

Chapter 10: Support from voluntary agencies for people with HIV

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The HIV Voluntary Sector over the last 10 years

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My personal involvement in the HIV sector began in 1992 when I became a volunteer with the predecessor of Sahir House in Liverpool. At that time, voluntary agencies were foremost in providing direct support, information and empowerment to those living with, and affected, by HIV. Our volunteers worked with people with chronic health issues and our years were marked by the number of funerals we attended.

So what has changed today? Well, during the past 10 years since North West monitoring started, the HIV world and the voluntary sector have gone through many changes.

Now as a paid worker, I notice that we are providing all the services we did in the past but they have evolved and changed with the times. We are also seeing many more people but with little increase in financial resources. The removal of ring-fenced HIV funding has made planning service provision difficult for voluntary organisations. Many of the services we offer today are not funded by Government grants but by individual trust funds which are constantly under pressure as HIV charities around the country all scramble to obtain pots of money to keep projects going.

People are sometimes still unwell, but today the reasons may be due to the side effects of antiretroviral medication which, as well as providing hope for those who choose to take it, has for some, created other problems.

Obviously people living with the virus also have many other issues in their lives besides their health, so we are increasingly getting involved in areas such as housing and asylum. I have also noted that we have had a massive increase in the uptake of complementary therapies and especially counselling to help people cope with side effects and other issues related to living longer with HIV.

Other developments have reflected the changes in HIV and our society. In the early days our membership was almost exclusively white and male, however, today Sahir House truly mirrors the global pattern of HIV. Over 40% of our service users come from black and minority ethnic groups and women and children are very evident.

In recent years I feel that our partnership with statutory workers in health and social services has grown and that our opinions and expertise are valued. Our skills as trainers and our involvement in service development are being acknowledged, and the voluntary sector is now being regarded as a useful and powerful ally.

I feel that as our organisation celebrates 21 years of support and information on Merseyside we have come a long way. Our survival has been based on a willingness to adapt with the times and this has always been driven by the needs of our service users.

The HIV voluntary sector should always be a major part of service development. It gives a voice to those who feel unable to speak out as individuals due to the stigma and prejudice that unfortunately still exists. My hope is that the dedication and professionalism of the voluntary sector continues to be rewarded with increased long-term funding to enable us all to continue with our vital work.

Introduction

Voluntary agencies in the UK have provided invaluable additional support to people living with HIV (PLWHIV) since the first gay men who lived in London were seen to die of AIDS related illnesses in the early 1980s¹. The recognised need for support for people diagnosed HIV positive outside London resulted in the development of the Body Positive network in the mid-1980s and the establishment of phone line services around the country (e.g. Warrington AIDSline). Many smaller voluntary agencies combined forces in the late nineties in response to the emerging diversity of people living with HIV. Due to volunteers' direct experiences of HIV, voluntary organisations are uniquely placed to offer services tailored for HIV positive people. One of the first schemes set up by voluntary organisations, such as Terrance Higgins Trust, was to provide support through 'buddying' that countered the isolation and shock felt by people diagnosed with AIDS¹.

HIV community organisations are identified in the Department of Health's AIDS Service Grant circular as key providers of social care². Local authorities (LAs) are encouraged to develop, jointly with primary care trusts (PCTs) and neighbouring local authorities, common application forms and monitoring arrangements for the voluntary services that take into account the principles of the *Compact on Relations between the Government and the Voluntary and Community Sector in England*³. Where LAs are thinking of commissioning services from voluntary agencies early indications of purchasing intentions should be given, even if these are only in principle, and streamlined and timely procedures are important because many organisations do not have significant financial reserves. The Department of Health anticipates an increasing role for the voluntary and independent sector in HIV and sexual health care services as set out in the White Paper *Our health, our care, our say: a new direction for community services*⁴.

The new British HIV Association (BHIVA) standards published in partnership with The Royal College of Physicians, The British Association of Sexual Health and The HIV British Infection Society recognise that voluntary agencies are experts in providing patient education, and recommend that NHS commissioning groups that include PCTs, Sexual Health Centres and Mental Health Trusts should also include voluntary and community groups. It also recommends that HIV testing facilities need to be extended and proposes that voluntary and community organisations should be included in this expansion⁵.

Voluntary agencies provide a wide range of services including counselling, information services, training, awareness raising campaigns, complementary therapies, advocacy, free condoms, financial assistance, fundraising, support groups and help lines. Some also offer medical services such as nurse appointments with local PCT staff. Most agencies provide services for a variety of PLWHIV and may run special sessions for women, gay men, African people and young people. Some services, such as the Black Health Agency and Barnardo's provide care to specific groups affected by HIV, but the majority see a wide variety of people. Most services also provide care and support to the friends and family of those affected by HIV.

As mentioned earlier (see vignette by Steve Earle), voluntary agencies are increasingly involved in helping people with asylum applications and housing and financial problems. Voluntary agencies provide valuable support to migrants and people seeking asylum in the UK and the National AIDS Trust (NAT) recommends that voluntary services be strongly involved in issues of dispersal⁶. NAT has been key in changing the National Asylum Support Service policy so they now give a longer period of notice to failed asylum seekers living with HIV. NAT have also, in the case of those who are being dispersed around the country, pushed to ensure clinicians must be satisfied that arrangements are in place to ensure continuity of care. Accommodation providers now have a formal obligation to ensure PLWHIV register with a GP in their dispersal area⁷. The implementation of these new responsibilities show the strength of large national voluntary agencies and also indicate how much more important their role in care of asylum seekers living with HIV may be in the future.

The voluntary sector differs from the statutory sector not only in the services it provides but also in the way these services are run and financed. Although some NHS centres have volunteers (e.g. Armistead in Liverpool), the majority of their staff will be paid, professional employees (see Chapter 12 for more details on the economics of HIV care in the North West). Volunteers in the sector are an invaluable source of support for people living with HIV. An investigation into the economics of HIV in the North West found that overall 66% of the funding for the seven largest North West voluntary agencies came from the statutory sector but the combined value of the volunteers and non-statutory income means that the statutory sector gets £2 of services for every £1 spent⁸.

The importance of the contribution made by voluntary agencies to the care of people living with HIV is highlighted by the number of people seen by North West voluntary agencies who had not been seen in the same year in statutory treatment centres. In the last ten years since North West monitoring began, an average of 24% of people seen by the voluntary sector each year had not been seen by the statutory sector in the region in the same year, with the highest proportion (30%) in 2004. Those people not seen in the statutory sector will not be included in the North West annual dataset sent to the Health Protection Agency (HPA) and thus excluded from the national figures. However, caution must be used interpreting these figures as people who have provided inconsistent personal details to voluntary agencies may not be matched to the statutory dataset and may therefore be counted as different individuals.

Collection of data from North West voluntary agencies

The North West HIV/AIDS Monitoring Unit has been collecting data from North West voluntary agencies since monitoring began in 1996. Voluntary agencies provide significant additional support to people living with HIV as well as their carers and those affected by HIV. The data included in this chapter comprise all data provided over the past ten years with the exception of 1998 where data are not available. It is important to note that not all agencies are able to provide data every year and not every person seen by an agency will be reported to the North West HIV/AIDS Monitoring Unit. Only people for whom an agency can provide a valid soundex, date of birth and sex can be included, so those with non-attributable information are not included. The numbers reported to the HIV/AIDS Monitoring Unit do not necessarily include all HIV positive people seen, as agencies often see clients for one off or anonymous contact and are not given personal details. Additionally, most services also provide a significant amount of support for families and friends affected by HIV and therefore the numbers included in this chapter do not represent full workload. It is also worth pointing out that there are some voluntary agencies in the North West who are not able to supply data and who are providing a valuable contribution to the care of PLWHIV.

Aim

This chapter aims to examine the changes in ethnicity and exposure route of PLWHIV attending North West voluntary services since 1999. Given that the voluntary sector has consistently provided care to a proportion of people who are not seen in the statutory sector, this chapter also aims to compare the characteristics and demographics of these individuals to those who access the statutory sector. Finally, historical data are used to make projections regarding the expected number of PLWHIV who will be attending North West voluntary agencies in coming years.

Methods

As the number of agencies and the total number of people reported was so low in 1997, and the data for 1998 were not available, most of the analysis in this chapter is based on the data received since 1999.

Trends over time in the composition of the population served by the voluntary sector were investigated by taking the proportions reported in each year as one variable and time as the second variable, and calculating Spearman's rank correlation coefficient (a non-parametric test).

The profile of the voluntary sector and statutory sector populations were compared by looking at proportions reported in the 2005 annual report from statutory treatment centres¹⁰ and the distribution of infection routes and ethnicity at the voluntary agencies. Chi-squared goodness of fit tests, excluding those where routes of infection or ethnicity were unknown, were used.

To examine the relationship between voluntary sector attendance and deprivation, place of residence (stored as lower output area) of all individuals seen in both statutory treatment centres and voluntary agencies in 2005 were allocated an Index of Multiple Deprivation (IMD) score based on the LSOA (all LSOA data were supplied by the North West Public Health Observatory). The higher the IMD score, the more deprived an area. Records without a valid postcode or those who live outside the North West region were not allocated an IMD score and were excluded from the analysis. Individuals were allocated to three groups depending on where they had attended in the year: *statutory only*, *statutory and voluntary* and *voluntary only*. Valid LSOAs and IMD scores were obtained for 85% of people seen across the statutory and voluntary sectors. There was variation between the groups as to the proportion of people who could be allocated an IMD score. IMD scores were allocated to 81% of the statutory only group, 96% of the statutory and voluntary group and to 79% of the voluntary only group. As expected, those seen by both the sectors had a greater proportion of valid postcodes as information was supplied by at least two agencies increasing the chance of obtaining valid details. Voluntary and statutory datasets were matched using identifying details (soundex and date of birth). The reliability of this matching depends on accurate coding of surname to soundex and recording of date of birth by all organisations, and is thus likely to underestimate the true overlap between voluntary and statutory services.

The projected numbers of HIV cases were based upon historical trends. Various equations were applied to the data from 1999 to 2005 for each variable against year of report following the methodology in chapter 2. A cubic equation ($y=a+bx^3+cx^2+dx$) best described the trend for the existing data for all variables and predictions were made by extrapolating this best fit line. Where line of best fit was curved and indicated a decline in cases a linear line of best fit is also provided.

Results

People seen in North West Voluntary Services

Table 10.1 shows which agencies were able to provide data in each year and the number of people for whom data were provided by each agency. Over the years, an increasing number of agencies reported to the system. Despite the fact that not all agencies were able to provide data every year, it is clear that voluntary agencies are providing

support to more people than ever. For example, in 2005 George House Trust (GHT) provided data on almost twice as many people as in 1999. GHT is one of the largest HIV charities in the UK and provides services to the largest number of people in the North West.

Table 10.2 shows the increasing proportion of individuals seen at North West voluntary agencies who are from black and minority ethnic (BME) groups, from 7% in 1999 to 31% in 2005. When the ethnic categories are collapsed into 'white', other categories that make up 'BME' and 'unknown' there is a significant relationship between ethnic category and year with more individuals from BME groups being seen in recent years (Spearman's $r_s = 0.893$; $n=7$, $P=0.007$). This increase is similar to the change in the attendances at North West statutory centres with the voluntary centres seeing slightly fewer individuals from the BME community than the statutory (10.4%) in 1999⁹. However, by 2005 32% of the clients seen in both sectors were from BME communities. Statistical analysis confirms that the proportion of BME groups seen by each sector did not differ in 2005 (chi-square goodness of fit of voluntary sector population to an expected distribution of 68.2% white: 26.4% black African: 5.4% other/mixed¹⁰, chi square=0.9, $df=2$, $P=0.637$). These proportions of people from BME groups, from both the statutory and voluntary sectors, are still far below the UK national figures for all people seeking HIV treatment and care.

Table 10.3 reveals that in 1999, only 12% of people seen by the voluntary sector were infected through heterosexual sex. By 2005, however, this proportion had increased to 33%. There is a significant relationship between infection route and year, with the proportion infected through heterosexual sex showing a year on year increase ($r_s=0.893$; $n=7$, $P=0.007$). This reflects what is happening in the general trends of infections in the North West. The proportion of people infected through sex between men has fluctuated, but shows a non-significant decreasing trend from 1999 to 2005 ($r_s=0.714$, $n=7$, $P=0.071$). The population served by the voluntary sector differs significantly in terms of infection route to the statutory sector, with proportionally more MSM, fewer heterosexuals and fewer people infected through blood products seen in the voluntary sector (chi-square goodness of fit of voluntary sector population to an expected distribution of 54.8% MSM: 39.5% heterosexual: 2.4% IDU: 1.7% mother to child: 1.5% blood¹⁰, $chi=28$, $df=4$, $P<0.001$).

Table 10.1: Number of HIV positive individuals reported by each voluntary agency by year

Voluntary Agency	Year of Report							
	1997	1999	2000	2001	2002	2003	2004	2005
BARL				14	9	5		
BARM					23	38	60	111
BHA		18	17	9	23	44	59	114
Blackpool HEAL		53	74	77		40	34	43
BP Blackpool		47	34	83	71	42	65	65
BP CNW	14	43	47	44	66	68	80	38
BPNW		517	466	347	252		248	716
CAD	9							
GHT		664	625	698	790	934	1146	1225
SAHIR	79	76	83	104	140	121	145	154
WAL	4							

For a list of abbreviated agency names please refer to appendix 2. Columns cannot be totalled as some individuals may appear in more than one row (i.e. those attending two or more agencies), thus exaggerating the totals.

Table 10.2: Number of HIV positive individuals seen by all agencies each year by ethnicity

Ethnicity	Year of Report						
	1999	2000	2001	2002	2003	2004	2005
White	847 (83.7%)	846 (84.3%)	862 (77%)	909 (81.1%)	865 (71.1%)	1098 (68.1%)	1328 (68.2%)
Black Caribbean	9 (0.9%)	3 (0.3%)	5 (0.4%)	3 (0.3%)	12 (1%)	7 (0.4%)	10 (0.5%)
Black African	40 (4%)	50 (5%)	86 (7.7%)	173 (15.4%)	280 (23%)	415 (25.7%)	509 (26.1%)
Black Other	7 (0.7%)	5 (0.5%)	11 (1%)	4 (0.4%)	29 (2.4%)	26 (1.6%)	15 (0.8%)
Indian/Pakistani/ Bangladeshi	13 (1.3%)	9 (0.9%)	10 (0.9%)	9 (0.8%)	1 (0.1%)	1 (0.1%)	13 (0.7%)
Other Asian/Oriental	4 (0.4%)	13 (1.3%)	13 (1.2%)	10 (0.9%)	10 (0.8%)	19 (1.2%)	16 (0.8%)
Other/Mixed			1 (0.1%)	13 (1.2%)	17 (1.4%)	30 (1.9%)	42 (2.2%)
Unknown	92 (9.1%)	78 (7.8%)	132 (11.8%)		2 (0.2%)	16 (1%)	14 (0.7%)
Total	1012	1004	1120	1121	1216	1612	1947

Table 10.3: Number of HIV positive individuals seen by all agencies each year by route of infection

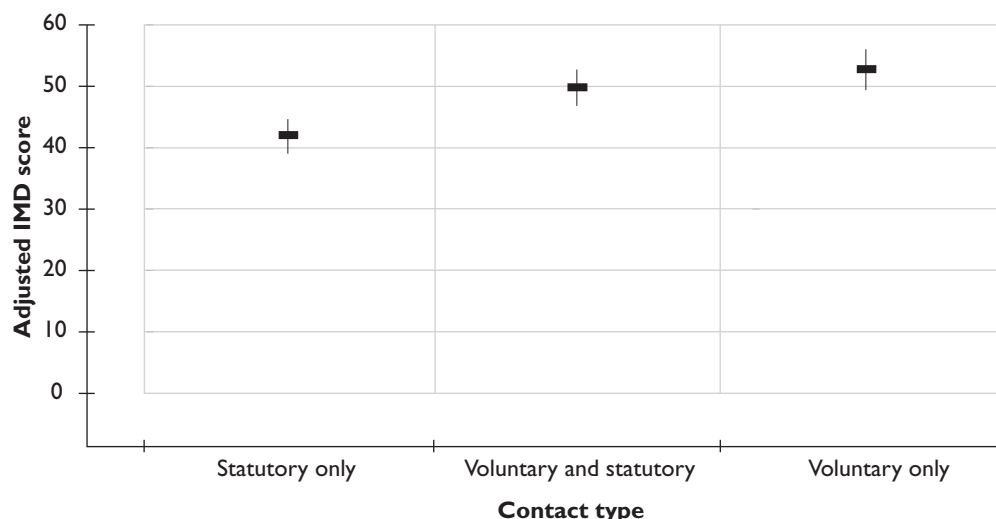
Route of Infection	Year of Report						
	1999	2000	2001	2002	2003	2004	2005
MSM	659 (65.1%)	692 (68.9%)	643 (57.4%)	728 (64.9%)	701 (57.6%)	931 (57.8%)	1114 (57.2%)
Injecting drug use	65 (6.4%)	59 (5.9%)	7 (0.6%)	56 (5%)	13 (1.1%)	52 (3.2%)	44 (2.3%)
Heterosexual	118 (11.7%)	143 (14.2%)	181 (16.2%)	264 (23.6%)	423 (34.8%)	511 (31.7%)	638 (32.8%)
Blood/tissue	17 (1.7%)	17 (1.7%)	2 (0.2%)	16 (1.4%)	6 (0.5%)	15 (0.9%)	15 (0.8%)
Mother to child	13 (1.3%)	12 (1.2%)	4 (0.4%)	18 (1.6%)	24 (2%)	24 (1.5%)	30 (1.5%)
Undetermined	140 (13.8%)	81 (8.1%)	283 (25.3%)	39 (3.5%)	49 (4%)	79 (4.9%)	106 (5.4%)
Total	1012	1004	1120	1121	1216	1612	1947

Attendance in voluntary sector and deprivation

To investigate the deprivation profile of the population served by the voluntary services, in comparison with those seen in the statutory sector, the relationship between deprivation, based on area of residence, and attendance in the voluntary sector was explored. Of the 4,757 individuals seen in the voluntary and statutory treatment centres in 2005, the majority (59%) were seen in only the statutory sector, 12% were seen in only the voluntary sector and 29% were seen in both the statutory and voluntary sector.

IMD scores for the three groups were compared and it was found that those who had only been seen in the voluntary sector had a significantly higher mean IMD score (52.5), and therefore lived in more deprived areas than statutory and voluntary (48.9) and statutory only (41.2: $F_{2,3871}=84.2$, $P<0.001$). In order to confirm that this relationship was not solely caused by differences in ethnicity or infection route of the people seen in the two sectors, all these variables were combined in a general linear model. The pattern remained the same: those seen in the voluntary sector alone had a significantly higher mean IMD score than did those seen in both sectors, who in turn had a higher IMD score than those seen only in the statutory sector (see figure 10.1).

Figure 10.1: Adjusted mean IMD score^a by sector contact, showing significantly higher deprivation^b among HIV positive individuals attending voluntary agencies with 95% confidence bars



^a adjusted for infection route and ethnicity using a general linear model (total model $F_{9,3864}=49$; contact type: $F_{2,3864}=84$; route: $F_{5,3864}=8$; BME: $F_{2,3864}=82$; $P<0.001$ for all)
^b all IMD means significantly different from each other after multiple comparisons ($P<0.001$)

Future caseload of North West voluntary organisations

The following figures show the observed and predicted number of people with HIV seen in the voluntary sector using the same methods that were used to generate the trends in chapter 2. A cubic equation was found to best fit the relationship between the variables examined and the year of report and explained 96% - 99% of variance (from $P<0.001$ to $P<0.05$).

Figure 10.2 shows observed numbers of white and black African people attending North West voluntary services from 1999 to 2005 and projected numbers of people to 2008. Projections were made using only data on white and black Africans as these are the two largest ethnic groups and make up 94% of all people reported in 2005 (table 10.2). The numbers of individuals from other ethnic groups are too small to use for an accurate projection. The model predicts that the number of white people seen by voluntary agencies will increase steadily and by 2008 voluntary agencies will be seeing 3,259 white people. By 2008 the model appears to show a slight levelling off of black African cases, however, we must be careful when extrapolating into the future, and only use this as an indication.

Figure 10.3 shows observed numbers of people seen by voluntary agencies from 1999 to 2005 who acquired HIV through MSM and heterosexual sex and projected numbers of people to 2008. People infected through injecting drug use (IDU), blood products or vertically are not included as numbers are too small to make accurate projections. According to the model the number of individuals infected through MSM will continue increasing and by 2008 voluntary agencies will be seeing 2,683 men infected through sex between men. The model appears to show a slight levelling off in heterosexual cases as 2008 approaches; however, as this line is generated purely by the historical trend we must be careful when extrapolating too far into the future.

Figure 10.4 shows observed numbers of males and females seen by North West voluntary agencies from 1999 to 2005 and projected number of males and females to 2008. The numbers of both males and females are expected to rise over the coming years and the sharpest increase will be in the number of men. According to this model by 2008 there will be 3,784 males and 763 females seen in the voluntary sector. This indicates a total of 4,547 people: a 349% increase in the 10 years since 1999. As for the heterosexual prediction, the number of females appears to level off; again, this should not be extrapolated too far into the future.

Figure 10.2: Observed and projected numbers of white and black African PLWHIV seen in North West voluntary agencies, 1999 - 2008

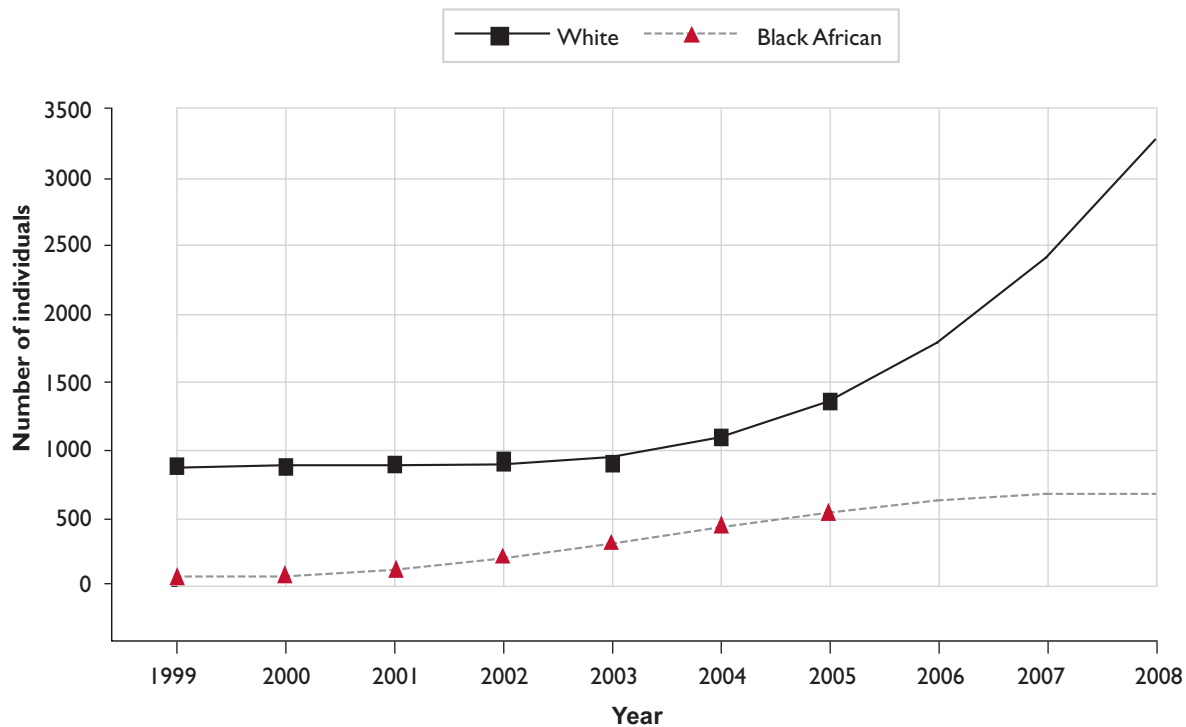


Figure 10.3: Observed and projected numbers of people infected through MSM and heterosexual sex seen by North West voluntary agencies, 1999 – 2008

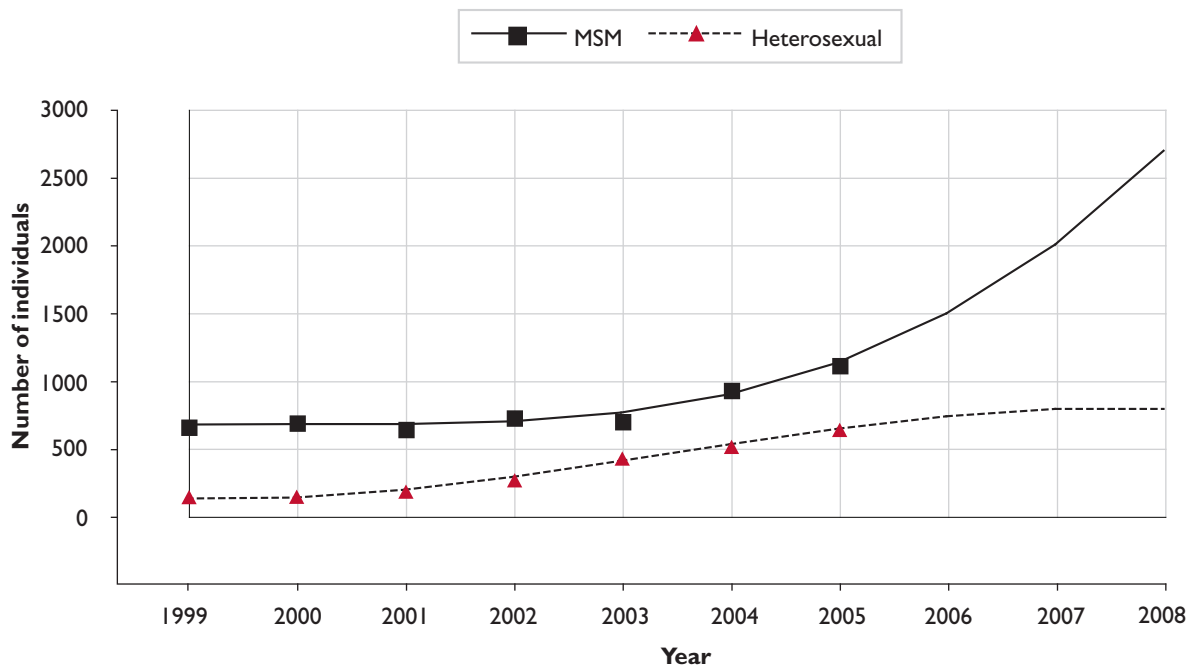
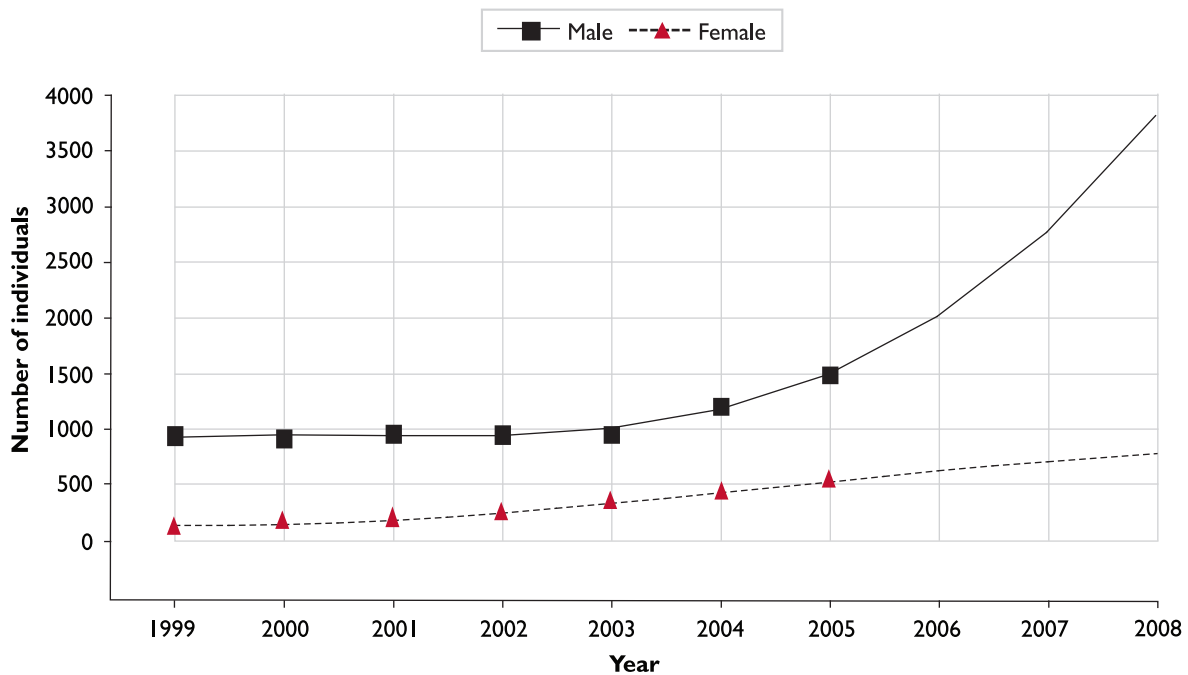


Figure 10.4: Observed and projected numbers of males and females seen by North West voluntary services, 1999 – 2008



Discussion

HIV/AIDS monitoring in the North West is unique in that comprehensive data are collected from many voluntary agencies, social service departments and drug services in addition to statutory centres. In 2005, of all people seen in North West statutory and voluntary centres, 29% of people who access statutory centres also access the voluntary sector. An additional 12% appeared not to access any statutory treatment at all. This breadth of sources of information provides a much more comprehensive picture of the situation in the North West than data from the statutory sector alone because it also includes those who choose not to visit NHS hospitals and clinics. Unfortunately such data are not collected at a national level, and therefore no comparisons can be made with other regions.

Over the past ten years, approximately a quarter of people seen in voluntary services were not seen in the same year in statutory centres (data not shown). This suggests that if we consider only the statutory figures the epidemic will always be underestimated. However, some caution needs to be applied when interpreting these results, as unreliable and missing identifying details (soundex and date of birth) will affect the matching between the voluntary and statutory datasets. The accuracy of this depends on the correct coding of surname to soundex and recording of date of birth by all organisations, and is thus likely to underestimate the true overlap between voluntary and statutory services.

The epidemiology of HIV in the UK has changed in the last ten years so that a large proportion of new infections are occurring amongst heterosexuals and BME populations (see chapter 1 for UK trends and chapter 2 for North West trends). The voluntary agencies have developed their services to accommodate these new groups of people and appear to have responded well to the demands and needs of the changing HIV positive population. They are seeing more clients than ever and more people from BME populations and those who acquired HIV through heterosexual sex. Since the withdrawal of ring-fenced HIV funding in England in 2004 local HIV charities have coped in an uncertain financial climate and with even fewer resources, yet have managed to provide invaluable services to many more people (see the vignette by Steve Earle at the beginning of this chapter).

Analysis has shown that in 2005, the North West voluntary agencies saw a higher proportion of MSM and a lower proportion of heterosexuals and people infected through blood products than would be expected based on people attending the North West statutory centres in the same year. This may be because historically many voluntary agencies were set up to support HIV positive gay men and, being the longest established, these MSM groups within organisations may still be the strongest and attract the largest numbers of people. HIV positive gay men, as the most longstanding group within most organisations, tend to be the public face of those with HIV and have established themselves within the awareness of the general public. People infected through blood products tend to be haemophiliacs who also have a number of other medical conditions that may lead them to access separate support systems and agencies not necessarily concentrating on HIV. Heterosexually infected individuals tend to be

from BME groups¹⁵ and may also be asylum seekers or temporary visitors to the UK. Such individuals may access other support services that are not just concentrated on their HIV status, for example asylum and BME support services. One such agency, the Black Health Agency, has supplied the HIV/AIDS Monitoring Unit with data since 1999.

Changes in infection route reflect changes in the ethnicity of those living with HIV as most heterosexual infections now occur in people from BME communities both in the North West (71% of heterosexual infections in 2005¹⁰) and in the UK as a whole (75% in 2005¹¹). The analysis in this chapter shows that the proportion of people from BME groups accessing care in the voluntary sector in 2005 did not differ from those seen in the statutory sector with both sectors seeing a similar proportion of people from white and BME groups.

This chapter presents, for the first time, a comparison between the relative poverty of those accessing the voluntary and statutory sectors. These results show that in 2005 the people who use voluntary services reside in more deprived areas than those who access the statutory treatment centres. Explanations for this may be to do with effective referral systems from statutory and social service sector that encourage the most vulnerable to access these services. Voluntary agencies are likely to have a high visibility and those from the more deprived areas who are in greater need are therefore more likely to accept these services. Many voluntary agencies have specific groups set up to support people from BME populations, and these populations tend to reside in relatively deprived areas of the UK¹².

The relationship between deprivation and ill-health has been well documented^{13,14}, and in terms of people with HIV, those in the most deprived areas of the North West are more likely to be admitted to hospital for HIV-related care¹⁵ (see chapter 4 for further analyses on HIV and deprivation in the North West). Research into health inequalities has also found that the most deprived areas of the North West have the highest levels of a number of health indicators including binge drinking, smoking, births to lone mothers, mental health conditions, claimants of disability living allowance and mortality from all causes¹⁶. The evidence that voluntary agencies provide services for more people from deprived areas highlights the importance of the voluntary services in reaching those who are in most need of extra support. Voluntary agencies should also be aware that there is a potentially vulnerable group, who are significantly more likely to be living in poverty and who do not appear to regularly access support from the statutory sector, and should provide further support to encourage such individuals to access appropriate treatment if necessary.

Mismatching due to incorrectly coded soundex or recorded date of birth may underestimate the real overlap of patients seen in the voluntary and statutory centres. This may introduce bias into the deprivation analysis as those individuals with names that are unfamiliar to the English tongue (e.g. black Africans) are more likely to live in deprived areas and may be more likely to be miscoded. The higher rate of missing postcodes of those seen only in the voluntary sector (21% missing) would be expected to dilute the results and give weaker relationships. However, despite this the relationship between sector attended and deprivation is still highly significant ($P < 0.001$). Thus the finding that the voluntary sector sees people who are on average living in more deprived areas appears robust despite possible non-matching and missing data.

The projections in this chapter are based on the information provided by voluntary agencies in the North West since 1999. It is important to remember that this will not represent full caseloads because of the problems some agencies have with providing accurate identifiable data as well as the support given to those affected by HIV but who are not HIV positive. These projections regarding black Africans and heterosexuals cannot take into account any future changes in policy or migration that may affect the numbers of both these groups within the North West and numbers could be affected by any unexpected outbreaks or changes in population. It must also be remembered that these figures do not necessarily reflect the HIV positive population in the North West; only those that choose to access the voluntary sector.

The projections appear to show exponential growth in people infected through MSM and lower rates of increase in those infected through heterosexual sex (see figure 2.6). They suggest that in the next five years, the information provided to the North West HIV/AIDS Monitoring Unit by the voluntary agencies will include a lot more people overall and specifically more people infected through MSM, white people and males in general. This group represents the largest number of people infected in the UK (chapter 2), and remains an important focus of HIV care and prevention. Moreover, analysis presented in chapter 4 has shown that prevalence of HIV amongst gay men is higher in poorer multicultural areas of the North West. Past evidence has shown that men from lower social classes and less educated men tend to be less accepting of homosexual behaviour¹⁷, so it may be presumed that those living in these poorer areas will experience more negative responses and possible hostility to their sexuality. Those with HIV are likely to face further stigmatisation and barriers to disclosure of their status. However, predictions of slower increases in BME groups infected through heterosexual sex seen in the voluntary sector do not reflect the current increases in such infections that are being seen in the North West and the UK as a whole. Voluntary agencies will need to continue to work hard to reach the increasingly large HIV positive heterosexual and black African populations if they are to continue to fulfil the need in the community and appeal to the whole HIV positive population. We have seen that voluntary agencies seem to be MSM focused at the moment and may be even more so in future. This will need to be monitored over the coming years but analysis in this chapter shows strong

evidence that voluntary agencies are reaching out to the poorer members of the HIV positive population regardless of ethnicity and sexuality.

Voluntary agencies need to ensure that links with the statutory sector remain strong, since all people, especially those who are vulnerable, need to be encouraged to attend treatment centres to benefit their health. In addition, their appearance in the statutory sector ensures that they will be included in national statistics and monitoring, which has funding implications for the North West (see chapter 12). It is also important that, since the voluntary agencies are seeing the most deprived and vulnerable people, links with social services and housing groups are maintained to ensure all available support is accessible to those in most need.

To conclude, analysis has demonstrated that voluntary agencies are appealing to and reaching the most deprived members of the HIV population, regardless of ethnicity, sexuality or gender. Voluntary agencies are seeing more people year on year, and extrapolations of this historical trend suggest sharp increases in the total number of people seen, particularly MSM. It is only with the recording and analysis of high quality, comprehensive data that the full extent of the importance of the voluntary sector may be seen. The North West HIV/AIDS Monitoring Unit relies on the time and support of voluntary agencies to provide accurate data once a year. It is important that voluntary agencies are represented in the report wherever possible to enhance the surveillance of HIV in the region. The annual reports and the analysis presented here continue to demonstrate the extent of the contribution to the care of people with HIV by the voluntary sector in the North West.

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