

## BEDFORDSHIRE BODY POSITIVE

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**W**ORKING WITH PEOPLE LIVING WITH AND AFFECTED BY HIV & AIDS

**Snapshot Survey : 2004**

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## Snapshot Survey of Services and Service Users : 2004

*A Snapshot Survey of services accessed by some current service users in the twelve months ending 20th April 2004*

This *Snapshot Survey* necessarily provides limited information about responding service users known to Bedfordshire Body Positive and the services which they accessed during the twelve months ending 20th April 2004. Although representative of the approximately 200 service users registered or in contact with the organisation the information is supplemented by the more detailed statistics contained in the Bedfordshire Body Positive Annual Report for 2003 / 2004.

The *Snapshot Survey* was considered necessary prior to the production of the Annual Report to assist the organisation's management team in identifying and exploring issues and trends likely to emerge in the short term ( 2004/2005 ) and medium term ( 2005/2007 ) planning periods. Those emerging issues and trends are examined in detail by the management team and service users as part of a continuing strategic development process.

Limited human and physical resources meant that the *Snapshot Survey* was conducted by confidential, postal questionnaire commencing 30th March 2004 with a strictly observed closing date of 20th April 2004.

The survey was conducted on behalf of Bedfordshire Body Positive by independent consultants and the statistics have been rounded to the nearest whole figure.

Simon Philpott  
Chair : Bedfordshire Body Positive  
10th July 2004

## Responses and Respondents

Of the questionnaires issued 36% were returned within the time limit with more than twice as many responses from women ( 69% ) as men ( 31% ). Of the responses received 28% were obtained by personal interview at the request of the respondents. Four late returns were disallowed.

The geographical location of respondents is shown in Table 1 and indicates that although almost two thirds of the organisation's service users live in Luton, where Bedfordshire Body Positive's facilities are based, more than one third travel from other parts of the County, and beyond, to access support services.

<b>Location</b>	<b>%</b>
Luton	72
South Bedfordshire	13
North Bedfordshire	8
Mid Bedfordshire	5
Other Counties	2

For the purposes of this *Snapshot Survey* respondents were invited to define their own ethnic origins rather than place themselves within a standardised framework. The results are shown in Table 2. It should be noted that fully 15% of the respondents chose not to define their ethnic origins.

<b>Origin</b>	<b>%</b>
Black African	56
Not Defined	15
British	13
West European	7
Black Caribbean	3
Black British	3
Black Asian	3

Approximately two thirds of the respondents replied to questions relating to economic and educational activities and the results are shown in Tables 3 and 4. The combination of replies relating to ethnicity ( *Table 2* ), Employment Activity ( *Table 3* ), asylum-related benefits and Asylum Team service uptake ( *page 4* ) suggests that a significant number of respondents may be trapped in the inordinately lengthy process of seeking the Right to Remain in the UK during which period they are forbidden to work or seek work and may be reluctant to indicate their actual employment activities. Similarly, issues of disability may impact on employability. The organisation needs to undertake more work to identify the causes of reluctance to answer in both of these areas since issues of actual or perceived disadvantage and discrimination may play a major role in reducing access to employment and educational opportunities.

<b>Table 3 : Employment Activity of Respondents</b>	
<b>Activity</b>	<b>%</b>
Employed Full Time	23
Employed Part Time	21
Actively Seeking Employment	18
No Response	38

<b>Table 4 : Educational Activity of Respondents</b>	
<b>Activity</b>	<b>%</b>
Full Time Education	15
Part Time Education	33
Actively Seeking a Course	18
No Response	34

The age distribution of the respondents is shown at Table 5. No responses related to individuals under 16 years or over 65 years and, although broadly reflecting national trends, there is an indication that:

- (a) the 0 – 24 age group ( 5% ) is substantially lower than the national trend at 16% and
- (b) the 36 – 45 age group ( 38% ) is somewhat higher than national trends of about 27%

The organisation will need to review its age-related reporting system to secure more accurate and detailed figures and, additionally, will need to consider appropriate responses to:

- i. service accessibility and relevance for those under 24
- ii. the significance, if any, of increased numbers in the 36 – 45 group

<b>Age</b>	<b>%</b>
0 – 24	5
25 – 35	39
36 – 45	38
46 – 55	15
56 – 65	3

In general terms, of the responses received, it is worth noting that 54% described themselves as having regular partners ( although one third did not live with their partner ) and the balance, 46%, described themselves as having no partner.

56% of all respondents had children and, of these children, fully 36% were not resident in the United Kingdom and their care and future well being caused considerable anxiety to respondents. The development of more effective support services for families separated in this way needs to be explored.

Replies indicated that 21% of all respondents were registered as disabled and a total of 53% were in receipt of state benefits the most common of which were Disabled Living Allowance ( 21% ), Income Support ( 18% ) and Asylum-related benefits ( 16 % ).

Within the preceding twelve months 42% of the service users had applied for or received support from public sector social workers and 20% had requested assistance from the Asylum Team

## Diagnosis, Duration and Development

97% of respondents confirmed their HIV status as being positive and 3% were uncertain. Of those who were positive the perceived route of infection is shown in Table 6 and it should be noted that the expression '*medical procedure*' included specific references to '*traditional treatments*'.

Given established understanding of the most common routes of HIV infection it would appear that the organisation needs to give additional consideration to enhancing its present culturally supportive activities to include delivery of more specific information and support services empowering service users to more fully explore the possible origins of their infection.

<b>Route</b>	<b>%</b>
Sexual	67
Not Known	15
Medical Procedure	13
Family/Social Contact	3
IVDU	2

HIV+ status was diagnosed for the respondents mainly by GUM Clinics ( 49% ) followed by hospitals ( 41% ) and finally by General Practitioners ( 10% ). The length of time that respondents had been aware of their diagnosis is shown in Table 7.

Since 59% of service users contact the organisation within two years of diagnosis it is important to maintain efforts towards the provision of quality information services to help address that initial phase, However, 14% of respondents have been aware of their diagnosis for between 10 and 20 years and consideration must be given to the anticipation of future service needs for a more senior *body positive* population.

<b>Time</b>	<b>%</b>
Under 1 year	21
1+ to 2 years	38
2+ to 3 years	2
3+ to 4 years	10
4+ to 5 years	2
5+ to 10 years	13
10+ to 15 years	3
15+ to 20 years	8
20+ years	3

Although 49% of respondents described themselves as being free from all HIV-related symptoms 41% said that they were experiencing some infection-related problems and 10% reported that they were currently experiencing many symptoms of illness.

It is clear to the organisation that, in addition to its continuing work with people already experiencing HIV-related symptoms, substantial efforts need to be devoted to assisting service users who are currently well in maintaining that position and to studying relevant and appropriate intervention outcomes in this field.

## HIV Status and Reported Problems

Respondents were invited to comment on the difficulties which they had experienced as a direct result of their HIV+ status.

Many of the reports relate to the failure of professional service standards within the public sector although problems with co-workers, employers and Faith Groups were also reported ( 9% ). 23% also reported difficulties arising from having told friends about their diagnosis.

In general comments 56% reported the time of diagnosis as one of the most difficult periods and 42% experienced serious difficulties from telling their immediate family. The same percentage described difficulties and anxieties in trying to understand and respond to ill-health episodes which they feared may be indicative of HIV-related illness.

Of those with partners some 5% had deliberately not informed them of their HIV status and those who did inform them reported experiencing more than one of a spectrum of difficulties the most common of which are shown in Table 8.

After diagnosis 19% of respondents faced the additional burden of their partner dying of an AIDS-related illness and 5% lost their partners to illnesses not classified as AIDS.

<b>Table 8 : Difficulties with Partners</b>	
<b>Difficulty</b>	<b>%</b>
Increased family tension	48
Partner coping badly	14
Partner refuses safer sex	14
Partner refuses sex	52
Accused of infecting partner	9

The organisation finds it particularly disappointing that its service users had cause to complain of bad treatment attributable to their HIV+ status from one or more of the public services shown in Table 9.

It would appear that substantial efforts towards the continuing education of the service personnel involved are still required.

<b>Service</b>	<b>%</b>
GPs	18
GP Nurses	10
GP Support Staff	16
Dentists	13
Dental Nurses	3
Dental Support Staff	3
Hospital Doctors	13
Hospital Nurses	16
Hospital Support Staff	21
Police	2
Social Workers	18

It is worth noting in relation to services provided by General Practitioners and Dentists that, overall, 28% of services users found it necessary to change their GP and 18% found it necessary to change their Dentist. The most common reasons given, in descending order of significance, were:

- Judgmental Conduct
- Bad Attitudes
- Poorly Informed
- Breach of Confidentiality
- Treatment Refused

The organisation holds the view that having to cope with stigma and discrimination from representatives of essential publicly funded services at a time of profound anxiety and distress is wholly unacceptable. Bedfordshire Body Positive and its service users will actively investigate better models and practice standards in these spheres.

## Services Accessed and Requested

*Accessed* The organisation has particularly noted that its continuing efforts in the provision of HIV-related education and information services enjoys the support of high numbers of service users and that, similarly, the opportunities created for both organised and informal group activities are very well attended.

It is also clear that the need for benefits advice as well as legal and non-legal advocacy remains significant and it should be noted that between its introduction in January 2004 and 20<sup>th</sup> April 2004 ( the closing date of this survey ) the free immigration legal advice has been accessed by 31% of service users.

The poor uptake of men's support services reflects the organisations current lack of funding to undertake such work effectively although, currently, attempts are being made to remedy the situation by appointment of a part-time men's group facilitator secured through a minimum, non-recurring grant.

Service users may access multiple services. Table 10 shows the level of access by all users of services offered.

*Requested* The survey responses express a clear need for additional provision in relation to education and information services as well as group activities and the organisation will review its current service levels and content in an attempt to identify and respond to unmet needs.

Issues relating to the specialist fields of housing and employment advice are affecting about one in ten service users but, within a family context, have the capacity to impact detrimentally on far larger numbers. Since these topics are frequently raised anecdotally the organisation will explore means of securing such support.

Although reflected in only 3% of responses, the issue of specialist support for long term survivors is anticipated to grow in significance within the next few years and, combined with the organisation seeing more than average users up to the age of 55, there is a need to examine and respond to this emerging need. The organisation hopes to secure support to commission relevant research.

Table 11 shows the full level of requested activities.

<b>Service</b>	<b>%</b>
Information Services	67
Drop In Area	66
Complementary Therapies	63
Open Afternoons	61
Talks & Workshops	59
Telephone Advice / Helpline	56
Women's Support Group	55
Counselling Services	49
Welfare Benefits Advice	44
Non-legal Advocacy	41
Children's Activities	39
Women's Pamper Days	37
Fundraising Events	37
One-to-One Peer Support	37
Free Immigration Legal Advice	31
Internet Use	21
Befriending Schemes	21
Referral to other Agencies	20
Home Visits	16
Hospital Visits	16
HIV Family Support Worker	13
Essential Baby Grant	5
Men's Support	3

<b>Service</b>	<b>%</b>
Educational Workshops	28
Increased Social Activities	21
Increased Therapies	13
Employment Advice	10
Housing Assistance	8
Men's Support Work	5
Long Term Survivors' Group	3
Full Time Health Adviser	3
Expanded Drop In Service	3
No reply / Unrelated Replies	6

## Observations

Bedfordshire Body Positive recognises that the process of informing and empowering people living with and affected by HIV and AIDS is immensely complex and the organisation does not, and cannot, seek to address all of those complexities.

This *Snapshot Survey*, however, touches upon some of the current and emerging issues reflected in the lives of our service users. Some, such as discrimination, stigma and disadvantage are common to most people affected by HIV / AIDS. Others, such as racism, xenophobia and homophobia are more specialised in their assault on human dignity.

The observations made in this section are not meant to be an exhaustive analysis of our service users' needs and the way in which they may be addressed. The observations are topics which will move forward, along with others, to more detailed discussion as part of our strategic planning process.

### **SECTION 2      RESPONSES AND RESPONDENTS**

a. With 36% of respondents reporting serious anxiety having dependant children living abroad, and with 48% reporting family tension increases attributable to their HIV+ status, there is a need to explore more effective ways of alleviating such situations and increasing, if appropriate, the uptake rate of Family Support Worker assistance which currently stands at only 13%.

b. Since 21% of respondents are classed as disabled, 53% are in receipt of benefits and 42% had sought assistance from social workers in the preceding twelve months the organisation will seek means to expand its Welfare Benefits Information Service.

c. Observations about the age distribution of service users are made in the text of Section 2.

### SECTION 3      D I A G N O S I S ,   D U R A T I O N   A N D   D E V E L O P M E N T

a.      Unwillingness to examine the possibility of infection routes within the generally accepted framework *may* impede the personal development of effective health belief and health behaviour systems. Although issues of cultural heritage and ethnic background may play a role in this area a clearer exploration of these and other factors may be needed.

### SECTION 4      H I V   S T A T U S   A N D   L O C A L   P R O B L E M S

a.      Since 5% of respondents report deliberately not informing their partners of their own HIV+ status ( a figure which is anecdotally higher ) and 14% of partners refusing to use safer sex practices there is a need to explore the role of ethnic background and cultural heritage influences on health belief systems and health-related behaviours.

b.      42% of service users report difficulty in understanding and responding appropriately to episodes of ill health and, therefore, require reassurance and information. This is reflected in the high uptake rate ( 67% ) of existing information services and the request for even more information by 28% of respondents. The organisation will now consider the most effective ways to provide training, information and support in this area.

c.      The organisation is deeply concerned by the high level of its service users' dissatisfaction with publicly funded care services and will urgently explore with service users, providers and other relevant organisations ( particularly in relation to health care provision ), means of recording, monitoring and reporting upon such matters to better implement the recommendations contained in, for example, the October 2003 "*Recommended Standards for NHS HIV Services*" ( *Medical Foundation for AIDS and Sexual Health* ) and the July 2004 *Commission for Healthcare Audit and Inspection's* statement that: "*.. the NHS must serve the whole nation, not just those .... best able to demand healthcare of good quality .... solving inequalities in healthcare will also require .... partnership between local authorities, schools, healthcare organisations and others.*"

**SECTION 5** SERVICES ACCESSED AND REQUESTED

a. Observations about services accessed and requested by service users are contained in the text of Section 5.

b. It appears to the organisation that if it is to maintain and improve its present levels of service and effectively respond to emerging challenges reflecting the needs of its service users, other service providers and the community at large more dynamic, co-operative and pro-active means must be put in place locally and regionally for the creation and delivery of sustainable core funding and project maintenance.

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