



## **HIV NEEDS ASSESSMENT**

**An assessment of the social support needs of  
individuals living in Greater Glasgow with HIV**

2006

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## Acknowledgements

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## References

Weatherburn P, Anderson W, Reid D, Henderson L (2002) What do you need? Findings from a national survey of people living with HIV. London, Sigma Research.

# Table of Contents

<i>Chapter 1</i> .....	7
<i>Introduction</i> .....	7
<b>Background</b> .....	7
<b>Purpose of the study</b> .....	8
<b>Methods</b> .....	8
Participants.....	8
Procedures.....	9
<b>Results- Response Rate</b> .....	9
<b>Demographics of the Greater Glasgow sample</b> .....	10
<b>Drug Use, Co-infections, Conditions and Impairments</b> .....	12
Drug Use-past and present .....	12
Hepatitis C Infection .....	12
Haemophilia.....	12
Physical Impairment and Learning Disability .....	12
<b>Employment History</b> .....	12
<b>Drug Therapy Treatment</b> .....	16
<b>Relationship Status</b> .....	17
<b>Children</b> .....	17
<b>Living arrangements</b> .....	18
<b>Summary</b> .....	18
<b>Chapter 2</b> .....	20
<i>Needs</i> .....	20
<b>Activities of Daily Living</b> .....	20
<b>Needs as being a result of being HIV positive</b> .....	21
<b>Identified Need</b> .....	22
<b>Role of HIV support services in meeting need</b> .....	24
<b>Unmet Need</b> .....	24
<b>How needs are met</b> .....	28
<b>HIV Support Services</b> .....	28
<b>Family/Partner Support</b> .....	30
<b>Other Needs</b> .....	30
<b>Summary</b> .....	31
<i>Chapter 3</i> .....	32

<i>Sexual Health Needs</i> .....	32
<b>Information Needs</b> .....	32
<b>Sexual Health Services</b> .....	32
<b>Sexual Health Group Work</b> .....	34
<b>Sexual Problems and Information</b> .....	34
<b>Summary</b> .....	37
<i>Chapter 4</i> .....	38
<i>HIV Support Services-PHACE Scotland</i> .....	38
<b>Background</b> .....	38
<b>Knowledge and Usage of the Service</b> .....	38
PHACE Scotland Support and Advocacy Services and Crusaid .....	39
Gay Men’s Services-Information.....	39
Gay Men’s Services- Condoms .....	39
Gay Men’s Services- Gay men’s groups .....	40
Gay Men’s Services – Internet outreach and one to one .....	40
Gay Men’s Services – Telephone support, outreach and scene events.....	40
Other services.....	41
<b>Evaluation of PHACE Scotland</b> .....	41
<b>Benefits and Barriers</b> .....	41
<b>Changes</b> .....	42
<b>Summary</b> .....	42
<i>Chapter 5</i> .....	43
<i>HIV Support Services - Body Positive</i> .....	43
<b>Background</b> .....	43
<b>Knowledge and Usage of the Service</b> .....	43
<b>Evaluation of Body Positive</b> .....	45
<b>Benefits and Barriers</b> .....	46
<b>Changes</b> .....	47
<b>Summary</b> .....	48
<i>Chapter 6</i> .....	49
<i>HIV Support Services - HIV Carers</i> .....	49
<b>Background</b> .....	49
<b>Knowledge and Usage of the Service</b> .....	49
<b>Evaluation of HIV Carers</b> .....	50
<b>Benefits and Barriers</b> .....	50

<b>Changes</b> .....	51
<b>Summary</b> .....	51
<b>Chapter 7</b> .....	52
<b><i>Lesbian and Gay Switchboard</i></b> .....	52
<b>Background</b> .....	52
<b>Knowledge and Usage of the Service</b> .....	52
<b>Summary</b> .....	53
<b>Chapter 8</b> .....	54
<b><i>Social Work</i></b> .....	54
<b>Knowledge and Usage of the Service</b> .....	54
<b>Referral to Social Work</b> .....	54
<b>Allocated Social Worker</b> .....	55
Child Care Services.....	55
Practical and Financial Support .....	56
Emotional Support .....	58
Information and Advice Services.....	59
<b><i>Summary</i></b> .....	64
<b>Chapter 9</b> .....	65
<b><i>Summary and Recommendations</i></b> .....	65
<b>Summary</b> .....	65
Needs.....	66
Service Knowledge and Usage .....	67
<b>Recommendations</b> .....	68

# Chapter 1

## Introduction

### ***Background***

The number of individuals living with HIV in Glasgow has increased dramatically over the past few years. Since 1998 there has been a 341% rise in the number of newly diagnosed cases from 34 in 1998 to 120 in 2005. However the number of deaths has fallen dramatically. Compared to a peak of 42 deaths in 1994-1995, in 2005 there was 1 AIDS related death recorded in NHS Greater Glasgow. This is mainly due to the effectiveness of Highly Active Anti-retroviral Therapy (HAART), which became widely available in 1997. This change in epidemiology has implications for the way in which HIV services are delivered. The SIGMA report 'What do you need?' (2003) attempts to encapsulate the current needs of people living with HIV in the UK and how these may have changed in light of improved treatments. It states that *'medicine may have shifted the pattern of need, but it has not transformed it'*. It concludes that the challenge for service providers in the era of combination therapy is responding sensitively, flexibly and creatively to the variety of needs of people with HIV and recognizing the individuality of need.

Traditionally, the bulk of non-clinical support services have been provided by non-statutory HIV organisations. These organisations have played an important role in the lives of many individuals with HIV. However, most were established before the advent of HAART/combination therapy and were tailored to meet the needs of individuals whose quality of life and life expectancy were much poorer than that experienced by individuals now. Many of these organisations have responded by adapting to the changing needs of the HIV positive community, however, there has been no independent investigation of the support services provided to determine if they actually meet the current needs of Glasgow's HIV positive population.

## ***Purpose of the study***

In Glasgow the numbers of HIV positive individuals accessing non-clinical services is low compared to the numbers accessing treatment and there is a need to understand why this is the case. The purpose of this study was to examine the current social support and sexual health needs of HIV positive people living within the Greater Glasgow NHS Board Area, and to establish whether the existing service providers adequately meet their needs.

In order to do this seven key objectives were established. These were to:

- Establish the level of knowledge of existing non-clinical HIV support services currently available in Glasgow including those offered by the Brownlee Centre
- Identify patterns of use at these existing social support services including frequency of use, past use and reasons for discontinuing use
- Establish some of the reasons why people choose not to use non-clinical HIV Support services
- Identify which facets of particular services individuals with HIV find most useful and why
- Identify if there are needs among Glasgow's HIV population that are not currently being met by existing services
- Identify if there are common traits amongst those who feel their needs are not being met
- Identify if there are periods in individuals' lives when non-clinical HIV support services are particularly necessary e.g. on diagnosis

## ***Methods***

### Participants

To ensure as representative a view as possible it was felt important to gather information from those currently using non-clinical services and those who were not. The majority of individuals who are diagnosed with HIV in Greater Glasgow attend the Brownlee Centre

for treatment and care and therefore it was felt that targeting individuals through the Brownlee Centre would ensure as wide a range of views as possible.

Ethical approval was sought for this research in August 2004. In order to safeguard those who were newly diagnosed from any further distress, no-one who was diagnosed with HIV after the 31<sup>st</sup> of December 2003 was approached to take part in this study.

### Procedures

Ethical approval was sought from the West Glasgow Ethics Committee and the Research and Development Department and approval was granted on the 18<sup>th</sup> of August and 9<sup>th</sup> of November 2004. At that time, a total of 478 individuals were eligible for the study. Questionnaire packs were administered to Brownlee patients during scheduled appointments or by post if patients had previously given the Brownlee permission to send documents to their home address. The pack contained an information sheet and questionnaire. The information sheet outlined the purpose of the research, indicated that participation was entirely voluntary and gave the details of people individuals could contact should they have any questions or if they required support in completing the questionnaire. An information sheet and reply slip also invited people to take part in one-to-one interviews or focus groups. Two prepaid envelopes were supplied so that the names of those agreeing to participate in the focus groups could not be attributed to the questionnaire. Given the method of distribution, no reminders were sent or given to individuals. A deadline of 3 months was set for distributing questionnaires.

### ***Results- Response Rate***

Of the 478 targeted patients, questionnaires were successfully administered to 374 individuals (78.2%). Only 3 individuals who were approached refused outright to take a questionnaire. Of the other 101 individuals, 26 had moved from the area and were no longer attending the department, 6 died during the study period before administration of the questionnaire and the remaining 69 were unable to be reached during the 3-month study period. Of the 374 questionnaires sent out, 129 questionnaires were returned giving approximately a 34% return rate, which is reasonable for a postal questionnaire with no follow-up reminder. A further 5 questionnaires were returned after the deadline.

As the Brownlee Centre also cares for patients who are not resident in GGNHSB the questionnaire was distributed to all eligible patients, which included people from outwith Greater Glasgow. Of the 129 questionnaires returned, 98 (76%) clearly identified themselves as being from Greater Glasgow, 21 (16%) were from outwith Greater Glasgow and 10 (8%) did not supply their postcode and therefore the area they lived in could not be determined.

### ***Demographics of the Greater Glasgow sample***

The remainder of this analysis relates to the 98 individuals who clearly identified themselves as being from Greater Glasgow. It should be noted that not everyone answered every question and therefore the percentages reflect the responses given rather than a percentage of the total sample.

Of the 98 individuals seventy-two individuals (73.5%) identified themselves as being male and 26 (26.5%) were female. The following graphs illustrate the demographics of these men and women by age, ethnicity, sexual orientation and length of diagnosis.

Figure 1.1 Illustration of the age, ethnicity, sexual orientation and the length of diagnosis of the males completing the questionnaire.

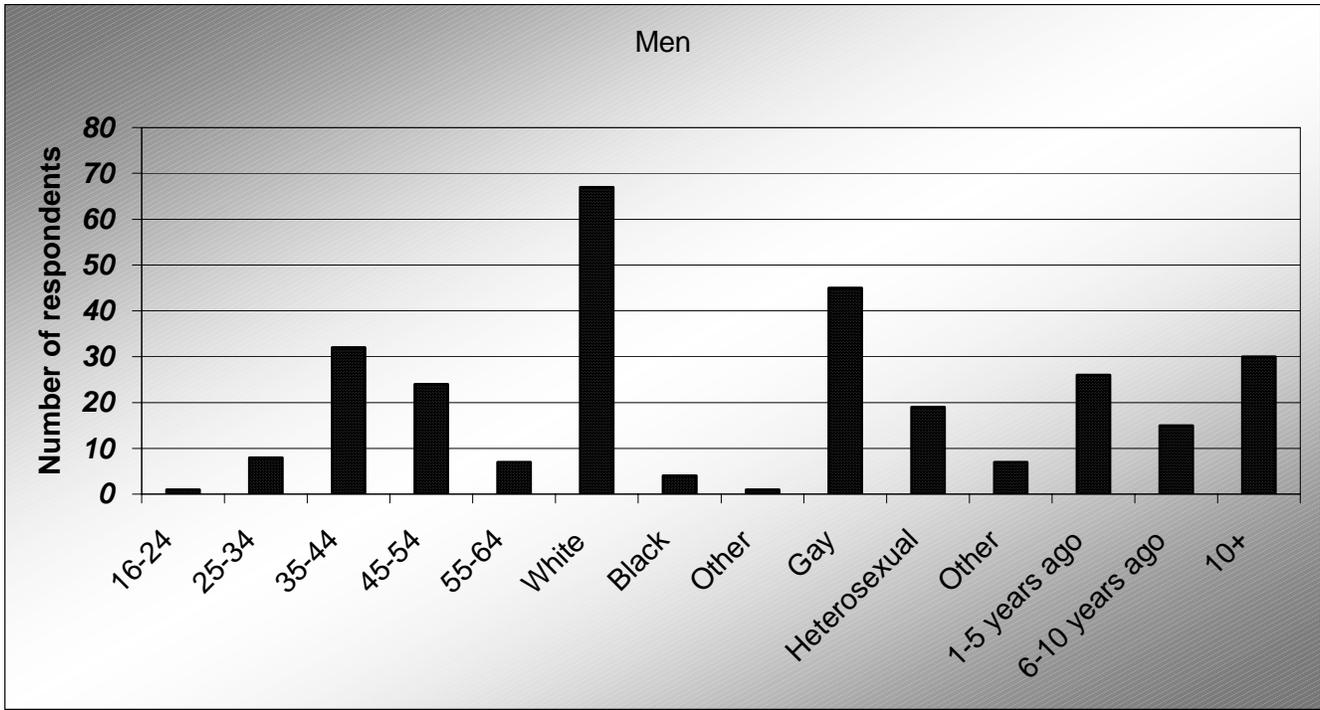
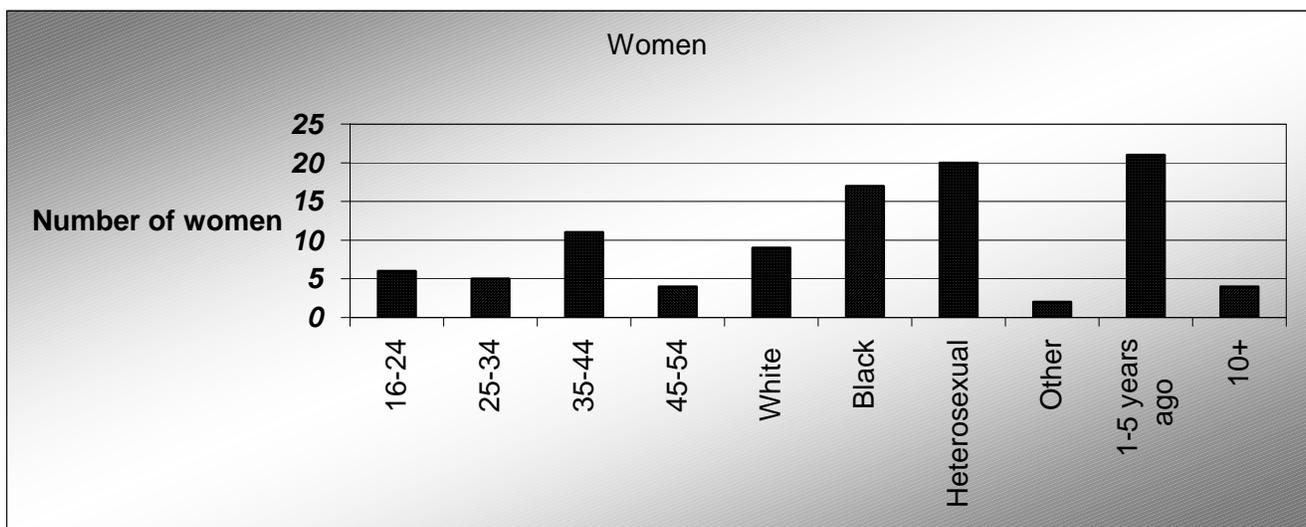


Figure 1.2 Illustration of the age, ethnicity, sexual orientation and the length of diagnosis of the women answering the questionnaire



## ***Drug Use, Co-infections, Conditions and Impairments***

### Drug Use-past and present

Thirteen individuals (13.5%) said that they had ever injected drugs; 10 (77%) were male and 3 (33%) were female. Of the 13 individuals who reported drug use, 2 individuals (16.7%), both of whom were male, reported that they were currently injecting drugs.

### Hepatitis C Infection

Seventeen of the 85 people (20%) answering the question indicated that they had Hepatitis C (HCV). Fourteen of the 17 individuals (82%) were male; 3 were female. Of the 14 males with HCV nine (64%) reported that had previously injected drugs.

### Haemophilia

Three individuals stated that they had haemophilia, which accounts for 3.5% of those answering this question (n=85).

### Physical Impairment and Learning Disability

Of the 85 respondents, 25 (29.4%) said that they had a physical/mobility impairment and 3 (3.5%) said that they had learning difficulties. Two of the three individuals who said they had learning difficulties were Black Africans.

At the time this data was produced it was found to be reasonably representative of the overall cohort attending the Brownlee Centre. Since the end of 2003 the cohort has increased to over 700 therefore the demographics may have changed slightly since this study was undertaken.

## ***Employment History***

More people chose to indicate their current employment status (n=97) than their employment status prior to being diagnosed with HIV (n=79).

Of the 79 individuals who chose to indicate their employment status both before and after diagnosis:

- 46 (75.9%) of these individuals reported that prior to diagnosis they were employed full-time.
- 5 individuals (6.3%) reported that they were involved in part-time work
- 3 individuals (3.8%) reported that they were self-employed.
- 1 individual (1.3%) reported that they were on long-term sick leave
- 14 individuals (17.7%) reported being unemployed
- 4 individuals (5.1%) reported being students
- 6 individuals (12.2%) reported being something other than what was listed

Since diagnosis of those previously in fulltime employment (n=46)

- 18 individuals (39.1%) reported that they were currently employed
- 5 individuals (10.9%) were now on long-term sick leave
- 12 individuals (26.1%) were now unemployed
- 7 individuals (14.3%) were now retired
- 2 individuals (4.3%) were students
- 2 individuals (4.3%) reported being something other than the options listed

Of those who were in part-time employment (n=5):

- 1 individual (20%) had become employed fulltime
- 3 individuals (40%) were now unemployed
- 1 individual (4.3%) reported himself or herself as being in the other category.

Of the 3 individuals who were self-employed:

- 1 individual (33.3%) remained so.
- 1 individual (33.3%) was now reporting unemployed.
- 1 individual (33.3%) was now on long-term sick leave.

The 1 individual who reported being on long-term sick leave remained so.

Of the 12 individuals who were unemployed before diagnosis

- 8 individuals (66.7%) remained so
- 3 individuals (25%) were now students
- 1 individual (8.3%) was now on long-term sick leave

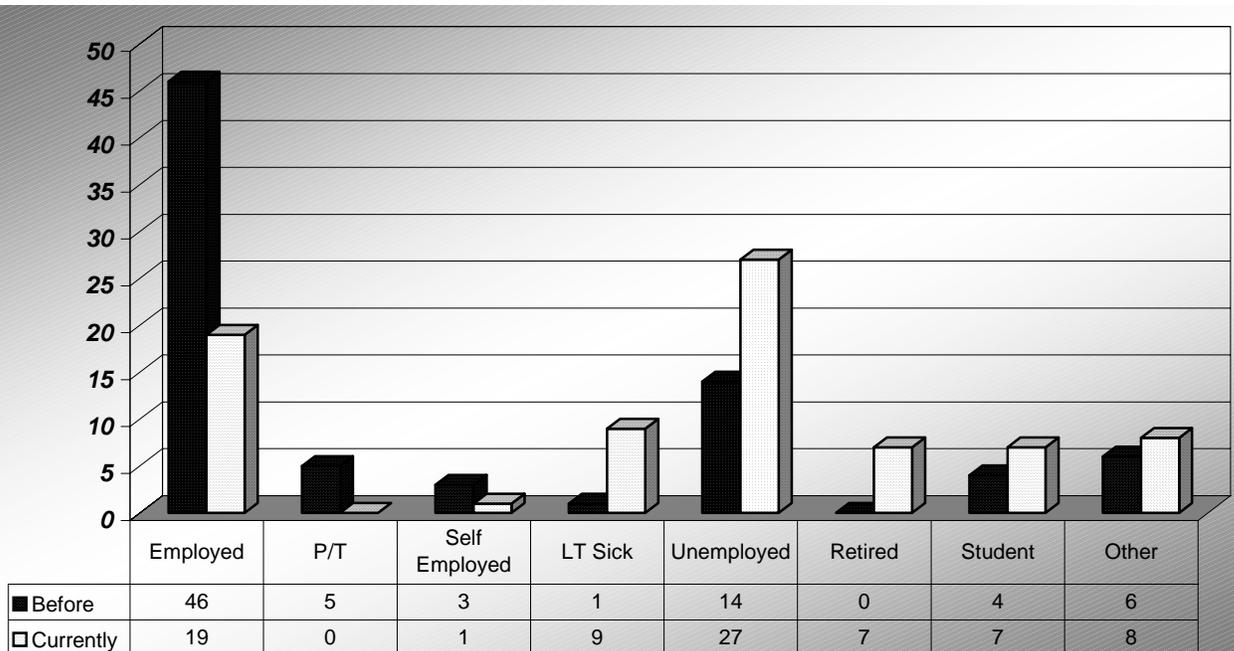
Of those who were students (n=4)

- 2 individuals (50%) remained so
- 1 individual (25%) was employed full-time
- 1 individual (25%) was now on long-term sick leave

Of the 6 individuals who reported being in the other category

- 5 individuals (83.3%) remained so
- 1 individual (16.7%) now reported being unemployed

*Figure 1.3 Illustration of the changes in the employment status of those who indicated their status before and after diagnosis*



Whilst the question was not asked as to whether any changes were a direct result of their diagnosis and how soon after diagnosis these changes occurred, it would appear employment could be an issue for some individuals. Of the 54 people who reported some form of employment prior to their diagnosis, 22 (41%) now reported being unemployed or on long-term sick leave. Additionally some of those who classed themselves in the other category were also clearly related to sick leave.

*“Early Retirement on grounds of ill health due to HIV.” (R4)*

*“Medically unemployed” (R89)*

The steering group managed to organise one focus group to which only 4 individuals attended. Therefore whilst some of the discussion arising from this group provided additional useful information, the views of the individuals attending should not be seen as being representative of the whole HIV cohort: the individuals themselves were keen to highlight this.

Those attending the focus groups reported that they had experienced issues with employment as a result of their status. Those who had been diagnosed before the advent of HAART reported that they had automatically been signed off work upon diagnosis, which they felt had led to them becoming deskilled and less marketable within the employment field. Individuals also reported that the work opportunities that were available to them were lower income jobs, which did not generate sufficient money to feed and house them. They talked about being stuck in a ‘benefits rut’ whereby it was financially more viable for them to stay unemployed than to seek work. There were also reports that individuals had been told or knew from a third person that the fields they could work in were limited because of their status i.e. they could not be involved in nursing which had led to some withdrawing from their studying.

Although the sample was small within the focus groups, similar issues were identified within the Sigma report “What do you need”. Around 27% of all respondents within the Sigma research felt unhappy about their opportunities within the job market. The idea of a ‘benefits trap’ was also identified with individuals highlighting their dissatisfaction

with the current benefits system leading to the lack of an incentive to enter employment particularly in relation to part-time work.

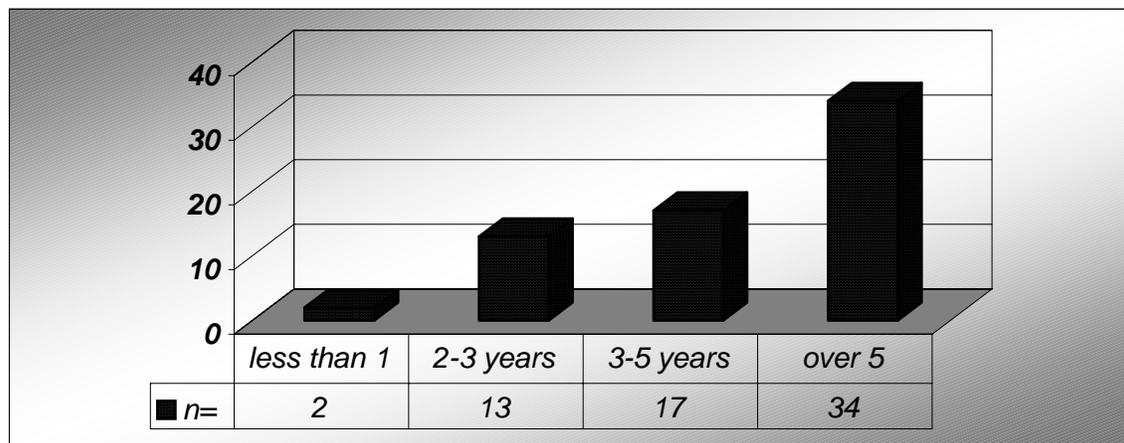
Whilst not all individuals with HIV will experience difficulties with regards to employment there will be some individuals for whom support is required. This support could involve working with individuals to find courses or develop skills for the workplace but it could also involve working with workplaces to ensure they are equipped to deal with an HIV positive employee and are informed about employment laws around HIV. A common wish amongst individuals taking part in the Sigma research was for a more flexible benefits system that did not put individuals at risk of losing their benefits because of enrolment in education and it maybe that whatever programmes/training opportunities are developed would need to consider this.

### ***Drug Therapy Treatment***

Participants were asked if they had ever used combination therapy. Of the 96 respondents, 69 (71.9%) had ever used combination therapy; sixty of whom (89.6%) said they were still currently taking it.

Of the 69 people who said they had ever taken combination therapy, 66 (95.7%) indicated when they had first started; for the majority this was over 5 years ago (n=34, 51.5%). When the categories were collapsed to look at those who had started in the last 1-5 years compared to those over 5 years ago the numbers were fairly similar (n=30, 45.5%, v's 34, 51.5%).

*Figure 1.4 Illustration of how long ago respondents started combination therapy*



Fifty-eight of the 60 who indicated that they were currently taking combination therapy responded to the question asking if they had ever had a break from therapy; 15 people (25.9%) said that they had. The most common reason that these 15 individuals gave for stopping therapy was that they had experienced problems with side effects (66.7%, n=10).

### ***Relationship Status***

Forty-three of the 97 (44.3%) people who answered the question about relationships said that they were currently in a relationship. The length of these relationships varied between 2 months and approximately 36 years, however the mean duration for all those in relationships was approximately 8 years.

Of the 43 individuals in relationships, 30 (69.8%) said that their partner had not been diagnosed with HIV, suggesting that the majority were in serodiscordant relationships. Eleven of the 43 (25.6%) said that their partner was HIV positive and 2 (4.7%) said they did not know.

The majority of those who reported being in relationships were male, however as a proportion of the overall sample, more of the women who answered the questionnaire were in relationships than men (14 out of 26 (53.9%) v's 29 out of 71 (40.9%). There was very little difference in the sexual orientation of those in relationships: there was virtually a 50:50 split between gay men (n=19, 46.3%) and heterosexuals (n=19, 46.3%). Two of the individuals in relationships were unsure of their sexual orientation; two did not indicate their sexual orientation and one identified himself as a man who had sex with men. None of those who described themselves as something other than those sexualities noted above indicated that they were in relationships.

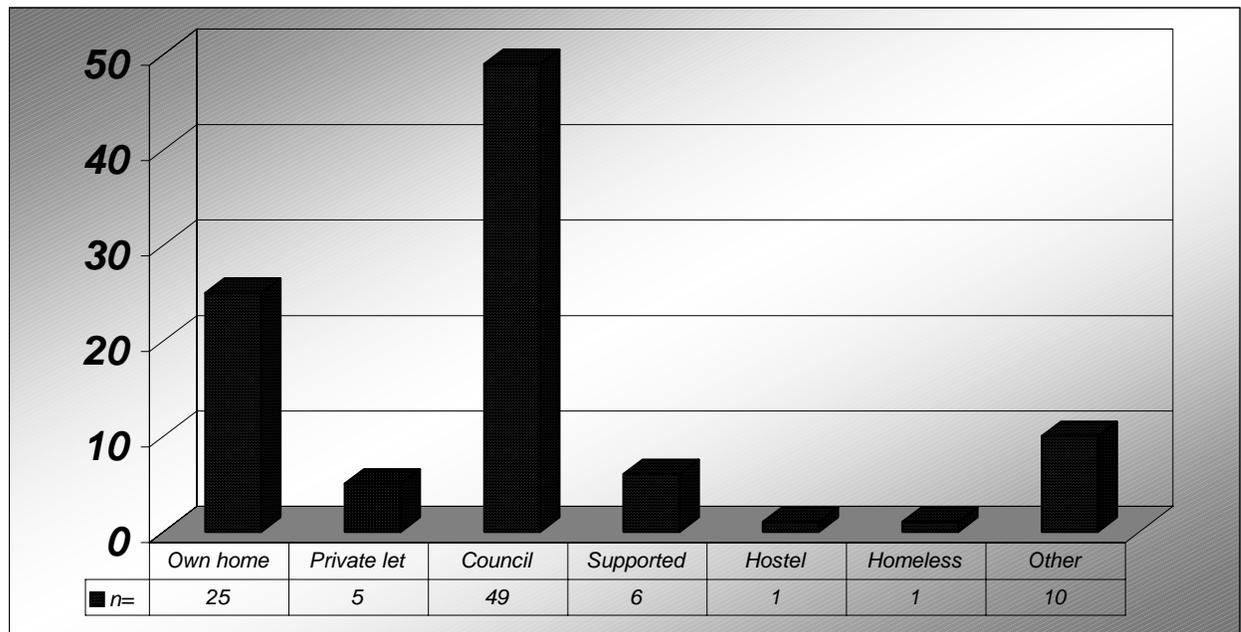
### ***Children***

Twenty-four individuals (25.5%) reported that they had children under the age of 16 of whom 15 (62.5%) said that these children were currently living with them. A further 2 individuals (8.3%) said that some of their children under the age of 16 lived with them. Of those indicating that they had children or some of their children living with them, the majority were Black African women (n=13, 50%).

## **Living arrangements**

When asked about where they lived, most people indicated that they lived in Council/Housing Association let (n=49, 50.5%). The main response within the “other” category was staying in the family home. People’s living arrangements are illustrated in figure 1.5.

*Figure 1.5 Illustration of where people with HIV in Glasgow live*



## **Summary**

The same characteristics of the sample appear to be fairly representative of the overall cohort of people living with HIV at the time that the questionnaire was distributed. The population has changed since the study began and might no longer be as representative of the HIV positive cohort. However, as the cohort is continually growing it is impossible to be completely representative and should therefore be seen as an important snapshot describing people’s thoughts, needs and experiences.

The majority of respondents were white gay men and most were aged between 35-44. Fewer women responded but the majority of these were Black Africans who on the

whole were younger than the male respondents and had been diagnosed in the last 1-5 years.

There was some evidence to suggest that people may be experiencing or have experienced difficulties in terms of employment since their diagnosis and that support around employment is a need for some people.

The majority of the sample had at some point been on combination therapy and there was virtually an equal split between those who had started in the past 5 years and those who had started over 5 years ago. Those who indicated that they had had problems with combination therapy and had stopped taking it mainly attributed this to difficulties with side effects. A number of those responding to the questionnaire were still taking combination therapy.

Just under half of the sample was currently in a relationship of whom most reported that their partner had not been diagnosed with HIV. A quarter of the sample reported that they had children under the age of 16 of whom the majority reported that these children lived with them. Most of the individuals answering the questionnaire reported that they lived in Council/housing Association let.

## **Chapter 2**

### **Needs**

#### ***Activities of Daily Living***

The majority of individuals (n=69, 72.6%) said that they did not need assistance with activities of daily living with just over a quarter of respondents (n=26, 27.4%) indicating that they did. Of the 26 individuals in this study, requiring assistance the majority (n=21, 80.8%) indicated that they had a carer: the remaining 5 individuals (19.2%) said that they did not. Those who needed support tended to be White European males who constitute the majority of the sample. Sexual orientation did not seem to be a factor with as many heterosexuals requiring support as gay men. Surprisingly, length of diagnosis did not seem to be a factor in determining the likelihood of requiring support with equal numbers of people diagnosed in the last 1-5 years (n=10, 38.5%,) requiring support as those diagnosed over 10 years ago (n=10, 38.5%). Black Africans often present at a later stage often when they have become unwell, and it could therefore be proposed that they may account for many of those identifying support needs particularly amongst those diagnosed in the past 1-5 years. Black respondents constituted only 15.4% of those with support needs around activities of daily living but 40% of those with needs who had been diagnosed recently.

Of the 5 people who indicated that they required support but were without carers, 4 were heterosexual, 3 were White European, 3 were male and 4 had been diagnosed in the last 1-5 years. Only 4 of the 5 answered questions relating to co-morbidities or impairments of whom 2 (50%) had HCV and 2 (50%) had physical impairments. These were not the same two individuals. None of the 5 individuals were in relationships and 4 of the 5 were living in council association housing.

What these findings would suggest is that for the vast majority of people with HIV responding to this question, support with activities of daily living is not required. Of those who do need support the majority have a carer, however there appears to be a small number of individuals who require support and are currently without a carer. This mirrors the findings from the Sigma research, which found that whilst overall most people felt



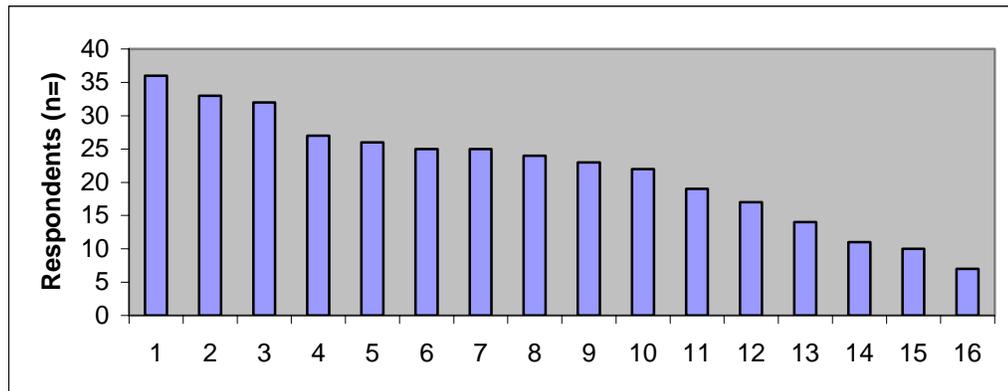
*Table 2.1 Table outlining the proportions of each subgroup reporting having needs*

<b>Suggested categories</b>	<b>Total number within overall sample answering question about need</b>	<b>Number within the sample reporting needs</b>	<b>Proportion of sample with needs</b>
White gay males	43	23	53.4%
White heterosexual males	16	9	56.25%
Black heterosexual males	2	2	100%
White heterosexual women	9	4	44.4%
Black heterosexual women	11	6	54.5%
White male other	6	2	33.3%
Black male other	1	1	100%
Black female other	2	2	100%
White respondents	74	38	51.4%
Black Minority Ethnic respondents	22	16	72.7%

### ***Identified Need***

Fifty-two of the 54 (96.3%) individuals with needs, identified what these needs were. Individuals were given a variety of options plus space to add any other needs that were not included in the provided list. The responses are illustrated in figure 2.1:

Figure 2.1 Illustration of the needs of people with HIV living in Glasgow



- 1 = General health and wellbeing (n= 36, 69.2%)
- 2 = Financial Support (n=33, 63.5%)
- 3 = Nutritional Advice (n=32, 61.5%)
- 4 = Physical Activity (n=27, 51.9%)
- 5 = Support with Drug Therapy Decisions (n=26, 50%)
- 6 = Relationship Support and Advice (n=25, 48.1%)
- 7 = Counselling (n=25, 48.1%)
- 8 = Support with drug therapy adherence and side effects (n=24, 46.2%)
- 9 = General Advocacy (n=23, 44.2%)
- 10 = Sexual Health Advice (n=22, 42.3%)
- 11 = Housing (n=19, 37.3%)
- 12 = Support with HIV disclosure (n=17, 32.7%)
- 13 = Support finding employment (n=14, 26.9%)
- 14 = Smoking Cessation (n=11, 21.2%)
- 15 = Workplace Related Issues (n=10, 19.2%)
- 16 = Support with drug and alcohol use (n=7, 13.5%)

Other needs listed by individuals included practical help such as painting of houses, child care, transport and access to health professionals such as dentists and doctors through to social needs such as meeting friends and holistic therapies.

Although general health and wellbeing, financial support and nutritional advice were the top 3 needs when the data was looked at collectively, when examined by particular subgroups the needs reported were slightly different. Individuals from Black and

Minority Ethnic communities most commonly reported needs in relation to financial assistance (n=13, 86.7%), followed by physical activity (n=8, 53.3%) and relationship support and advice (n=8, 53.3%), whereas White respondents most commonly reported needs in relation to general health and wellbeing (n=29, 78.4%), nutritional advice (n=26, 70.3%) and support with drug therapy decisions (n=23, 62.2%). Men reported the same needs as White respondents and women the same as Black respondents which would make sense given that most of the men answering were White and most women were Black. Females also reported needs in relation to general health and wellbeing. With regards to sexuality, those who identified as gay reported similar needs as white males but with the addition of counselling, which was reported by the same number of people who reported support with drug therapy decisions. For heterosexuals financial assistance (n=12, 85.7%), followed by physical activity (n=7, 50%) and relationship support and advice (n=7, 50%) were the most commonly reported needs.

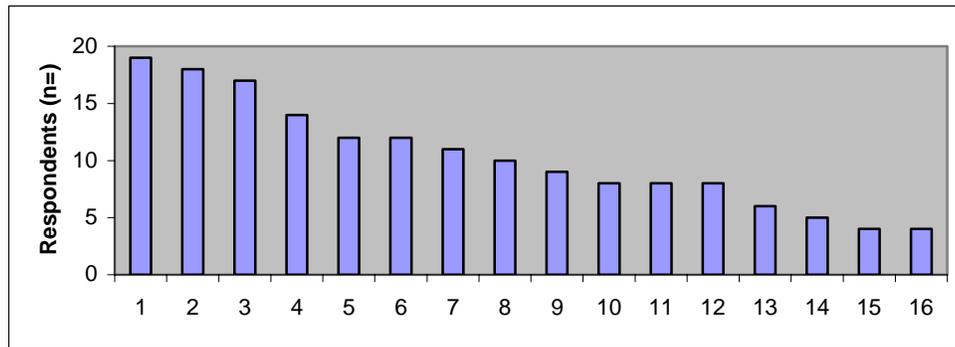
### ***Role of HIV support services in meeting need***

Of those who reported having needs as a result of their HIV infection, (n=54) 43 people answered the subsequent questions on whether they thought their needs could be met by HIV support services; 76.7% said yes (n=33). Reasons for saying no included, not really knowing what HIV services were or had on offer, not thinking their needs were really something that HIV support services would deal with and personal choice i.e. preferring their own space or relying on their own friends and family.

### ***Unmet Need***

Those who said that they had needs were asked if their needs were currently being met. Forty-six individuals responded of whom 37 (74%) said that their needs were not being met. Looking at the absolute numbers it would appear as if more males (n=25) than females (n=12) have unmet needs. However, proportionally as a percentage of those males and females with needs (n=38 v's n=16), more females (12 out of 16, 92.3%) than males (67.6%) reported having unmet needs compared with the number of males: (25 of the 38, 67.6%). The needs most commonly identified as not being met were as follows:

Figure 2.2 Illustration of unmet need



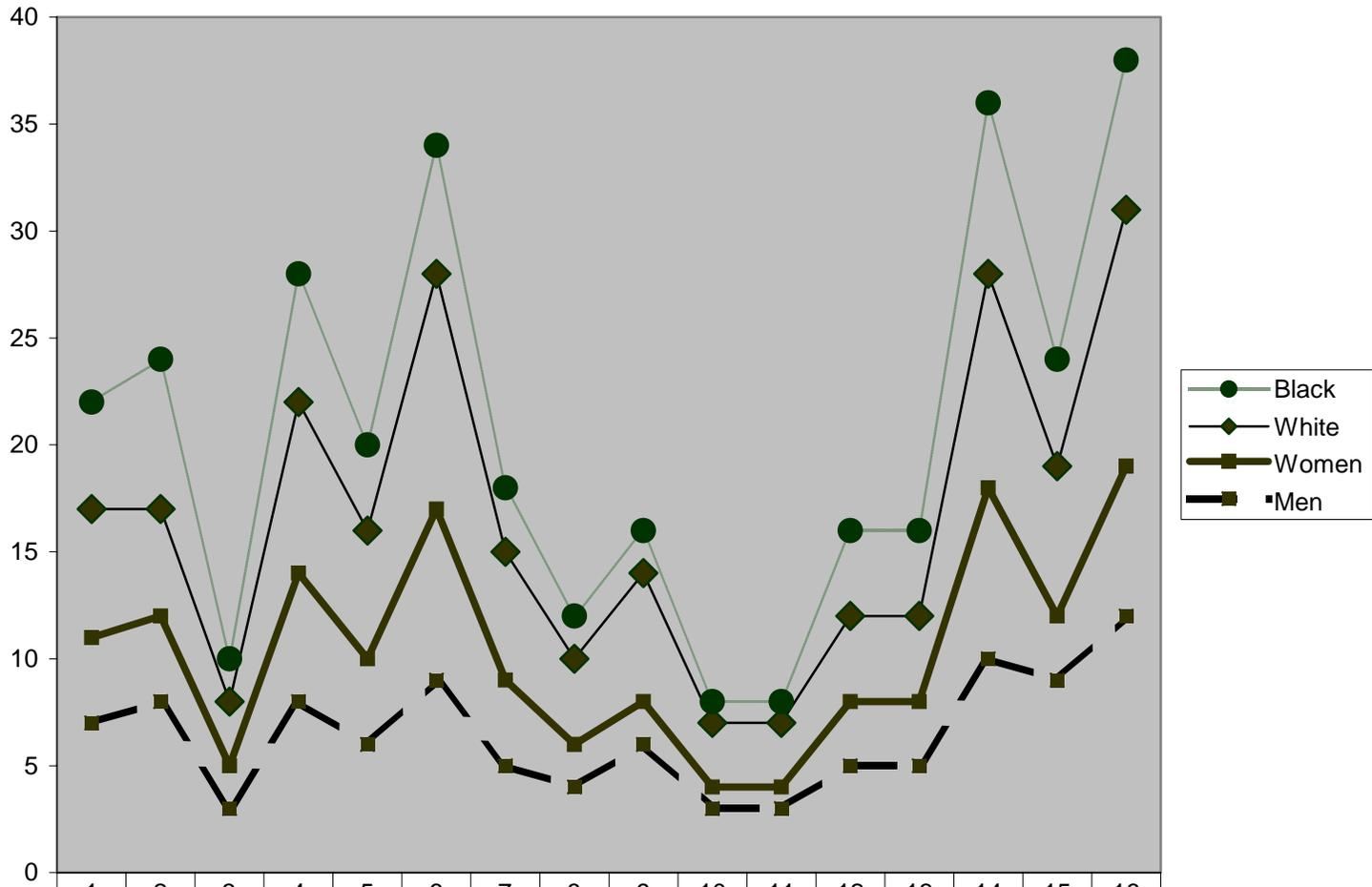
- 1 = Housing (n= 19, 52.8%)                      2 = Financial Support (n=18, 50%)
- 3 = Physical Activity (n=17, 47.2%)
- 4 = Relationship Support and Advice (n=14, 38.9%)
- 5 = Support Finding Employment (n=12, 33.3%)
- 6 = General Advocacy (n=12, 33.3%)
- 7 = Support with HIV Disclosure (n=11, 30.6%)
- 8 = General Health and Wellbeing (n=10, 27.8%)
- 9 = Nutrition (n=9, 25%)
- 10 = Support with Drug Adherence and Side Effects (n=8, 22.2%)
- 11 = Counselling (n=8, 22.2%)
- 12 = Sexual Health Advice (n=8, 22.2%)
- 13 = Drug Therapy Decisions (n=6, 16.7%)
- 14 = Workplace Related Issues (n=5, 13.9%)
- 15 = Smoking Cessation (n=4, 11.1%)
- 16 = Support with drug and alcohol use (n=4, 11.1%)

Other unmet needs cited by individuals were mainly social i.e. having nowhere to go to meet people and wanting a social space. Childcare was also mentioned, as was lack of somewhere to convalesce. Nineteen respondents (37.3%) reported that they had needs with regards to housing of whom 11 (57.9%) identified that this need was unmet. An additional 8 people indicated they had unmet needs with regards to housing, who had not previously said they had housing needs. It should be noted that there was a problem with the questionnaire when asking about needs because the tick box at the housing option was

missing and therefore people may have overlooked this. Therefore there may have been additional people who had housing needs who did not indicate that they did so.

Because White men dominate the sample as a whole, analysis was carried out to see if there were differences between the reported unmet needs of men and women and also to examine if there were differences on the basis of ethnicity. The results are shown in Figure 2.3.

Figure 2.3 Illustration of unmet need by gender and ethnicity



	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Black	5	7	2	6	4	6	3	2	2	1	1	4	4	8	5	7
White	6	5	3	8	6	11	6	4	6	3	3	4	4	10	7	12
Women	4	4	2	6	4	8	4	2	2	1	1	3	3	8	3	7
Men	7	8	3	8	6	9	5	4	6	3	3	5	5	10	9	12

1 = Support with HIV Status

2 = Support with finding employment

3 = Workplace related issues

4 = Relationship Support and Advice

5 = General Health and Wellbeing advice

6 = Physical activity

7 = Nutritional advice

8 = Support with drug therapy decisions

9 = Support with drug therapy adherence and side effects

10 = Support with drug and alcohol use

11 = Smoking cessation

12 = Counselling

13 = Sexual health advice

14 = Financial Support

15 = General advocacy

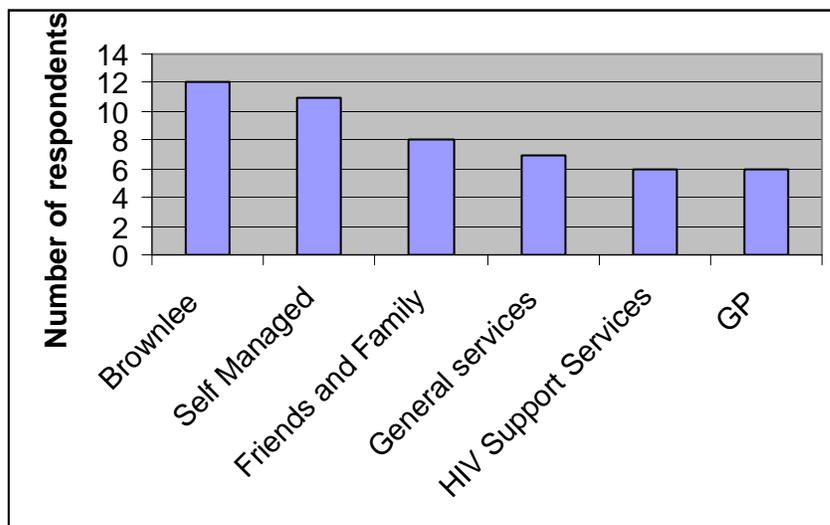
16 = Housing

Men, Women and White respondents reported the same unmet needs. These were housing, financial support and physical activity. However for females the order in which these needs were reported was slightly different with physical activity being the highest reported unmet need. For Black respondents the unmet needs changed slightly with a greater emphasis on financial support. Support finding employment was mentioned more often amongst Black Africans than in the other categories.

### **How needs are met**

Of the 13 people who said they had needs but that their needs were being met, all but one person said that their needs were met by the Brownlee Service (n=12, 93.2%). Eleven people said that their needs were self-managed (84.6%) and 8 said they managed their needs through friends and family (61.5%). Seven people reported using a general service such as social work (53.8%). HIV support services and GP's were reported as a means of meeting the needs of six respondents (46.2%). Figure 2.4 shows how those respondents with needs said their needs were being met.

*Figure 2.4 Illustration of how respondents have their needs met*



### **HIV Support Services**

All respondents (n=98) were asked whether they felt there should be specific support services for people with HIV. Of the 95 who answered (96.9%), 89 (93.7%) said yes,

meaning that only 6 (6.3%) did not think there should be a specific support service for people with HIV. There were few reasons given as to why individuals said no.

Those who said that there should be HIV support services were asked to tick from a list, the types of services that should be provided. The results were as follows:

*Table 2.1 Outlines what people think an HIV support service should provide*

<b>Service</b>	<b>Number of respondents</b>	<b>%</b>
Support from people with HIV	67	74.4%
General Health and Wellbeing advice	65	72.2%
Welfare	63	70.0%
Sexual Health Advice	61	67.8%
Information leaflets	60	66.7%
Condoms and Contraception	60	66.7%
Helplines	59	65.6%
Support for partners	57	63.6%
Support on how to study/get back to work	57	63.6%
Help with activities of daily living	56	62.2%
Workshops	55	61.1%
Social Drop in	52	57.8%
Information and advice on pregnancy	46	51.1%

This is really interesting because sexual health, condoms etc have more of a presence here than in the reported needs suggesting that individuals may actually have a need around sexual health but find it easier to identify when listed more specifically i.e. condoms and contraception as opposed to sexual health.

In general there is very little differentiation between the options, suggesting that most people ticked everything that was suggested. In hindsight, it would have been preferable to ask people to indicate the three choices they felt were most important to them. Other suggestions included holistic therapies and out of hour services.

Because there was very little differentiation between the responses, individuals at the focus group were asked to give 3 key things that they felt a support service should provide. Most of the responses were around the key theme of social support. People indicated a need for a safe space to socialise and talk openly about their status. Those

who took part indicated that this space was important so that people could be supported, could attend workshops on aspects such as self-esteem and could learn from one another. There was also a feeling that in the past this sharing had led to increased knowledge of drugs and side effects which people could report to GPs. Individuals also mentioned that they saw a role for themselves in terms of prevention.

### ***Family/Partner Support***

When asked about the level of support for families and partners, 41 individuals (52.6%) said that they thought there was enough support available for families and partners with 37 individuals (47.4%) indicating that they did not think there was enough support for families and partners.

Amongst those in relationships (n=43) the opinions appeared to be split with 17 individuals (45.9%) saying no and 20 (54.1%) reporting there was. Six people did not answer the question. In terms of the support that respondents thought their families could benefit from, suggestions included education about HIV and health implications, HIV treatment updates, having someone to talk to, either in the form of counselling or support groups and financial support. For partners, respondents thought that counselling, emotional advice and support, talking to someone with HIV and other partners of people with HIV, and advice on sexual health practices would be of benefit.

### ***Other Needs***

Space was left at the end of this section of the questionnaire to allow people to write any additional comments they had about their needs. Only a few people took the opportunity to do so. However of those who did, there did appear to be several individuals who were quite isolated and who required support. Some individuals felt they had nowhere to go for support and there were obviously social issues with regards to housing, finance and general emotional wellbeing. Some people required very practical support such as with shopping or housework, whilst others felt they required support with their medication. One individual wasn't aware of any of the services on offer and therefore felt that a needs assessment could be carried out with individuals soon after diagnosis presumably to ensure they were referred to appropriate services.

## **Summary**

The findings from this chapter would suggest that many people with HIV do not perceive that they have any specific needs as a result of their HIV status, or are finding ways of meeting their needs. These findings are similar to those outlined in the Sigma research around the needs of people with HIV. This is not to say that this support might not be needed and in Glasgow there were certainly a number of people who had needs that were not being met. Unmet needs were fairly similar for all individuals and centred around housing, financial support and physical activity. It is likely that issues with housing are a consequence of problems with finance or vice versa. For Black Africans employment was also an issue. Some individuals reported the need for very practical support such as support painting their house, support with shopping and being provided with lists of health professionals such as doctors and dentists who would accept people who were HIV positive.

Most individuals with needs felt that their needs could be met by an HIV support service and the vast majority of individuals, including those who said that they did not have any needs, felt that there should be a specific service for people with HIV. In terms of what this service should provide there was little clear differentiation between the suggestions provided. Social support i.e. having somewhere to meet socially as well as discuss their status and provide support to others seemed to be the main aspect that those attending the focus group were looking for a service to provide.

There did not appear to be a clear view on whether or not there was sufficient support for families and partners. Therefore it may be necessary to consider how support could be offered to these groups of individuals to include topics such as emotional advice, HIV treatment updates and sexual health practices.

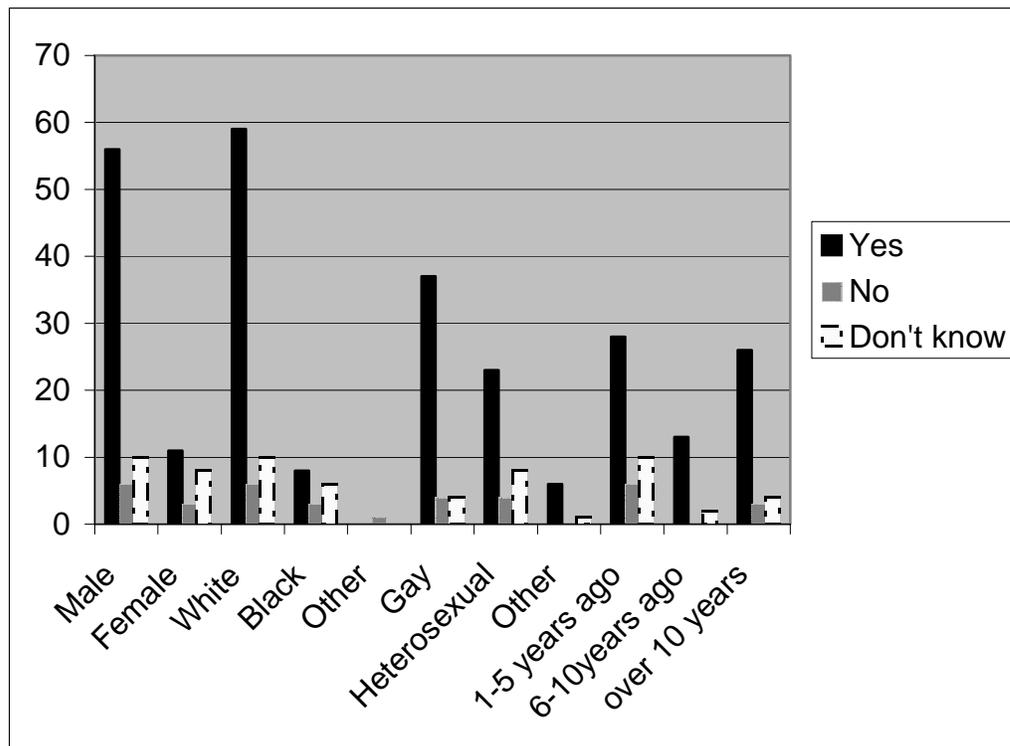
## Chapter 3

### Sexual Health Needs

#### **Information Needs**

Ninety-three people answered the question as to whether they felt they had enough information around sexual health. Sixty-eight people said yes (73.1%), 16 said that they were not sure (17.2%) and 9 said no (9.7%). Figure 3.1 illustrates people's sexual health information needs by gender, ethnicity, sexual orientation and length of diagnosis

*Figure 3.1 Illustration of respondents' sexual health information needs by gender, ethnicity, sexual orientation and length of diagnosis.*



#### **Sexual Health Services**

Individuals were asked if they knew where to go to access a sexual health service. Of those who answered the question (n=92, 94%), the vast majority said yes (n=80, 87%).

The places most commonly cited were the Sandyford Initiative<sup>1</sup> (n=31, 41.9%), the Brownlee Centre<sup>2</sup> (n=23, 31.1%) and the Steve Retson Project<sup>3</sup> (14.9%, n=11). Other responses included, PHACE Scotland (4.1%, n=3), Local Hospital (4.1%, n=3), GUM at Royal Infirmary, Internet and GP.

Of those who said that they did not know where to go (n=12), half were male and half were female. Most had been diagnosed in the last 1-5 years (n=9, 75%) were White European (n=7, 58.3%) and were heterosexual (n=8, 72.7%).

Those who indicated that they knew where to access a service and had indicated where they would go, were asked to confirm whether they had ever used the service and how well they thought this service catered to the needs of HIV positive people. Nearly 66% of individuals said that they had used this service, with the majority of people split between reporting that the service catered reasonably well (n=17, 36.7%) for those with HIV and extremely well (n=15, 30.6%). Table 3.1 outlines the ratings for the 3 services most commonly cited as where people would go for a sexual health service:

Table 3.1 How well sexual health services are perceived to cater for the needs of HIV positive people

Service	Not well at all	Reasonably Well	Well	Extremely Well
Steve Retson (n=10)	20% (n=2)	20% (n=2)	10% (n=1)	50% (n=5)
Sandyford (n=24)	8.3% (n=2)	54.2% (n=13)	25% (n=6)	12.5% (n=3)
Brownlee Centre (n=11)	0	9.1% (n=1)	45.5% (n=5)	45.5% (n=5)

<sup>1</sup> The Sandyford Initiative is a service providing sexual and reproductive health services for men, women and young people in Glasgow as well as counselling, information and a range of specialist services.

<sup>2</sup> The Brownlee Centre is a service offering counselling testing and treatment for HIV and Hepatitis.

<sup>3</sup> The Steve Retson Project is a sexual health service for gay and bisexual men. It is located within the Sandyford Initiative and also operates from the LGBT centre in Glasgow City Centre.

### **Sexual Health Group Work**

Group work sessions around sexual health and relationships for people with HIV are being run elsewhere in the UK. The question was therefore raised as to how useful individuals would find it to have discussions about sexual health and relationships. The results are tabled below in table 3.2.

*Table 3.2 Responses as to the usefulness of having sexual health and relationship groupwork*

Rating of usefulness	Number of respondents (n=)	%
Not useful at all	24	26.7
Reasonably useful	19	21.1
Useful	13	14.4
Very Useful	16	17.8
Don't know	18	20

These opinions were looked at by length of diagnosis, gender and sexual orientation. Opinions varied greatly across each of the groups, making it difficult to suggest one group who might find it more useful than others. A number of people indicated that they did not know, which would suggest that people perhaps needed more information about what the group would entail.

### **Sexual Problems and Information**

Ninety of the 98 (21 females, 69 males) Greater Glasgow respondents filled in the grid relating to sexual issues/problems and desire for support/information in relation to these issues/problems. Because some of these issues are gender specific i.e. impotence (erectile dysfunction), the data is analysed according to gender.

Both women (n=15, 71.4%) and men (n=49, 71.4%) were most likely to report having experienced low self-esteem in relation to sex and relationships with around 50% of both women and men still experiencing this and numbers reporting that they required

information and support around this. Figures 3.2 and 3.3 illustrate the sexual problems and information/support needs for women and men.

*Figure 3.2 Illustration of sexual problems experienced by women with HIV living in Glasgow*

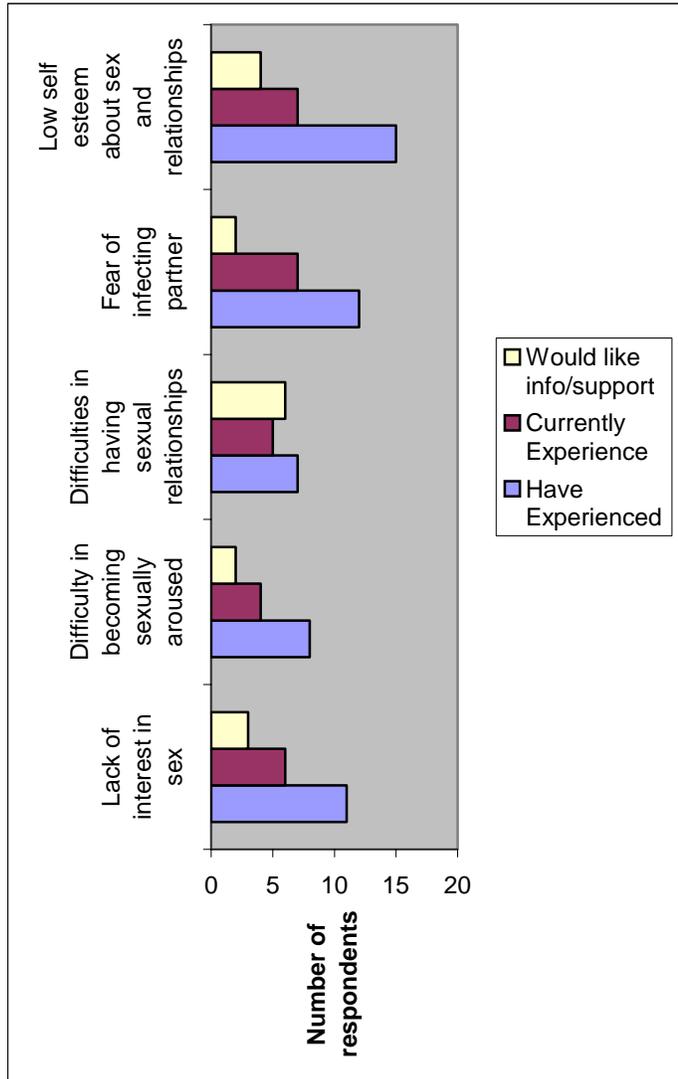
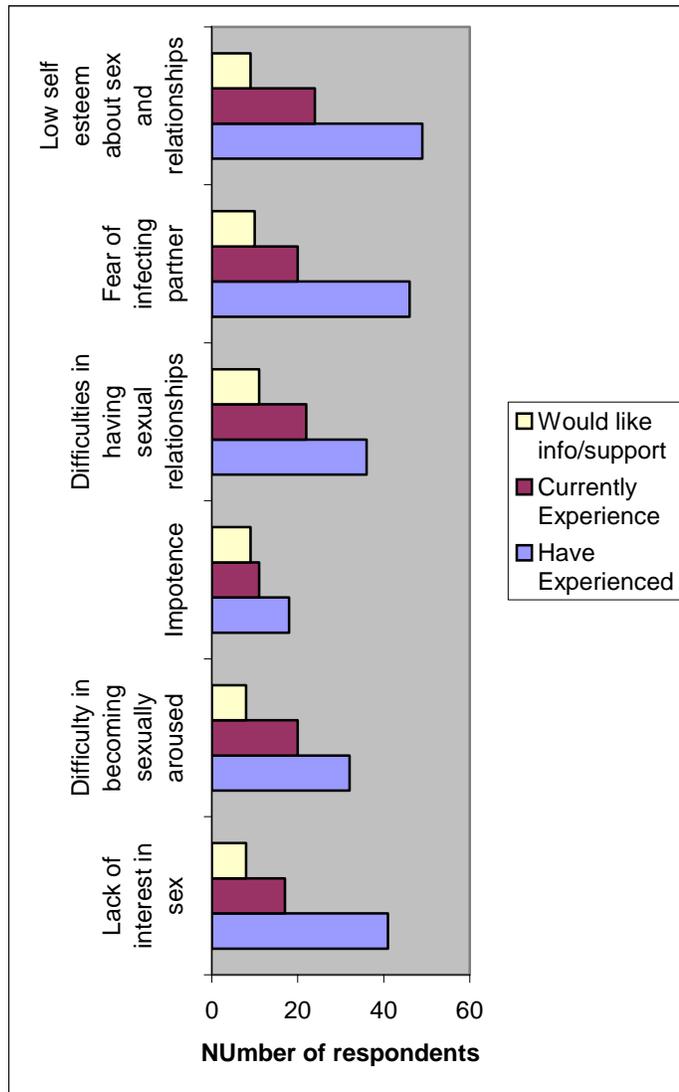


Figure 3.3 Illustration of sexual problems experienced by men with HIV living in Glasgow



There were relatively equal numbers of individuals responding to the questions around difficulties in terms of those in relationships and those who were not (42 vs 48). Those who were not in relationships were significantly more likely to have reported having experienced difficulties in having sexual relationships (n=30, 62.5%, p=0.006) and with low self-esteem (n=40, 83.3%, p=0.009) than those who were in relationships (n=13, 31.7% and n=23, 56.1%).

Within “What do you need” 40% of individuals reported being unhappy about their sex lives and 51% reported having experienced problems similar to those in this study in the

previous 12 months giving further evidence to suggest that people with HIV may require support around sexual health. Although sexual health advice was not rated highly as a need, relationship support and advice was and was the 4<sup>th</sup> highest unmet need reported.

### **Summary**

The majority of respondents felt that they had enough information on sexual health and knew where to access a sexual health service. However once again for small groups of individuals this does not appear to be the case and there is a need to ensure that this information reaches these people who do not feel they have sufficient information or are not sure if they have adequate knowledge in this area.

Respondents seemed to think that the sexual health services they had used catered well for the needs of people with HIV, however it would be worth seeing where improvements could be made and what roles these services might have in meeting individuals unmet information needs.

Many of the respondents seemed to be having issues with regards to sex, whether that be with low self-esteem or difficulties in having relationships. This would suggest a need to provide support to individuals, particularly to those not in relationships where these difficulties appeared to be more pronounced. The idea of groupwork was met with mixed responses therefore it may be that a variety of approaches are required in addressing this need as it is unlikely that one approach will suit everyone.

## Chapter 4

### HIV Support Services-PHACE Scotland

#### ***Background***

PHACE Scotland formerly known as PHACE West is a Scotland wide service offering sexual health information and support. It offers a range of services to a variety of groups of individuals including people who are HIV positive. The two main areas in which PHACE Scotland offers services are Gay Men's services and Support and Advocacy services. Individuals with HIV and AIDS can also apply through PHACE Scotland to the Crusaid Hardship Fund. This fund provides grants, usually one off, to help improve the quality of life for individuals with HIV and AIDS.

#### ***Knowledge and Usage of the Service***

When asked if they had ever heard of PHACE Scotland (formerly PHACE West), 83% of respondents (n=78) said yes they had.

Of the 17 individuals who had not heard of them, 9 were male of whom 7 were white, 5 were heterosexual and 5 had been diagnosed in the last 1-5 years. The remaining 8 individuals were female of whom 7 were heterosexual; one female chose not to identify her sexual orientation. Five of the eight females were White European and 7 had been diagnosed in the past 1-5 years.

Of those who had heard of PHACE Scotland, 67.9% (n=53) said that having looked at the list of services listed as being on offer that they had used PHACE Scotland.

Those who had heard of PHACE Scotland but indicated that they had never used them were asked why. Reasons given included

- Feeling that they did not currently need such a service.

*“Never felt the need to” (R11)*

- Not knowing what the service offered

*“Because I didn't no that all this services are provided” (R66)*

- Issues associated with confidentiality

*“Fear of confidentiality. Glasgow has a small gay scene – I would rather access services one to one anonymously” (R77)*

#### PHACE Scotland Support and Advocacy Services and Crusaid

The most commonly used services were the welfare rights and the crusaid hardship fund.

- Thirty-four respondents (65.4%) said that they had used the welfare rights service of whom 21 (61.8%) indicated that they had used it in the last 12 months.
- Thirty-one individuals (62%) reported having used the crusaid hardship fund of whom 20 (62.5%) had used it in the last 12 months.
- Only 3 respondents (6.4%) indicated that they had ever used the nightowl service and 16 (32%) reported that they had used the buddying/advocacy service.

#### Gay Men’s Services-Information

With regards to the Gay Men’s Services run by PHACE Scotland, 12 people said that they had used the information available through gay men’s services of whom 11 were male, 10 were White European and 10 were gay or unsure of their sexual orientation. One person reported being female, one reported being heterosexual and one person did not identify their sexual orientation. Three of the 12 respondents indicated that they had used this service in the last 12 months

#### Gay Men’s Services- Condoms

Eighteen individuals (32.7%) said that they had used the condoms from PHACE Scotland’s Gay Men’s services. Of these 18 individuals:

- **16 were male** and 2 were female
- **14 individuals were gay, or unsure.** Three people said they were heterosexual and 1 did not indicate their sexual orientation.
- **16 were White** and 2 were Black
- **8 were diagnosed in the past 1-5 years.** Three were diagnosed 6-10years ago and 7 were diagnosed more than 10 years ago.

- **10 were in relationships, 8 were not**

There are many places that people can access condoms either for free or for a charge. Fourteen individuals equates to approximately a quarter of those with HIV in this sample who identified as either being gay, unsure of their sexual orientation, bisexual or having had sex with men. There are many reasons why condoms may not be accessed from PHACE by HIV positive gay and bisexual men: for example they may be getting them from elsewhere, they may not need to use them or they may not be aware that it is PHACE who supplies them. However it could be that some work is required to raise awareness of the existence of this service to gay and bisexual men or men who are unsure of their sexual orientation with HIV. Half of those who indicated that they had accessed condoms from PHACE Scotland said that they had used this service in the last 12 months.

#### Gay Men's Services- Gay men's groups

Five people indicated that they had used the gay men's group run by PHACE Scotland, one of whom was a female. This person had ticked every box therefore it is likely that this is an error. Her data therefore has been excluded from the rest of the service usage analysis. Four gay men accessing this service equates to 10.6% of those men who had heard of PHACE Scotland and who identified as gay, having sex with men, bisexual or unsure. Three of the four said they had used this service in the last 12 months.

#### Gay Men's Services – Internet outreach and one to one

Nobody indicated that they had used the internet outreach service. Five males said that they had used the one to one service, all of whom said they had done so in the last 12 months.

#### Gay Men's Services – Telephone support, outreach and scene events

Seven men said that they used the telephone support which equates to 17.9% of the HIV positive men who said they had used PHACE Scotland and 14.9% of those who had heard of them and were gay, bisexual, had sex with men or were unsure of their sexual orientation. Six of the seven reported having used this service in the last 12 months.

The outreach services within parks and saunas were reported to have been used by 2 individuals neither of whom had accessed this in the last 12 months.

PHACE Scotland runs scene based event and seven gay men identified that they used this service 4 of whom said they had done so during the last 12 months.

#### Other services

Individuals were given the opportunity to list any other services they had accessed through PHACE Scotland. One individual reported training days and someone else mentioned the Social Work Department. One individual indicated that they did not think that PHACE Scotland offered many of the services listed, suggesting a lack of awareness of everything on offer. However the services in question were gay mens services and the respondent was a Black African heterosexual female which may explain why she was not aware of them.

### ***Evaluation of PHACE Scotland***

Those who had had used PHACE Scotland were asked to rate their experience. The majority of individuals said that they had found it either satisfactory (n=25, 50%) or very satisfactory (n=20, 40%). Only five individuals (10%) said that they had had an unsatisfactory (n=2) or very unsatisfactory experience (n=3).

### ***Benefits and Barriers***

Individuals were asked to indicate if they had experienced any benefits and barriers with regards to attending PHACE Scotland. Forty-eight (94.1%) individuals said yes they had experienced benefits, the majority of whom indicated that this was with regards to welfare assistance (68.8%, n=33). People also listed things such as practical support i.e. filling in applications.

In terms of barriers, only 8 individuals (16.3%) indicated that they had experienced difficulties. Three people (37.5%) mentioned issues with access, whilst other barriers listed by individuals were mainly unsatisfactory experiences with certain services e.g. buddying and financial support.

## **Changes**

Twelve individuals (26.1%) said that they would change something about PHACE Scotland. Suggestions mainly focused on the development of a drop in service with activities such as arts and crafts, holistic therapies and group work. Other people suggested more information: one indication was that this should be for gay men, with another saying more sexual health information for heterosexuals.

Those who had previously used PHACE Scotland but were not anymore were asked why this was the case. Most indications were that they had little need for it currently, with other comments including that there was little on offer for them as heterosexual, that they only used them for financial assistance or that they were currently experiencing difficulties with the service.

*“ No need” (R42)*

*“I don’t get the support I need.” (R54)*

*“It has a very limited amount to offer me as a hetero-male”  
(R104)*

## **Summary**

Most people had heard of PHACE Scotland and about 58% of those people who had heard of them had used them at some point. Those who had used them had for the most part found their services satisfactory or very satisfactory and had derived benefits mainly around financial assistance. There were some barriers for people but the numbers were relatively small and suggested changes to the service focused around providing drop ins and organised activities.

The most commonly used services were the welfare rights services and the crusaid hardship fund, which is perhaps reflective of people’s needs with regards to financial assistance.

With regards to the services offered by Gay Men’s Services, the usage was quite low and although there could be a number of reasons for this i.e. not needing to use the service or not wanting to use the service, it may be that these services need to be more widely promoted to ensure individuals are aware of them.

## Chapter 5

### HIV Support Services - Body Positive

#### **Background**

Body Positive Strathclyde was a self-help group run by and for people infected and affected with HIV. The aim of the organisation was to provide members with access to a range of services that would address some of the issues associated with being HIV positive and these included a drop-in facility, support groups, outreach work, one-to-one support, an information centre, transport and complementary therapies. The organisation had experienced some difficulties in recent years and these problems and issues escalated during the reporting period. In April 2005 after withdrawal of funding by several organisations including NHS Greater Glasgow Body Positive ceased to operate.

#### **Knowledge and Usage of the Service**

Seventy-nine individuals said they had heard of Body Positive Strathclyde (84.9%) of whom 77 (97.5%) indicated whether or not they were members or if they had ever used the service. Thirty-eight people (49.4%) said that they that they were members of Body Positive and 45 people (58.4%) reported having ever used Body Positive.

Of the 45 people who reported having ever used Body Positive, the majority were White gay men (n=22 51.2%). Nine of those reporting having ever used Body Positive's services were heterosexual males (21%), and 5 were Black African heterosexual women (11.6%). Over half (n=23, 52.9%) of those who had used Body Positive had been diagnosed over 10 years ago, with 13 (29.5%) having been diagnosed in the past 5 years and 8 (18.2%) between 6 and 10 years ago.

Those who had heard of Body Positive but had never used them cited reasons such as:

- Not needing them  
*“Haven't felt a need to use services. I try to live as near a pre HIV life as possible.” (R81)*
- Having heard rumours about in-house fighting

*Word of mouth about how dysfunctional and damaging its endless infighting has affected the people involved” (R57)*

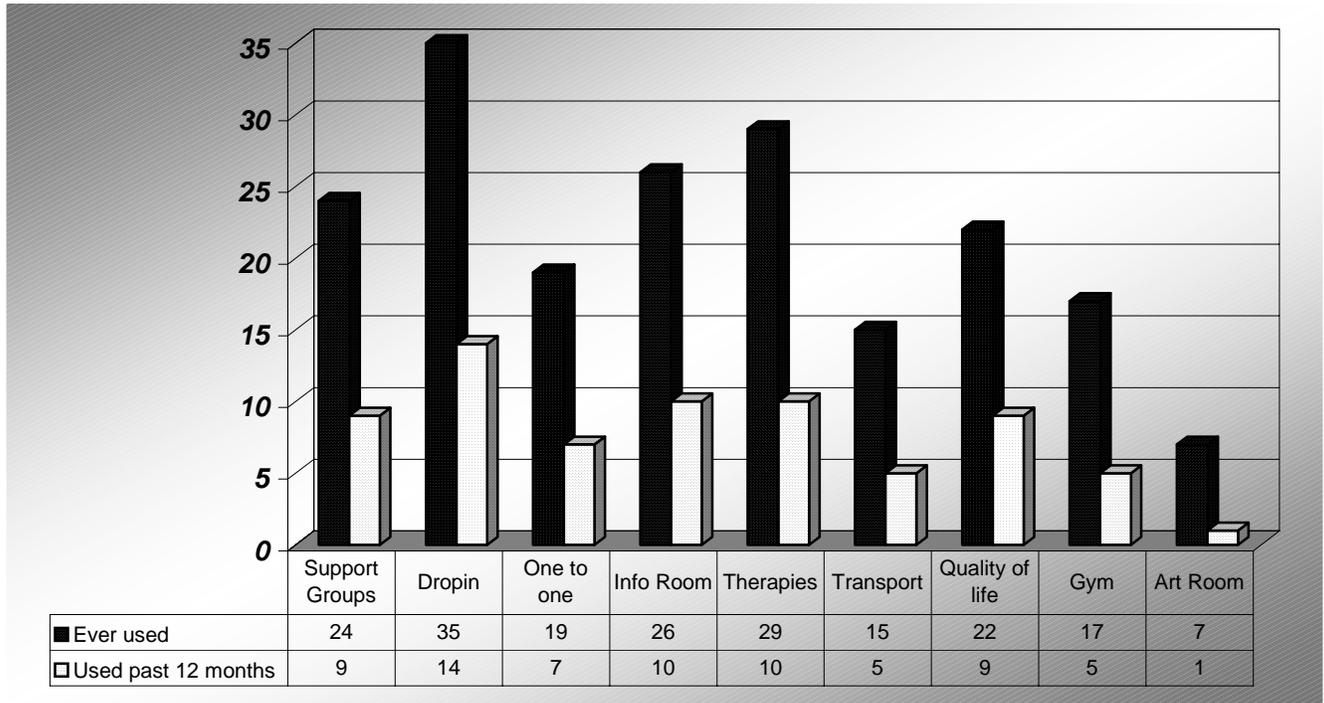
- Concern about meeting people who may be sicker than them and resulting fear of what might be to come.

*“.....I have a worry that by using some services on offer I am going to make myself more aware of being HIV. By mixing with people who are not as currently healthy as me I become more afraid of what the future might bring.....” (R99)*

Those who had not heard of Body Positive (n=14) were mainly male (n=8, 57.1%), White European (n=8, 57.1%) heterosexual (n=8, 61.5%) and had been diagnosed in the past 1-5 years (n=10, 71.4%).

The service most commonly reported as being used, was the drop in service (n=35, 77.8%). Fourteen of the 35 individuals (40%) said that they had used it in the last 12 months. Most of these 14 individuals were male (n=9, 64.3%), heterosexual (n=8, 61.5%), White European (n=11, 78.6%) and had been diagnosed in the past 1-5 years. Other services that showed reasonable levels of usage included the complimentary therapies (29, 64.4%) and the support groups (n=24, 53.3%). Figure 5.1 illustrates the usage of services offered by Body Positive.

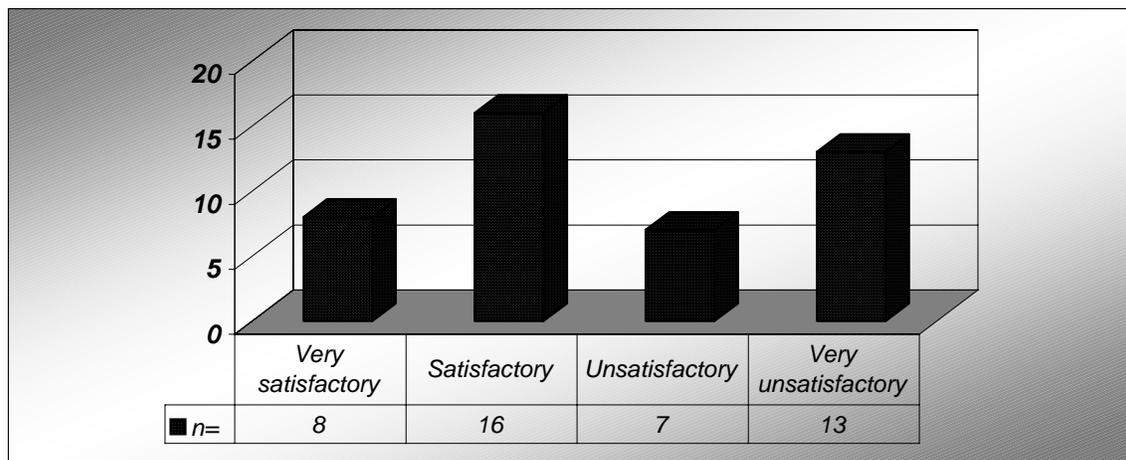
Figure 5.1 Illustration of the usage of the services offered by Body Positive



### Evaluation of Body Positive

Forty-four of the 45 individuals who had used Body Positive services, chose to rate their experience. The responses were very mixed as can be seen in figure 5.2

Figure 5.2 Illustration of how people rated their experience of Body Positive

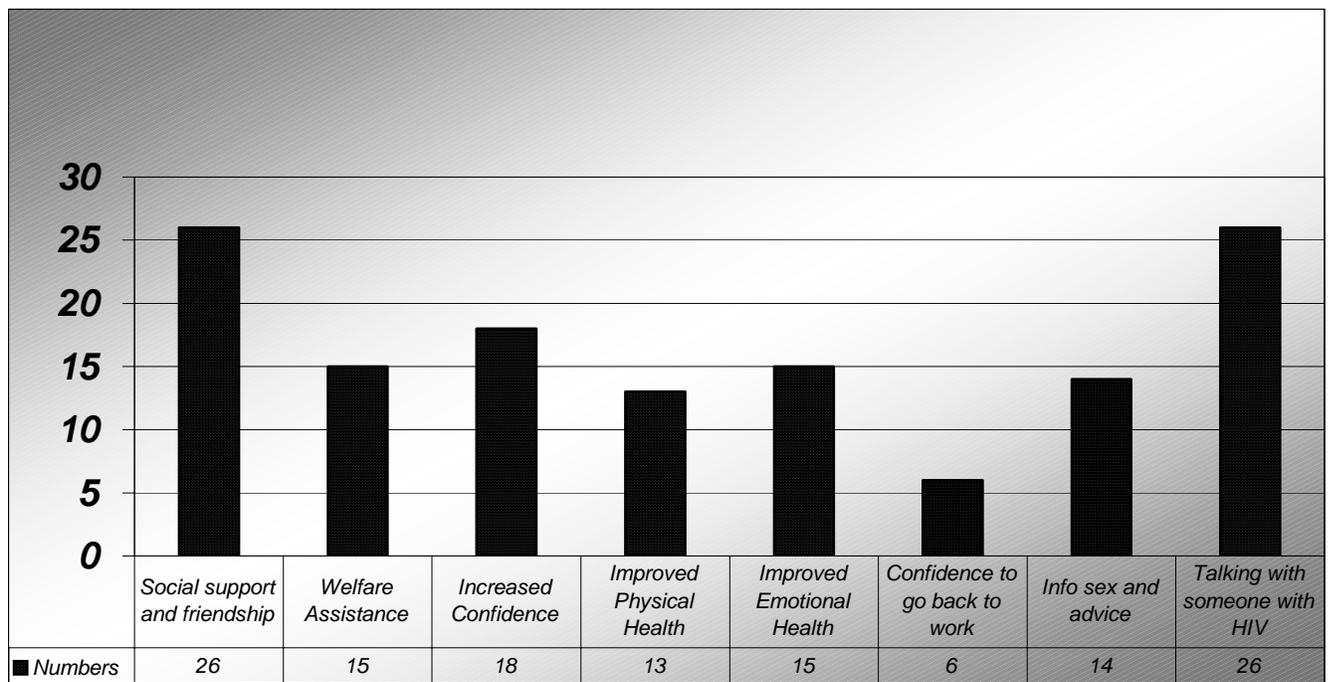


Some individuals noted that whilst they had once found it a very satisfactory service, more recently it had become quite the opposite and those who had had negative experiences seemed to have quite strong views about it as a service.

### **Benefits and Barriers**

The majority of those who had used BP said that they did derive some benefit from using the service (n=34, 77.3%). The most commonly reported benefits were social support and friendship (n=26, 76.5%) and talking to someone with HIV (n=26, 76.5%). Other benefits included increased confidence (n=18, 52.9%) and improved emotional health (n=15, 44.1%). Some people listed their own suggested benefits, which included respite and complimentary therapies.

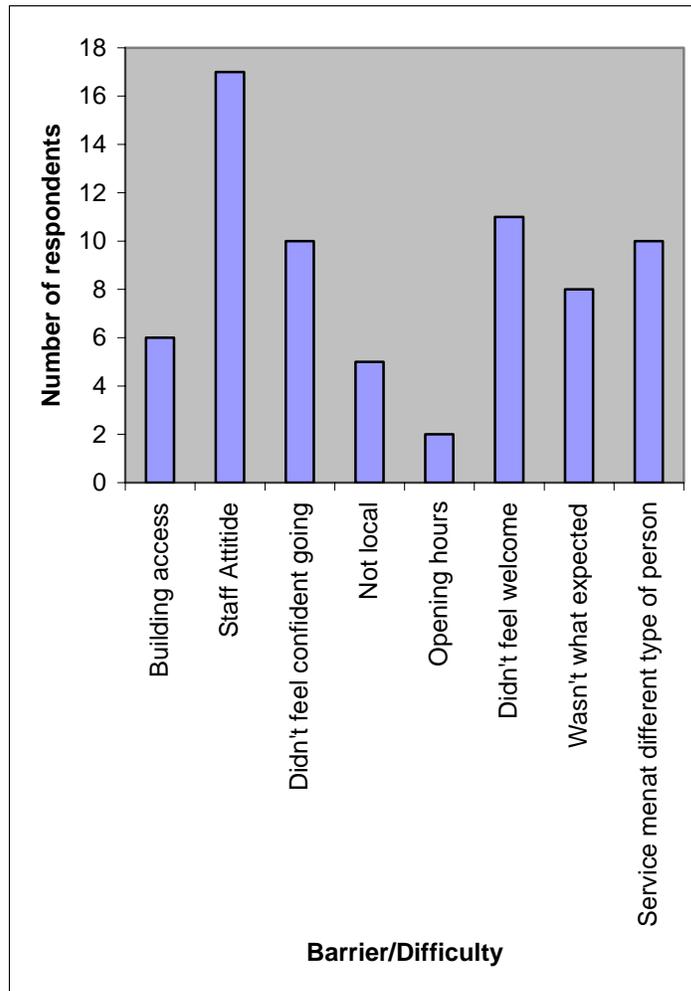
*Figure 5.3 Illustration of the benefits derived from using Body Positive*



Twenty-seven individuals (62.8%) said that they had experienced barriers to using Body Positive. The most commonly experienced barrier from the provided list of suggestions was staff attitude (n=17, 63.0%) followed by not feeling welcome (n=11, 40.7%). Those

who chose to write in the box provided tended to also mention staff attitude alongside backstabbing, being too cliquy or that the service was too tailored to certain groups of individuals.

Figure 5.4. Illustration of barriers/difficulties experienced in using Body Positive



### **Changes**

The majority of respondents (n=25, 71.4%) said that they would change something about Body Positive. Responses to this question ranged from those who said that they would wish it to reopen to those who indicated that the best thing that could of happened was for it to have closed down and opinions were obviously reflective of the difficulties some had experienced. Individuals suggested things such the service should not allow smoking; that the service should reopen as a generic service for people with chronic conditions,

that professionals should run it for members rather than members themselves running it and that the family centre be shut.

Those who had used Body Positive but were no longer doing so were asked why. The responses again were quite varied but the main reason given seemed to be that it had been shut down. Other reasons included that there was racism towards members, that individuals' needs had changed, staff attitude, that they had derived no benefits and that the organisation was a waste of time and money.

*“Because the place no longer runs due to funding problems”*

*(R23)*

*“Staff attitude” (R28)*

*“Totally think it is a waste of time and money” (R33)*

## **Summary**

Large numbers of the respondents had heard of Body Positive of whom around 59% indicated that they had used Body Positive at some point. The most commonly used service was the drop in service and many of the other services also showed a reasonable usage in the past. Large numbers of people derived benefits from this service mainly in relation to social support, friendship and talking to someone with HIV. However many also reported a range of barriers and many of the comments written in the space indicated that people had experienced great difficulties and distress from accessing this service. There seemed to be much dissatisfaction with the way the service was run. The diversity of views was born out in how people rated their experiences suggesting that it may have once been a service that people had benefited from attending but that in more recent years there had been huge problems.

The difficulties faced by Body Positive illustrate that the self-help model is a difficult one to sustain as it was also apparent that for some of those who had heard of the service but chosen not to use it, stories of in house fighting etc had influenced that decision.

## Chapter 6

### HIV Support Services - HIV Carers

#### ***Background***

The HIV-AIDS Carers & Family Service Providers Scotland offer support and services to carers, families, partners and friends who have a loved one with HIV or AIDS. The stated aims of the organisation is to provide practical and emotional support to carers, families, partners and friends of individuals living with HIV or AIDS.

#### ***Knowledge and Usage of the Service***

Thirty-four of the 94 respondents (36.2%) said that they had heard of the HIV Carers. Of those who had heard of the carers only six (17.6%) reported that their parents/carers were members of whom 4 said they were not aware of how often their parent/carer used the service. One person reported that their parent/carer used the service occasionally and the other individual said their parent/carer did not use the service at all. Seven individuals did not know (20.6%) if their parents/carers were members.

Four respondents (11.4%) said that they themselves were members of the HIV Carers and ten individuals (28.6%) said that they had used the service. Those using the service were mainly male (n=8, 80%) and White European (n=7, 70%). With regards to sexual orientation there was a 50:50 split between gay men (n=5) and heterosexuals (n=5).

Those who had heard of the service but never used it cited a variety of reasons including:

- Not needing that type of service

*“I have never needed that type of support” (R17)*

- Thinking that it was not for them service

*I didn't feel it was for me. Without any evidence I assumed it was a mums and wives type of project” (R104)*

- Not knowing where they operated

*“I don't know where they are.....”(R38)*

Reported use of the service overall was low (n=10), however the most commonly used service was the information service (n=5, 50%), with 30% of respondents (n=3) replying that they had used the one to one support. Only 1 or two people reported using the telephone support (out of hours and during office hours), the caravan, the hospital visiting service, the advocacy and bereavement services. Nobody indicated that they had used the home or prison visiting service.

### ***Evaluation of HIV Carers***

Of the ten people who indicated that they had used the service, most people had been pleased with the service they received. Eight people reported that their experience as satisfactory (n=2, 20%) or very satisfactory (n=6, 60%). Two people (20%) said that they had found it unsatisfactory.

### ***Benefits and Barriers***

Six of the nine people who responded (66.7%) indicated that they had received benefits from attending and that these benefits were:

- Social support and friendship (n=3)
- Welfare assistance (n=3)
- Increased confidence (n=3)
- Improved emotional health (n=3).

Nobody reported any benefits with regards to information about sexual health advice, improved physical health or confidence to go back to work.

Three individuals said that they had experienced difficulties/barriers to using the HIV Carers (33.3%). These were:

- Staff attitude (n=2)
- Not feeling confident to attend (n=2),
- Not feeling welcome (n=2)

- Opening hours (n=1)
- Building being difficult to get in and out of (n=1)
- Service not being local (n=1).

There was also a report of difficulties due to inhouse fighting.

### ***Changes***

Three of the five people who answered said that they would change something about the HIV Carers. The suggestions made were in relation to staff and location of the service.

Several individuals reported that they had used them in the past but didn't anymore and cited reasons such as staff attitude, location, their needs were now being met elsewhere and that they had moved on and no longer needed support.

### ***Summary***

The overall awareness of the HIV Carers amongst the respondents in this study was fairly low with only around a third of respondents having heard of the HIV Carers. Individuals with HIV did not appear to be aware of many of their parents/carers utilising the service and very few individuals themselves were using the service for support.

The majority of those individuals with HIV who had used the HIV Carers reported benefits from using the service and rated their experience well. There were a couple of individuals who had experienced barriers in using the HIV Carers and there were suggestions as to how the service could be changed such as staff and location.

It should be noted that the HIV-AIDS Carers & Family Service Providers Scotland are predominately set up to support carers/families and partners of people with HIV, therefore asking people with HIV as to their usage or their parents/carers usage may not give an accurate reflection of the overall usage of the service.

## Chapter 7

### **Lesbian and Gay Switchboard**

#### ***Background***

Lesbian and Gay Switchboard was established in 1976 as a support service for people in the West of Scotland experiencing issues relating to sexual orientation. Switchboard offers a wide range of services to lesbians, gay men, bisexuals, transvestites, transsexuals and their families and friends. The main focus of their activity is a telephone helpline which operates every night of the year, offering advice, support and referral around a range of issues including HIV and sexual health.

#### ***Knowledge and Usage of the Service***

Sixty-one of the 83 respondents (73.5%) indicated that they had heard of the Lesbian and Gay Switchboard. A number of people chose not to answer any of this section (n=15), of whom the majority were Black African (n=11, 73.3%).

Although 61 individuals had heard of the Lesbian and Gay Switchboard only 12 reported having ever used them (19.7%), of whom all were White European men who were either gay or unsure about their sexual orientation. With regards to diagnosis 7 (58.3%) had been diagnosed in the last 1-5 years with the remainder being diagnosed over 10 years ago (n=5, 41.7%).

Individuals indicated that in terms of what they had used the service for the majority used it for information about HIV (n=6, 54.5%) and sexual health information (n=5, 45.4%). Some had used it for advice on coming out (n=3, 27.3%), icebreakers/monthly social group (n=2, 18.2%) and advice on welfare assistance (n=2, 18.2%). Individuals also gave other uses such as information about gay venues and the scene.

Eleven of the 12 chose to indicate whether or not they had found the service useful of whom 10 said that yes they had. Seven (70%) said that they had derived some benefit from the service, which included someone to talk to and access to information and

advice. Three individuals indicated that they had experienced some difficulties, which included:

- Not being able to get through (n=3, 100%),
- That the information and advice was not what the person needed (n=3, 100%)
- That the service wasn't what person expected (n=2, 66.7%),
- That the opening hours didn't suit (n=2, 66.7%),
- Staff attitude (n=1, 33.3%)
- Not feeling confident calling (n=1, 33.3%).

### **Summary**

The majority of respondents had heard of this service even though only a few had ever used it. This is perhaps not surprising given the nature of the service. The Lesbian and Gay Switchboard is a telephone support line predominately used by people experiencing problems with their sexuality and therefore although they offer support and advice around sexual health and HIV, it is not specifically aimed at people with HIV and many people with HIV may therefore not utilise this service for support on this issue, particularly as it is targeting a specific group of individuals.

Those who had had found it a beneficial service although there were some barriers with regards to individuals reporting that they were not able to get through or that the information had not been useful.

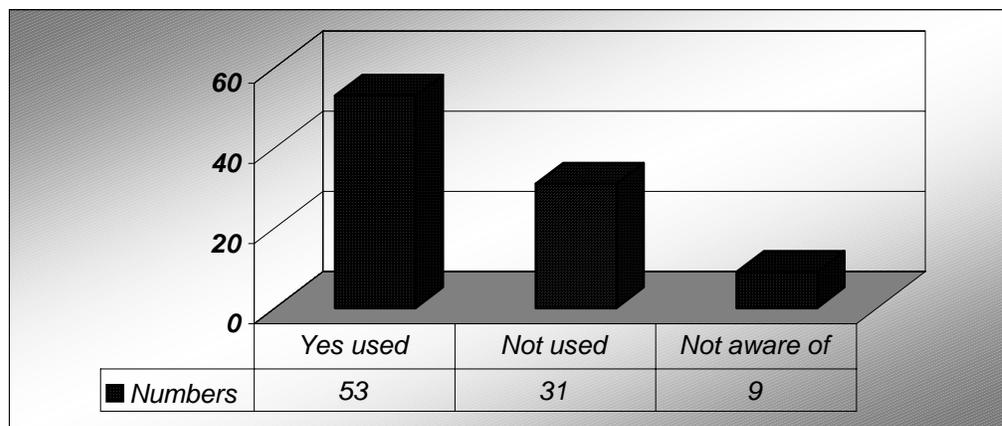
## Chapter 8

### Social Work

#### ***Knowledge and Usage of the Service***

Over half of those who responded indicated that they had used Social Work services at the Brownlee (n=53, 57%). A small number of individuals were not aware of this service (n=9, 9.7%) of whom the majority were White gay men. In terms of length of diagnosis most had been diagnosed in the last 10 years (n=8, 88.9%) with only one (11.1%) individual having been diagnosed over 10 years ago. Figure 8.1 illustrates respondents' usage of social work services.

*Figure 8.1 Illustration of the usage and awareness of social work services*



Just over a third of those responding (n=32, 34.4%) said that they had used social work services outwith the Brownlee Centre (34.4%). Of these 32 individuals, 22 (71%) had also used services at the Brownlee, 6 (19.4%) had not used the Brownlee Social Work services and 3 (9.7%) were not aware of the Brownlee Social Work Service.

#### ***Referral to Social Work***

Individuals most commonly reported that they had been referred to social work by a nurse/doctor from the Brownlee (n=42, 67.7%), with the next biggest referral being self-referral (n=10, 16.1%). Other referrals included PHACE Scotland, services in London, housing services and Ruchill Hospital.

### ***Allocated Social Worker***

Twenty-three individuals of the 57 individuals who answered (40.4%) said that they had an allocated social worker. A further 23 respondents said that they did not (40.4%) and 11 were unsure (19.3%). Of those who had used social work services either within the Brownlee or outwith, 25 reported having an allocated social worker (44.6%).

### Child Care Services

#### **Support**

Of the Forty-five people answering the question:

- **Twenty-nine (64.4%)** said that they did not need to use child care support services
- **3 (6.7%)** did not want to use these services
- **13 (28.9%)** were not aware of the services

Of those with children under the age of 16 who chose to answer this question (n=8), six were not aware of this service. One individual (12.5%) did not want to use the service and 1 (12.5%) did not need to use it.

#### **Respite**

In terms of usage of the respite service:

- **29 individuals (65.9%)** said that they did not need to use this service
- **13 individuals (29.5%)** said that they were not aware of the service
- **2 (4.5%)** indicated that they didn't want to use the service

Five of the 6 parents who had children under the age of 16 living with them were not aware of the respite service. One person indicated that they did not need to use the service (16.7%).

#### **Other Comments**

Comments in this section generally reflected the lack of awareness of these services. One person had obviously found it beneficial but had not indicated so in the tick boxes.

*“I would not have the first clue how to access this support and as a single ..... parent might benefit from this” (R104)*

*“I found the service is very useful and help me with any inquiry I have. “VERY SUPPORTIVE”” (R70)*

## Practical and Financial Support

### Home Care

With regards to homecare:

- **26 individuals (48.1%)** said that they did not need this service
- **19 individuals (35.2%)** were unaware of the service
- **4 individuals (7.4%)** said they had found the service beneficial
- **4 individuals (7.4%)** said that they had not found the service beneficial
- **One person (1.9%)** indicated that they did not want to use the service.

Within the needs section of the questionnaire 26 people said that they needed support with activities of daily living, 19 of whom answered the question about home care. Of the 4 people who had stated that they had not found the service beneficial, 3 required support with activities of daily living. Equal numbers of those requiring support (n=6, 31.6%) indicated that they were not aware of the service or did not need the service (n=6, 31.6%). Of those who were not aware of the service:

- **2** were White heterosexual males
- **2** were Black heterosexual women
- **1** was a White heterosexual woman
- **1** was a White gay man

Three of the six had been diagnosed in the past 1-5 years, 2 had been diagnosed in the past 6-10 years and one in the last 10 years.

Another group who may benefit from knowledge of this service are those who identified as having physical/mobility impairment. Sixteen individuals (64%) with physical impairments answered the question relating to homecare. Of the 16:

- **7(43.8%)** were not aware of the homecare service
- **4 (25%)** said they had not found the service beneficial
- **2 (12.5%)** said they had found it beneficial
- **3 (18.8%)** said that they did not need to use the service

### **Home Helps**

Most people once again indicated that they did not need to use the service (n=25, 49%) but there were similar numbers (n=18, 35.3%) who said that they were unaware of the service. Looking at those who had previously indicated that they needed support with activities of daily living six were unaware of the service (n=6).

Of those with physical impairments responding to this question (n=14), most were unaware of the service (n=5, 35.7%). Equal numbers of individuals (n=3, 21.4%) stated that they had found it beneficial, had not found it beneficial or did not need the service.

### **Emergency Financial Assistance**

- **27 (50%)** said that they were not aware of this service
- **20 (37%)** saying that they did not need to use the service
- **4 (7.4%)** saying that they had found it useful
- **3 (5.6%)** saying that they had not found it beneficial

Those who had not found it beneficial were all male, white, gay or unsure about their sexual orientation. Those who did not know about the service but said they had financial needs were mainly diagnosed in the past 5 years and were fairly evenly spread in terms of gender, sexual orientation and ethnicity.

### **Respite for Adults**

Social work services offer respite for adults, however 23 (42.6%) of those responding to the questionnaire were not aware of the service, with an equal number saying that they did not need such a service. A further two individuals (3.7%) said that they did not want to use the service and 6 had found the service beneficial (11.1%).

It could be postulated that those most likely to need such a service would be those individuals who identified that they need support with activities of daily living, although other individuals may also need such a service. Fourteen of the 23 individuals who were unaware of the service were male (60.9%) and nine were female (30.1%). Over half of those who were unaware of the service were White European (n=16, 69.6%) and over half were heterosexual (n=15, 68.2%). Of those who said they needed support with activities of daily living (n=26) 8 did not know of respite care (30.8%). There was little difference between those with lack of awareness when looking at gender, ethnicity and sexual orientation combined.

### **Other Comments**

The comments under the practical and financial support box were quite varied. Some people expressed that they had found these services extremely beneficial and were grateful for this service, others felt that they might be able to benefit from such services however had not been aware of this service and were unsure as to how they could access it. Some of those who had accessed aspects of these services expressed their displeasure with the service they were given.

*“Excellent” (R72)*

*“I did not know I could get financial help” (R55)*

*“Very limited support too 9-5” (R40)*

### **Emotional Support**

#### **Emotional Support**

When asked about the emotional support aspect of social work services, there were again a reasonable number of people who claimed to be unaware of these services (n=27, 41.5%). Of those who were unaware of the service

- **10** were White gay men
- **7** were White heterosexual males
- **4** were Black heterosexual females

### **Other Comments**

As with the practical and financial support section, the comments were mixed. Many felt the service had been extremely beneficial however equally there were individuals who seemed to have issues with this service and the staff. Others simply were not aware of its existence.

*“The social services at Brownlee are excellent” (R105)*

*“I find the staff cold-detached-lacking interest and empathy...” (R91)*

*“Didn’t know this was available” (R74)*

### **Information and Advice Services**

As part of social work services, information and advice is offered on a range of topics. Individuals were asked to comment on their use of the various elements of this service.

### **Housing**

Of the 59 individuals answering the question many said that they had found this service beneficial (35.6%, n=21), although similar numbers were not aware of the service (30.5%, n=18). 12 of the 19 people with unmet housing needs answered the question about the social work service offering information and advice about housing. Of the 12 individuals:

- **6 (50%)** were unaware of this service offered by social work
- **2 (16.7%)** individuals said they had found it beneficial
- **2 (16.7%)** said it was not beneficial
- **2 (16.7%)** said they either did not need or did not want to use the service.

### **Drug and Alcohol use**

Most people said that they did not need to use this service (n=29, 64.4%). Of those who had previously admitted to injecting drugs (n=13), 8 (61.5%) responded to the question about drug and alcohol advice services:

- 3 (37.5%) said that they were not aware of the service
- 2 (25%) thought it was beneficial
- 2 did not need it (25%)
- 1 (12.5%) did not want to use the service

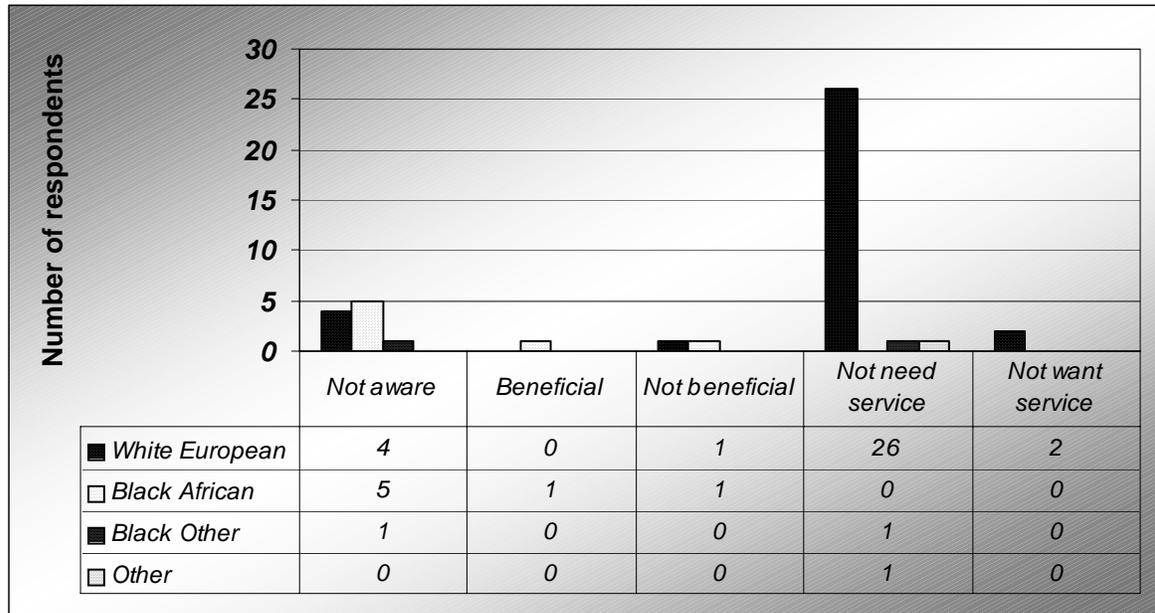
### **Child Care**

Given that most people did not have children it is perhaps not surprising that most individuals responded to this question by saying that they did not need this service (n=27, 62.8%). However of those with children under 16 of whom all or some were living with them, 80% were unaware of this service (n=8).

### **Asylum status and Refugee Council**

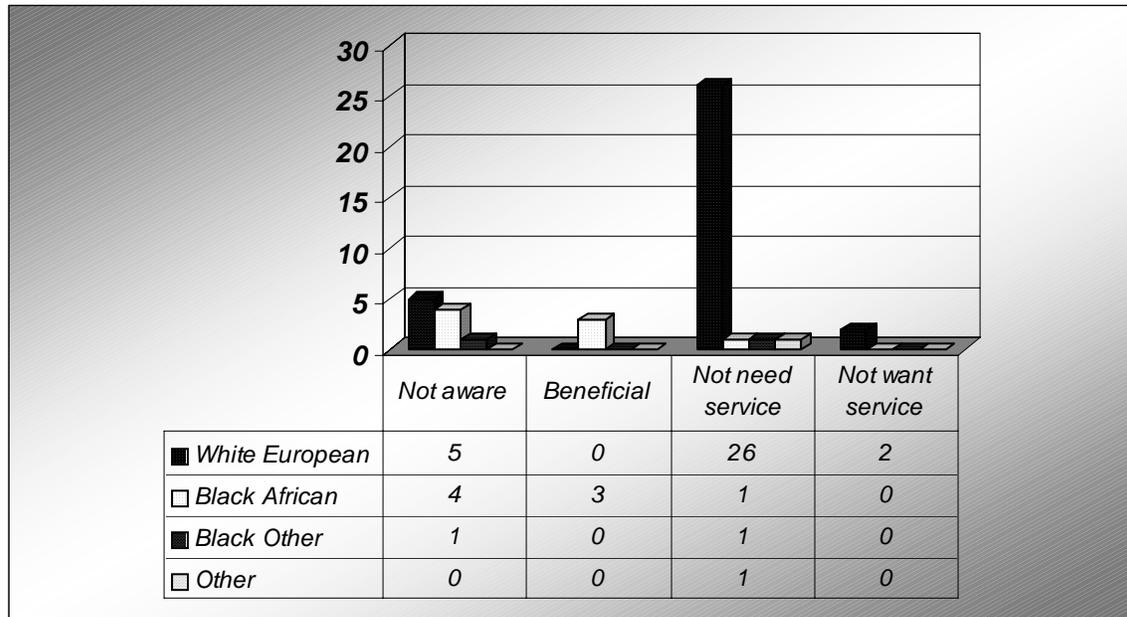
This service is not applicable to UK residents. Unfortunately no question was asked as to asylum status therefore there is no way to accurately crosstabulate usage based on asylum status. Whilst it should not in anyway be assumed that asylum status can be judged by ethnicity, it is likely, based on what is known about Glasgow's asylum seeking population that a number of those identifying as Black Africans could be asylum seekers or refugees and therefore cross tabulating ethnicity and usage may give the best indication of whether those in need are accessing or aware of the service. This was also the case with regards to information and advice about the Refugee Council. Of those Black Africans responding, most were unaware of information and advice around asylum status (71.4%). Most White Europeans unsurprisingly said they did not need such a service. Figure 8.2 illustrates these findings.

Figure 8.2 Illustration of usage of information and advice service in relation to asylum status by ethnicity



With regards to information and advice about the refugee council, again most of the White Europeans responded that they did not need this service, with 5 saying that they were not aware. Amongst Black Africans there was almost a 50:50 split between those who found it beneficial and those who were not aware. Figure 8.3 illustrates these findings.

Figure 8.3 Illustration of the usage of the information and advice service about the Refugee Council by ethnicity.



### **Residential nursing care**

Fifty-five people chose not to respond to this question, which is over half the overall sample. Of those who did respond (n=43) most individuals said that they did not require such a service (n=28, 65.1%) with 12 (27.9%) saying that they were not aware of such a service. When crosstabulated with length of diagnosis and also whether people said they needed support with activities of daily living, the findings were as follows:

Table 8.1 Usage of information and advice service about residential nursing by length of diagnosis

Usage / Diagnoses	Not Aware	Beneficial	Not Need to use	Not want to use
1-5 years	7	0	13	1
6-10years	0	1	4	0
10years +	5	0	11	1

Those not aware of these services (n=12) were split evenly between males and females. Seven of the 12 were White European, with the remaining 5 identifying as Black African. Eight individuals were heterosexual and 3 identified as being a gay man.

*Table 8.2 Usage of the information and advice service about residential nursing by those requiring support with activities of daily living.*

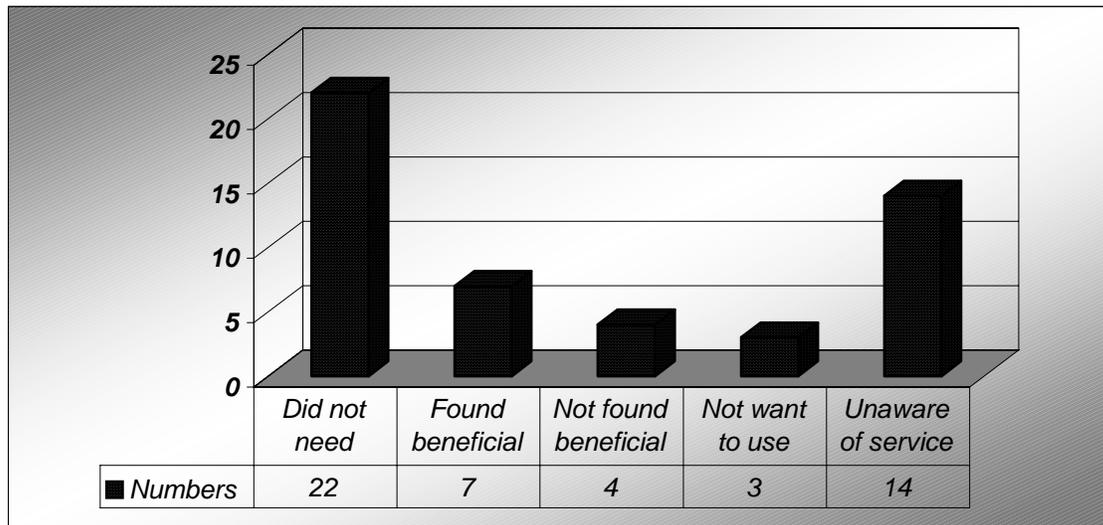
Usage Support	Not Aware	Beneficial	Not Need to use	Not want to use
Yes	4	1	7	1
No	8	0	21	1

Those requiring support with activities of daily living but who were not aware of these services were mainly women (n=3) and heterosexual (n=3). In terms of ethnicity 2 respondents were White European and 2 were Black African.

**Residential nursing care**

Fifty individuals responded to this question of whom 22 (44%) said that they did not need information on such a service. The responses are illustrated below.

*Figure 8.4 Illustration of the usage of the information and advice service on mental health*



Of those who were unaware of such a service (n=14), 9 were male (64.3%), 5 were female (35.7%) and most (64.3%, n=9) had been diagnosed in the last 1-5 years.

**Occupational/Therapy aids**

Of those with physical impairments or who indicated that they required support with activities of daily living the majority indicated that they had found the service beneficial

(n=9, 60% and n=7, 43.8% respectively). There were however 5 people (31.3%) of individuals who required support with activities of daily living and 3 people with physical impairments (20%) who were unaware of this service.

### **Education/Training/Employment**

Most people seemed to be unaware of this service (n=24, 47.1%) of whom a number were currently unemployed (n=6, 25%) or on long-term sick leave (n=3, 12.5%).

### ***Summary***

Just over half of those who responded to this section (n=53, 57%) had used social work services within the Brownlee with an additional 9 people stating that they had used social work services outwith the Brownlee. Perhaps unsurprisingly, given that only 54 respondents (56.3%) said they had specific needs as a result of being HIV positive, the majority of individuals stated that they did not need to use many of the services offered by social work. For many of these questions only around half of the overall cohort responded, which may be a consequence of them not having used the service and this needs to be taken into consideration.

What is worth noting is that often people seemed unaware of the services offered by Social Work and while for some respondents there might be no requirement to use them, there is evidence to suggest that some individuals might benefit from knowledge of these services, for example those with financial needs, those with housing needs and those requiring support with activities of daily living or with a physical/mobility impairment. There may therefore be a need to raise the profile of the services offered by social work and how to access them.

## **Chapter 9**

### **Summary and Recommendations**

#### **Summary**

The purpose of this study was to examine the current social support and sexual health needs of HIV positive people living within the Greater Glasgow NHS Board Area. In order to do this seven key objectives were established. These were to:

- Establish the level of knowledge of existing non-clinical HIV support services currently available in Glasgow including those offered by the Brownlee Centre.
- Identify patterns of use at these existing social support services including frequency of use, past use and reasons for discontinuing use.
- Establish some of the reasons why people choose not to use non-clinical HIV Support services.
- Identify which facets of particular services individuals with HIV find most useful and why.
- Identify if there are needs among Glasgow's HIV population that are not currently being met by existing services.
- Identify if there are common traits amongst those who feel their needs are not being met.
- Identify if there are periods in individuals' lives when non-clinical HIV support services are particularly necessary e.g. on diagnosis.

Whilst a relatively small sample, the demographics of the sample that took part in this study were fairly representative of Glasgow's HIV population at the time the questionnaire was administered. The findings of this study can therefore be seen as giving a reasonably accurate picture of the views of people with HIV living in Glasgow at that time. In addition many of the key findings are similar to the findings of the Sigma report 'What do you need', which was a national survey of the needs of 1821 respondents with HIV.

## Needs

This study found that there was virtually an even split between those respondents who said that they had needs as a result of being HIV positive and those who said that they did not. The needs people identified were quite general, for example general health and wellbeing advice, financial support, physical activity and nutritional needs, however these did vary slightly when looked at in terms of gender, sexuality and ethnicity. Of those individuals with needs, many had found ways of meeting these needs, for example through services such as the Brownlee Centre, self management or through friends and family. This mirrors findings within the Sigma report, which states:

*“Many people with HIV have very few needs or have found satisfactory ways of meeting their needs. HIV can be a chronic manageable condition.”*

This is not however to say that this is the case for all, or that some of those stating that they currently have no needs will not require support in the future and there is a need to ensure, as amongst those without HIV, that those most in need have the support they require.

In this study there were a number of individuals who identified that they had needs that were currently not being met; most of which were in relation to finance, housing and physical activity. Black Africans more commonly also reported an unmet need in relation to finding employment. Additionally there were a small number of individuals who reported that they required support with activities of daily living but were currently without a carer and small number of individuals who felt they had insufficient information about sexual health suggesting they too may have unmet needs.

Although when examined collectively, relationship support and advice was not in the top 3 needs listed, it was reported highly and indeed was the 4<sup>th</sup> highest response with regards to unmet needs. Just over 70% of both male and female respondents reported having experienced low self esteem in relation to sex and relationships with many still experiencing difficulties and wishing information and support. Individuals also reported having had or were experiencing problems in terms of lack of interest in sex, fear of infecting partners and difficulties in having sexual relationships. Those individuals who

were not in relationships were more likely than those in relationships to express low self-esteem and problems in having a sexual relationship. These findings are similar once again to the Sigma findings where 40% of individuals reported being unhappy about their sex lives and 51% reported having experienced problems similar to those in this study in the previous 12 months. This is clearly an area where people are requiring support and therefore ways of addressing some of the issues for people; particularly those not currently in relationships need to be examined. Group work should not be the only solution on offer as it was met with mixed responses.

Most of the unmet need identified in this study has the potential to be addressed through services such as social work and other mainstream providers. There is a need to ensure people with HIV are aware of what these services can offer and how to access them. Training for mainstream services around HIV will be vital in ensuring some of the barriers for people with HIV are tackled.

#### Service Knowledge and Usage

Most people had a reasonable awareness of the services asked about in this study. However there were again small numbers of individuals for whom this was not the case and who had never heard of certain services or who were not aware of aspects of these services. If people living with HIV are to have access to support as and when they require it, there is a need to ensure that everyone is aware of the services on offer and how to access them. There should also be ongoing monitoring to see how useful people are finding these services and people should be aware of how to feedback any difficulties they may be experiencing.

Respondents stated that use of services was varied. Not all of those who had heard of the services chose to use them, and the reasons cited were again variable with reasons cited including that people felt that they didn't need such a service or that they had heard negative things about the service. Those who did use the services using services often used only specific parts therefore some of the services offered by organisations were not as well utilised as others. Reasons people gave for no longer attending services included bad past experiences or just no longer feeling the need to attend such a service.

The most commonly reported benefits people received from attending services included financial assistance and the opportunity to talk to other people with HIV. Talking to someone with HIV and the importance of peer support is also featured in the Sigma report. This would appear to be an important area for some people with HIV and so ways of meeting this need should be looked at as part of service delivery. Barriers to accessing services were also identified by individuals in this study. These were variable but should still be taken into consideration when looking at reviewing or changing service delivery.

## ***Recommendations***

1. Development of a resource (or review of existing resources) to ensure maximum awareness amongst people with HIV as to where and how they can access services which may better meet their needs. This should be available upon diagnosis and readily available to people with HIV within the Brownlee Centre.
2. Services such as the “ Live Active” service<sup>4</sup> should be promoted by all staff within the Brownlee who are involved in the treatment and care of individuals with HIV. Exercise Counsellors from the scheme could come to do an input to staff and or patients highlighting what the service offers and how it could benefit individuals with HIV.
3. Stronger links need to be made between HIV services and mainstream services who might be able to meet some of the needs of people with HIV for example employment agencies. Training should be provided where appropriate to ensure that this happens and barriers are minimized.
4. Ways of helping people in terms of employment and training should be examined. Employment This support could involve working with individuals to find courses or develop skills for the workplace but it could also involve working with workplaces to ensure they are equipped to deal with an HIV positive employee and are informed about employment laws around HIV. A common wish amongst

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<sup>4</sup> The ‘Live Active’ service is a service that offers exercise counselling, support in becoming physically active and discounted rates with regards to leisure facilities access across Greater Glasgow. All staff have recently been trained in exercise counselling and providing appropriate programmes for people with HIV and the service accepts referrals from the Brownlee Centre.

individuals taking part in the Sigma research was for a more flexible benefits system that did not put individuals at risk of losing their benefits because of enrolment in education and it maybe that whatever programmes/training opportunities are developed would need to consider this.

5. Ways of addressing sexual health problems experienced by individuals needs to be investigated.
6. Social support needs need to be considered as part of service delivery. This has traditionally been in form of drop-ins sessions within services, although these may not necessarily be the best use of resources. Talking to someone else with HIV does appear to be important for many individuals with HIV, therefore ways of providing social opportunities may need to be looked at i.e. social events and peer support.