical services and recognised the value and limitations of the services they provided.

5.3.2 Self-help groups and centres

Self-help groups and centres helped participants overcome adversity and isolation – they were places where human contact and communication were gained both for their own sake and to ease the doubts and anxieties of life with HIV. Almost all of the women in the study used drop-in centres and support groups, and the accounts of some of the African women were remarkably similar to accounts from gay men earlier in the epidemic.

I think the support services are important because it helped me a lot when I met other women who were positive. I would not have listened to anybody else who was not HIV positive. It helped me to talk to somebody else in the same situation. I think that kind of support helps a lot. It just showed me that there was a life after HIV and it just showed me that there were other people living with the virus and getting on with their lives and it wasn't the end of the world. There was a point where I used to think I was the only woman in London living with the virus. I am sure a lot of people must have felt that. But just seeing other women living and seeing them carrying on so that kind of support.

– Black African heterosexual woman, not taking combination therapy

For many of the women in the study, self-help groups were the only places where they felt comfortable disclosing their HIV status and so were often the only opportunities to build new networks of informal support. In general, the gay men in the study were not as reliant on these services as the women, typically having a wider range of alternatives. However, facilitated contact with other positive people was still widely perceived to be important.

I got social support and it was like a safe environment for me to talk about my HIV. I mean I couldn't talk to my friends because they didn't know where I was coming from. I was worried about employment, I was worried about getting ill, I was worried about medication, and going there I could just air my views and there were people there on medication, there were people there who had been recently diagnosed like myself and I met friends I could talk to and I could ring up and say, 'I'm feeling really bad today', or, 'I'm feeling really down'. We got support off of each other.

– White gay man, taking combination therapy

The needs addressed through these services are described in a variety of ways: emotional support, social support, understanding, friendship, nutrition, information. Those who were taking treatment indicated that such needs had intensified around the time of starting combination therapy when sharing knowledge and experience with peers was particularly valuable. The particular methods used may have varied – ‘newly-diagnosed’ groups or courses, regular lunches and evenings at support centres, daily drop-in centres, facilitated support groups, volunteering – but at the heart of each method was always direct contact with other positive people. These services succeeded because of the flexibility of their approach and outcomes: participants could bring a variety of personal needs and negotiate their own way of addressing them.

Not everyone felt that peer support was a good way of meeting need. Participants from each sub-sample expressed reservations about the potentially competitive effect of sharing information about health status and treatment results. There was also some concern that use of support services could lead to HIV taking too prominent a place in daily life and undermining self-reliance (a problem which was also acknowledged by some of those who used self-help groups). In fact, it was in the self-help groups that tension between the two different understandings of what services did – increasing dependence or maintaining independence – was most acutely felt.

5.3.3 Publications and information services

Almost every source of help that participants turned to had a role in providing information, including partners, families, positive (and other) friends and acquaintances, doctors, nurses, counsellors and other professionals. Information is a service which most people and organisations are keen to provide.

Within their accounts of information-gathering, participants also mentioned organisations or publications whose purpose was HIV information-provision. These were almost always valued, although they were never the sole component of any approach to gaining knowledge. Published information was complemented by interaction with friends or professionals, especially if the subject was treatment.

I was a bit scared to go on it [combination therapy] so I gathered some information. So I was going to groups, talking to some people, so after finding out some information then the doctor also gave me a lot of things to read but I had to talk to people and find out more. So after that I went back to him and decided that I was ready to go on it.
– *Black African woman, taking combination therapy*

Use of information was usually characterised by this kind of exploratory approach. The needs which information addressed – for knowledge, understanding, confidence and clarity of purpose – required a process of comparison, criticism and discussion. The complexity of treatment options, the lack of any guarantees for the future, the disputes about HIV and the nature of AIDS, and the lack of consensus between different sources of advice all contributed to a degree of caution in the use of publications and other information services. Most participants felt that responsibility for any understanding and decision-making had to be shared (usually with a doctor). This was crucial for those who found the published literature too technical or who struggled to make sense of their own personal circumstances.

With a need for information came a number of anxieties – of never being sure who to trust, of always having more to read, of having to keep up with a rapidly changing field, and of having to

make choices between very different interpretations of HIV medicine. These anxieties were greatest among the participants who had chosen not to start combination therapy, for whom the process of questioning and exploring information often diminished personal confidence and clarity of purpose. A few found confidence in a rejection of the world-view of Western medicine, but most struggled on, trying to make the best sense they could of the complexity and contradictions they encountered.

5.4 OTHER SOURCES OF SUPPORT

A disparate range of other sources of help and support were identified by participants as being important in meeting their needs.

Religion was very important for several of the African women, expressed either in terms of the value of contact with other Church members or in terms of a spiritual relationship with God. One of the gay men also identified the Society of Friends as playing a central role in his support network, displacing the formal support services which he felt had consistently failed to meet his needs.

Drugs had a place in the accounts of many of the participants, not just those with a history of injecting drug use. Although managing dependency could be particularly difficult, this was precisely because drugs could be so effective in meeting immediate needs for well-being.

But I try many time [to give up drugs] because I have a daughter and I have nobody else in the world and I live for her and I care for her. She's in the first place in my mind. It's sometimes you don't want to feel pain anymore and it's a much more easy way, you know, just drugs. For me drugs is not for fun. For me drugs is just for a moment not to feel under pressure with my feeling and just be like this, you know.
– *White heterosexual woman (current IDU), not taking combination therapy*

Heroin does what I want it to do to a point. It just stops me from being in hell.
– *White heterosexual man (current IDU), taking combination therapy*

Only one participant identified her cats, as being important in meeting needs. For her, however, they had been and continued to be absolutely essential to her well-being:

Who or what has been most important to you?
The cats. I couldn't have got through it without them.
– *White heterosexual woman, not taking combination therapy*

6 Using services

6.1 EXPLORING SERVICES

Services are one of the ways in which people with HIV meet their needs, playing a crucial role for some and a relatively minor role for others. But services are not simply mechanisms for meeting need. In practice, they play a more complex role in people's lives.

Service use is easily conceived as a rational process in which individuals with specific needs identify and access the services which best meet these needs. Some providers, such as social services, formally adopt this model by assessing individual needs and creating care packages designed to fulfil them. The following personal reflection on service use illustrates this rational ideal.

The HIV support worker at Citizens Advice was brilliant in helping convince me that I should apply for DLA [Disability Living Allowance]. So he helped with all the forms and what have you. The counsellors helped me deal with issues with the relationship and where I am with HIV. Body Positive has helped me meet even more people even though I find myself in a little group of friends that stay talking to the same people every week I go. Each one has filled each kind of need. I've needed each one.
– *White gay man, taking combination therapy*

The explicit matching of needs and services in this example is extremely unusual. For most participants, service use was much messier. Personal needs are often poorly understood and poorly articulated; and the needs which services are supposed to address are rarely transparent to those who approach them. In general, the process of using services may not be perceived by service users to be about 'meeting needs' at all.

A lack of clarity about need or what services are for is not necessarily a disincentive to using them. Services were accessed for lots of reasons beyond immediate need: because participants feared being needy in the future, because they wanted to find out what was on offer, because they wanted to find out what they were entitled to, because they were curious, because they were bored, or simply because they could. For most participants, service use was a process of exploration: trying things out, seeing what worked (for whatever reason) and finding out what else might be worth trying.

I did visit St. Thomas' and there's a very good GP there who was doing some secondment work. Then I accessed some counselling at ICARE. I remember that when I was working because it had to be first thing in the morning. But I didn't like it so I stopped going. I started to go to FACTS sometimes but really just generally in the evening but I also wanted to be linked in somehow because I thought it was going to get worse and it would be nice to somehow join these things. I did things like join BP although I actually never went there. I just sort of joined up so I could get their newsletter.
– *White gay man, taking combination therapy*

This description of service use may seem fairly haphazard, but progress is made. Finding a range of services which worked was a task which inevitably involved trial, error and compromise. The task usually paid off: participants developed patterns of service use which worked well for them. The match between personal need and services improved, although the needs participants brought to services were often very different from those which the services were aiming to meet.

Even when there is a clear match between an individual's need and what a service claims to be for, the actual process of engagement may still be quite different from what the service provider anticipates. In the following example, a man with an explicit need to deal with his heroin use describes how he aims to do this by using up his dangerously free time in using services, regardless of what is actually on offer.

I've got a lot of time on my hands at the moment and I don't see too many people, you know, it's been a bit of a battle of wits in my head to stay away from illegal drugs. I could do with some extra money coming in so I'm kind of like looking for part-time work or even voluntary work just to be busy to keep me out of the house so basically I'm not sitting around my flat with too much time. I occasionally drop into the needle exchange and you can also go in and they give you like special teas and stuff and detox teas and they will talk to you for a while so occasionally I will drop in there. Like I was saying, hopefully if I can stick it out the next few weeks and then get myself into the Core Trust that will be really good because I will be busy like 9 to 5 seven days a week and I think that will help a lot. I do actually have a friend who lives around the area and he had a problem with heroin as well but he's been clean, like totally clean now for a year, and he goes to a lot of NA [Narcotics Anonymous] meetings. And even though I'm not really... I don't really adhere to the philosophy of NA but you can get different things from going to stuff like that so yes I will probably start maybe one or two evenings a week going to NA meetings and stuff.

– White bisexual man (current IDU), not taking combination therapy

The extent to which any individual succeeds in finding appropriate services varies enormously. Whereas some participants were creative and critical in their use of services, others simply took whatever was available in the hope that it would help. It was not easy to tell from participants' retrospective reflections how appropriate and useful their individual approaches to using services had been.

People with HIV may be creative in how they used services to meet their needs. But it is also true that many services were creative in how they shaped the service-using behaviour of their clients. In the following example, the participant's pattern of service use is principally determined by the skills of the providers in developing her perceptions about the value of services.

When you are newly diagnosed you don't even know what to do and you are scared of the groups because it is your first time. When I went to Landmark, the lady that was in charge took my number and then the following day she phoned me in the morning and she asked me, 'How are you? What are you doing at the moment?' I said that I was still sleeping. She said, 'Ah well I will call you later'. She phoned me in the afternoon and she said, 'Have you been out?' I said, 'No'. And then she said, 'Can you come to Angel to the office of Positively Women?' I said, 'I will try'. So I went there in the afternoon and we talked. She said, 'I am sending somebody. She's positive and she is a service worker with Positive Women and she will come and see you'. And she came and we talked. Then she just like encouraged me, 'You know you should keep on going to the group because you make friends there. At least you've got something to look forward to'. After a month then I started to going to Positively Women. And when I came out of hospital the people from Mildmay introduced me to Body and Soul and Positive Place so I've managed to go to that group. In Positive Place the group is Friday in the evening and that day they went to the pub. So I went to the pub and had a good time.

– Black African heterosexual woman, not taking combination therapy

6.2 EXPLORING NEEDS

One outcome of an exploration of services is often a better personal understanding of need. Rather than needs shaping service use, service use defines need. This can happen in a variety of ways. The failure of services to identify the needs they are addressing separately from their interventions (Hartley *et al.*, 1999) can be reflected in how people think of their own needs, such as having 'a need for counselling' or 'a need for complementary therapies'. But the effects are often more subtle.

– I went to counselling purely because I thought that I needed it, I needed some kind of support. I found more support out of my mates being around me and I got better support out of that. But later on after I moved back to London I started a 'newly diagnosed' group at London Lighthouse and that kind of filled all the gaps. That's what I needed. I needed someone who could say, 'Yes I'm going through it too, or, 'I've been there and don't worry you will be alright, this is how it is'. That's what I needed. I didn't need to talk at a counsellor to try and solve my problems. I needed someone to say to me, 'Look it's going to be alright. There are hundreds and thousands of people out there with HIV and you are not alone'.

– *White gay man, taking combination therapy*

This participant's initial attempt to address a vaguely sense of need (through counselling) failed. But the success of the 'newly diagnosed' group defines his own retrospective understanding of his needs. Through the group, he comes to understand that his need was for knowledge and reassurance. If the counsellor had been more skilled, he might now understand his needs quite differently. He came to understand his needs through his particular experience of resolving them. More generally, service use can profoundly affect self-understanding and attitudes to health and illness. Services provide a language for articulating need which is sustained by wider ideas of what it means to be healthy or fulfilled.

The impact of service use on understandings of self and of need is most evident in individual perceptions of dependency. In chapter 4, the value of personal autonomy was described as a key factor in shaping how participants went about meeting their needs. But attitudes to autonomy not only shape initial willingness to use services, they are themselves shaped by the experience of using services.

Lunch which was only £1 or £1.50 so it was all very handy for stuff like that. It was very handy but I found that unfortunately there was another side to it in that I was meeting people who were gay and HIV positive but who I found particularly negative. You've got to use these places wisely. You know what I mean, you've got to use them constructively and I think taking part in these things is important. I was still drinking at the time so my whole outlook was more negative. I was usually high when I got there. I'd have lunch and then watch TV in the TV room usually by myself while my laundry was doing. I've since learnt you've got to be a lot more active than that because that is like retiring. I mean that really is like being 70 [laugh] you know what I mean – sitting around waiting for your washing to do and watching TV with a lot of other people who are talking about medication, their illnesses, their benefits. Your whole life revolves around HIV. It's much healthier to do something like go to the gym. Okay you miss out on the cheap lunch but you can have lunch at home. Again, I got involved in Body Positive and I do their phone-line twice a month. Something like that even if it's just doing the training for that you are getting involved in a different way rather than being the passive recipient of these services. You can use them as well as taking part in them.

– *White gay man, stopped combination therapy*

As this example demonstrates, the process of exploring services and exploring need can occur at the same time. The use of services brings a clearer understanding of personal need which in turn leads to a more critical and effective service use.

6.3 CHANGING NEEDS AND CHANGING SERVICE USE

Every individual has a personal set of inter-related needs, of which health and confidence in the future are two of many. Every individual has a personal approach to meeting needs encompassing their inner resources, informal contacts and, to a greater or lesser extent, use of services. But use of services is complicated both by the exploratory, idiosyncratic approach of individual service users and by the reflexivity between service use and understandings of need. Given these levels of complexity, it is not surprising that changes in health and prospects have had diffuse and sometimes contradictory effects on patterns of service use.

The impact of combination therapies on many needs was minimal. Many participants were still living in poverty, with loneliness, depression or anxiety, with addiction, with the effects of disability. Improvements in health and prospects did not necessarily effect these needs, and hence did not necessarily impact on demand for services.

When changes in need had brought about changes in demand for services, the effects were contradictory. For some participants, better health meant that support services could be relinquished. For others, better health provided the strength and confidence to use services more often. Better prospects could mean moving away from dependency on services, or more active engagement with services.

For those participants with established patterns of service use, changing need was likely to have subtle effects, shifting how services were used rather than radically changing service choices. For those who had found strength from peer support, the same opportunities were now crucial in coping with treatment or the anxieties of when and how to start treatment. For those who had established regular contact with specific support services, the need to gain greater control over life was widely expressed in a shift from being a casual service user to becoming a volunteer. In making this change, participants were simply exploiting the opportunities of contact with services in ways which suited their needs.

In very general terms, a shift was taking place. Better health and/or better prospects were shifting people's needs from those dominated by managing the present to those concerned with shaping a range of possible futures. This did not usually mean radical changes in the services used, but changes in the ways they used those they were already familiar with. At a time when service providers were trying to work out how they should be changing their services to meet the changing needs of their users, those same users were manipulating the existing opportunities of the services to address, for themselves, their changing needs.

7 Conclusion

Combination therapy has affected everyone living with HIV, whether or not they are actually taking anti-HIV treatments. For those whose health has changed because of therapies (for better or for worse), there have been immediate and often considerable changes in daily needs. For everyone, perceptions of the possibilities of life, both current and future, have shifted. Only the few who perceive combination therapy as offering nothing (or worse) are unaffected.

The impact of these changed perceptions is highly individual, depending not only on personal circumstances, but also on the risks involved in change, including the risks of giving up current security; of exposing (sometimes battered) self-confidence to an often hostile world; or of investing in a future when everything gained could be lost again. Consequently, needs are extremely diverse. If people are to act in the face of these risks, they need stable contexts in which to do so, confidence, understanding of the potential consequences of their actions and the resources both to turn their actions into the outcomes they desire and to cope with the outcomes they do not desire. Of course, these desired outcomes are varied – building a social life, sustaining relationships, bringing up children, enjoying daily life, developing skills, finding employment (to name but a few).

How are such needs met? People usually meet most of their needs by themselves. When they do turn to others, their choices will be based on many factors – who they trust, who is around, who makes a difference. These judgements are always open to change, so patterns of support are never predictable. Partners, friends, family and services are all prominent sources of support, though they all play a part in creating needs as well as meeting them.

To understand the impact of combination therapy on the service use of people with HIV, we have to take account of much more than the impact of therapy on need. Anyone's engagement with services will have a history shaped by many factors, including their own sense of autonomy, the availability of informal support, their willingness to use services and their personal approach to getting what they want out of services. Service use cannot be treated as a simple reflection of need – people use services for many reasons and are creative about which services they use for what purposes. Consequently, the complex ways in which individual needs are changing may have little effect on demand for services. This may be because the services they use are marginal to the needs which are shifting or because they continue to use the same services for different reasons. Where there are changes, the effects may be subtle, such as the increase in the number of people choosing to become volunteers as well as service users.

Service providers and commissioners have to attend to overall shifts in demand if their services are to be effective and efficient in the long term. But this must not be at the cost of sensitivity to the individuality of need. People with HIV do not access services because they want 'to have their needs met'. They do so because they have some sense of need, often poorly articulated, which they want to explore and resolve, a process which usually involves adopting some of the service providers' understandings of need. But the needs of people with HIV are simply too complex and inter-related to fit the neat categories of service providers. Lots of people want to see their lives change, but they do not want their choices to be limited by the service providers' assumptions of what their futures should be. A service which respects the individuality and

complexity of need will succeed and be cherished. A service which imposes a view of need and how needs should be met will not. At a time of change, it is crucial that services do not assume that they must transform themselves and, in doing so, lose touch with the lives of the people they exist for.

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