HIV SOCIAL CARE NEEDS ASSESSMENT

Bolton Council
2009

Contents

AIMS & OBJECTIVES

This needs assessment aims to identify the social care needs of the HIV positive population, their families and carer's in Bolton. To examine how these needs can be effectively met using available resources. The needs assessment process requires the identification of:

- Prevalence of HIV people in Bolton, trends, projection of, for the next 5 years.
- Evaluation of current services and access to those services
- Consultation with Service Users
- Changes that will impact on service provision.
- Recommendations

Scope

The findings and recommendations included within this needs assessment have been based on epidemiology research, analysis of national and local policy and procedure, information from both

Data collection process to date

- Service providers

Since beginning this report in March 2008 voluntary services have been contacted to ask for their referral / access data alongside any issues they felt were indicated within the process of future commissioning of services. (A letter was sent out to all services and is attached in appendix 1.) The agencies were asked to provide data from the previous five years of contact with service users as well as to provide breakdown by ethnicity, gender, age, residency status, access numbers, work undertaken and care pathway where that data was available. The response has been varied.

- Service users views

Bolton council also provide direct services via the specialist social worker therefore to ensure a clear picture of service user views an independent reviewer / researcher has been commissioned directly to access and present the service users' stakeholder voice

Recommendations

These recommendations are detailed below, listed within section 1 of this report as well as within the executive summary.

Care pathways

1. Developed care pathways,
2. From this report, the service user feedback and the MedFash recommendations central to all services is the need for clearly defined pathways that enable service user speedy access to the appropriate level of support at the appropriate time.

3. Ensure all agencies have appropriate information and leaflets

4. Improve referral pathway and the profile of the HIV social worker within health settings
5. Specifically there needs to be improved links between health care settings and social care, alongside better defined links with third sector or voluntary agencies.

6. Increase links/ care pathways between paediatric services and HIV specialist social worker
7. Increased level of need for children with HIV indicates a greater need for referral pathways that are accessible and clearly navigated

8. Development of adult and children services working together to support children and there families that are infected and affected.
9. The increased needs of families living with HIV means that greater emphasis should be placed on services to offer joined up, multi-disciplinary action to support these families.

Information

10. Information available in common languages and appropriate to different groups.
11. Clearly identified need to ensure access to all population groups within Bolton.
12. Develop improve and simplify the internet and intranet information re HIV/AIDS
13. Improved use of technology to promote services and improve information sharing
14. Increase the profile of all HIV service available to Bolton residents

Transparency of service

15. development of recording system and monitoring for people who access HIV social worker in line with local Care first systems

16. Audit the number of people with HIV discharged from hospital who have a planned and documented package of integrated health and social care
17. Re initiate Bolton Sexual health network to over see that outcomes are delivered and to feedback into holistic HIV needs assessment
18. To provide oversight and governance to this area of work and link into the boarder sexual health network.

Support

19. Development of services user peer support group
20. Strengthen links with Specialist Social worker across all groups to improve access
21. Voluntary agency have been shown to be beneficial and there has been positive feedback from the services user consultation. It is recommended this continues

Background

What is AIDS?

Acquired Immune Deficiency Syndrome (AIDS) is a medical condition. People develop AIDS because HIV has damaged their natural defences against disease.

What is HIV?

HIV (Human Immunodeficiency Virus)

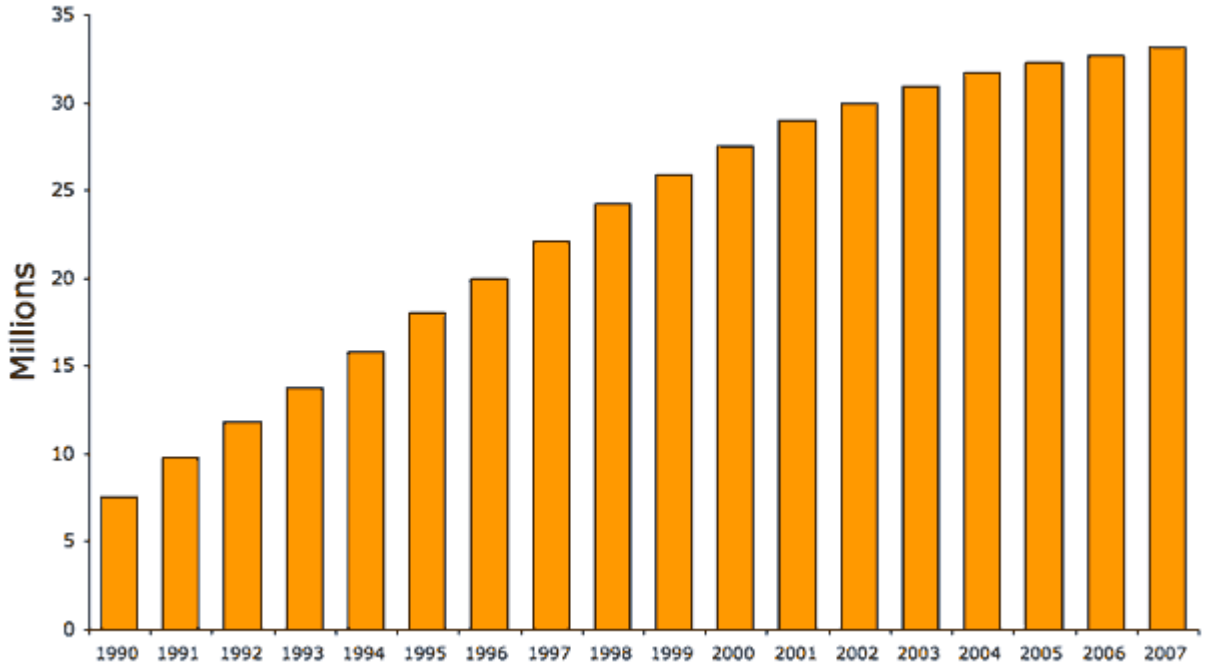
HIV is a virus. Viruses infect the cells that make up the human body and replicate (make new copies of themselves) within those cells. A virus can also damage human cells, which is one of the things that can make a person ill.

HIV can be passed from one person to another. Someone can become infected with HIV through contact with the bodily fluids of someone who already has HIV.

HIV stands for the '*Human Immunodeficiency Virus*'. Someone who is diagnosed as infected with HIV is said to be 'HIV+' or 'HIV positive'.

Figure 1

Global trends of HIV/AIDS 1990 - 2007



The number of people living with HIV has risen from around 8 million in 1990 to 33 million today, and is still growing. Around 67% of people living with HIV are in sub-Saharan Africa.

UK Trends

The UK has a relatively small HIV and AIDS epidemic in comparison with other parts of the world, with an estimated 73,000 people – or around 0.2% of the adult population – currently living with HIV. While the number of people living with HIV in the UK is relatively low, it has increased dramatically since the 1990's, alongside a general rise in the prevalence of sexually transmitted infections.

An estimated 73,000 people were living with HIV in the UK at the end of 2006, of whom a third were unaware of their infection.

In 2007, there were at least 6,393 new diagnoses of HIV, contributing to a cumulative total of 93,231 reported by the end of 2007.

There have been 23,596 diagnoses of AIDS in the UK. At least 17,932 people diagnosed with HIV have died, and at least 80% of these deaths followed an AIDS diagnosis.

Trends in HIV and AIDS statistics

When the tests for HIV antibodies became widely available in the mid 1980s, three main risk groups of HIV were identified. These were men who have sex with men, injecting drug users and people who have received treatment with blood products. Many of these people came forward for testing in the mid 1980s, after which there was a decline in the annual number of HIV diagnoses. This trend was reversed towards the end of the decade and there were between 2,500 and 2,800 diagnoses each year from 1990 to 1997.

Since 1999 there has been a steep increase in the number of HIV diagnoses. During 2007, reports show that at least 6,393 people were diagnosed with HIV in the UK. This number is expected to rise as further reports are received (estimates suggest it will reach around 6,840). The major component of the rapid increase in recent years has been in heterosexually acquired infections. Although around 80% of these are contracted in countries with high HIV prevalence, infections acquired within the UK have also risen. Another significant factor in recent increases has been the introduction of clinician reporting, which was only introduced for HIV diagnoses made after the beginning of 2000.

The use of HAART (Highly Active Antiretroviral Therapy) has proved effective in delaying HIV associated deaths and the onset of AIDS. This resulted in a steep decline in the number of AIDS cases reported each year between 1994 and 1998. Since then the number of cases has remained more or less

constant, averaging around 800 per year. The annual number of deaths has hovered around 500 since 1998, having peaked at over 1,700 in 1995.

Risk groups

By 1985, when heat treatment of blood products to inactivate the virus was implemented, most haemophiliac patients with HIV had had their infections diagnosed. Since then, three routes of infection - sex between men, heterosexual sex and injecting drug use - have been the main determinants of HIV infections in the UK.

Up until 1998, men who have sex with men formed the main exposure category for new HIV diagnoses. However, in 1999, heterosexually acquired HIV became the largest category, and has continued to be so ever since. The proportion of HIV infections acquired through injecting drug use has been much smaller in the UK than in many other European countries.

Men who have sex with men

Men who have sex with men remain the group at greatest risk of becoming infected with HIV in the UK. Throughout the 1990s, there were modest falls in the number of new HIV diagnoses among this group, except in 1996 when highly active antiretroviral therapy first became widely available and the advantages of early diagnosis became clearer. Since 1999, the figures have risen again from fewer than 1,400 to more than 2,500 per year - the highest levels ever recorded. It is likely that this trend is mainly due to an increase in HIV testing, though a rise in high risk sexual behaviour may also be a contributory factor.

As of the end of 2007, 41,520 men who have sex with men have been diagnosed with HIV in the UK, including those who have died. It has been estimated that, at the end of 2006, about 41% of all people living with HIV in the UK were men who had sex with men.

Heterosexuals

The number of heterosexually acquired HIV infections diagnosed in the UK has risen over the last 15 years. In 1999, for the first time, the rate of heterosexually acquired HIV diagnoses overtook the rate of diagnoses in men who have sex with men. The peak was 4,702 in 2004, since when there has been a slight decline. A total of 39,452 cases had been reported by the end of 2007.

Most of the new diagnoses are in people who probably acquired HIV in other countries, particularly in Africa. However, the number of infections probably acquired from heterosexual sex within the UK has risen from 183 in 1998 to 598 in 2006.

Injecting drug users

Injecting drug use has played a smaller part in the HIV epidemic in the UK than it has in many other developed countries. During 2006, a reported 168 people were diagnosed with HIV probably acquired through injecting drug use. By the end of 2007, reports showed that 4,790 people had acquired HIV by this route.

In this exposure category there have been differences within the UK. Scotland experienced rapid HIV spread through injecting drug users in the early 1980s, which was not the case in the rest of the UK as harm reduction measures such as needle exchange programmes were introduced in the mid-1980s, localised epidemics on the scale of Scotland have not occurred elsewhere in the UK.

Blood and blood factor recipients

Production of the clotting factor concentrates, used mainly for treating patients with haemophilia, involves the pooling of plasma from several thousand blood donations. Before the introduction of inactivation processes in 1985, a single donation infectious for HIV could contaminate a batch of concentrate used to treat many patients. There have been no recorded transmissions of HIV in the UK through concentrate use since the introduction of inactivation.

As soon as it was realised that HIV could be transmitted through blood, members of the groups recognised to be at higher risk were asked not to donate. Since October 1985, when suitable tests became available, all blood donations have been screened for HIV antibodies.

In total, 1,883 people had been reported as infected through treatment blood/tissue transfer or blood factor by the end of 2007, of whom 80% were diagnosed before 1991. Almost all of the recent diagnoses within this category relate to infections acquired outside the UK.

Children born to HIV-infected mothers

Surveillance of children recognised as born to HIV-infected women relies on confidential voluntary reports from paediatricians and obstetricians. A total of 8,161 children born in the UK to HIV infected mothers had been reported by the end of 2007. Of these, 804 had been diagnosed with HIV infection. Including children born in other countries, there have been 1,643 UK diagnoses of HIV in people who acquired the virus from their mothers.

The number of children born in the UK to HIV positive mothers more than doubled from 100 during 1991 to 252 during 1999, and then quadrupled to 1,139 during 2006. However, the proportion of such babies infected with HIV has fallen sharply since the widespread introduction of antiretroviral therapy and other interventions, which can dramatically cut the chances of HIV transmission from mother to child.

(Statistics and information www.avert.org)

Figure 2

UK HIV diagnoses, AIDS cases and deaths by sex and year of diagnosis or death

Year of diagnosis	HIV			AIDS			Deaths		
	Male	**Female**	Total	**Male**	**Female**	Total	**Male**	**Female**	Total
2000	2,480	1,391	3,871	589	245	834	386	98	484
2001	3,121	1,976	5,098	496	244	740	359	118	477
2002	3,614	2,654	6,268	563	334	897	413	107	520
2003	4,092	3,251	7,343	526	415	941	407	165	572
2004	4,403	3,181	7,585	507	377	884	347	149	496
2005	4,549	3,143	7,692	507	304	811	445	148	593
2006	4,370	2,906	7,276	424	295	719	371	145	516
2007	4,109	2,283	6,393	343	160	503	311	134	445
Total	65,064	28,123	**93,231**	19,032	4,564	23,596	15,409	2,520	**17,932**

National Agenda and Policies

Department of Health

Better prevention, Better service, better sexual health - The national strategy for sexual health and HIV 2001

The overall aim of the strategy:

"This sexual health and HIV strategy has been drawn up with experts and service users across the country, in line with the principles set out in the NHS Plan. It is part of a nationwide programme of investment and reform, to modernise services around the needs of patients and service users, tackle inequalities, and ensure that the NHS works to prevent ill health as well as treating problems once they arise".

Yvette Cooper
Parliamentary Under Secretary of State for Public Health
July 2001

This policy is principally concerned with two main areas regarding social care:

Social care and support for those living with/ affected by HIV

- Helping patient adhere to drug regimes
- Helping access to education / leisure facilities
- Ensuring people have their needs assessed and met for welfare, benefits, housing ,advocacy interpretation, peer support and other practical support for life in the community
- Support carers and families

- Making sure that people living with HIV can benefit from wider initiatives that promote social inclusion.

Planning and delivering HIV services

- Service users involvement provision based on partnership between statutory / voluntary services – models of provision that are able to respond quickly to changes in the heath and social car, provision that respects rights, including the right of privacy

This led to the Recommended Standards for NHS HIV services which include social care provision, for best practice and provision.

MEDICAL FOUNDATION FOR AIDS & SEXUAL HEALTH 2003

Empowering people with HIV - Standard 3

Aim

To facilitate the empowerment of people with HIV to have personal control and choice over the management of their HIV and to enable them to experience the best possible quality of life

Standard 3

All care should take place in a partnership between people with HIV and care providers so that there is joint decision-making and support to adopt and maintain a healthy lifestyle. Services should recognise the impact of HIV infection on an individual and the stigma and social exclusion unique to HIV.

Key interventions

• Culturally appropriate education, information, and peer support can improve knowledge, confidence and psychological wellbeing. This should be multi-lingual where appropriate, tailored to the needs of the individual, and include skills-based approaches.
• Personal care plans, developed in partnership between themselves and care professionals, can support the empowerment of people with HIV.
• Referral pathways which include services to combat social exclusion, as well as directly to tackle health problems, support the individual's ability to self-manage aspects of their condition.

Social care integrated with healthcare for people with HIV - Standard 6

Aim

To maximise the quality of life and value of clinical interventions for people with HIV, by enabling them, their carers and dependants to access a range of social care services which are provided in coordination with healthcare services.

Standard 6

All people with HIV should have access to social care services which are responsive, culturally appropriate and tailored to individual need. All people with HIV requiring multi-agency support should receive integrated health and social care.

Key interventions

• Provision of a range of social care services, responsive to local need, can help people with HIV lead healthier lives and improve their use of healthcare services.

• Providing health and social care services for people with HIV in an integrated way, in line with *The NHS Plan*, can improve the effectiveness of both, resulting in better health outcomes.

• Single points of access for the full range of health and social care services, as well as single health and social care assessments of individual need, can improve the integration of service provision for people with HIV.

• Integrated assessment of health and social care needs at the time of hospital discharge can improve the subsequent uptake of services and quality of care (see also Standard 11).

Care of families with HIV - Standard 9

Aim

To enable families affected by HIV to receive coordinated treatment and care services focused on their family needs.

Standard 9

Children, their families and carers should have access to specialist adult and paediatric multidisciplinary care including community care and support.

Key interventions

• Provision of multidisciplinary, multi-agency family services can ensure high quality care to meet complex needs in settings which ensure confidentiality for individuals and their families.

• Integrating the provision of social care with healthcare, including specialist social services provision within established family clinics, can help meet the multiple needs of families affected by HIV.

• A life span model of family care, provided by a multidisciplinary team, can respond to changing needs over time and allow transitional care as children move to adolescent and adult services.

Funding – The AIDS Support Grant

In the financial year 2006/2007 £16.5 million was made available through the AIDS Support Grant (ASG) as a contribution towards expenditure on HIV/AIDS related social services. The grant is in support of revenue expenditure; it cannot be set against capital expenditure**.**
The grant may be used to support the costs of staff training related to the provision of personal, social services for people with HIV or an AIDS diagnosis, although attention is drawn to the Training Support Grant, which will also support training in relation to HIV/AIDS.

As Bolton is three star social services, the allocation is sent automatically and in full. The 2008/2009 ASG funding is £77000 which is £8000 increase from 2007/2008. From 2004 Bolton Adult and Community services along with Bolton Primary Care Trust has operated a virtual pooled budget for the delivery of HIV/AIDS social care and prevention services. This budget consists of 46% contribution from the AIDS support grant and 54% PCT funding. The budget is administered by the PCT and funds a specialist HIV social worker and voluntary sector groups.

The break down is as follows:

Figure 3

Service	***Allocation***
HIV Specialist Social Worker Social Work Admin Support	£39843
George House Trust Body Positive North West (BPNW) Lesbian Gay Foundation (LGF) Barnardo's (Health through action programme) National AIDS Map (NAM)	£30424.22
Total planned expenditure for virtual pooled budget	£70,267.22

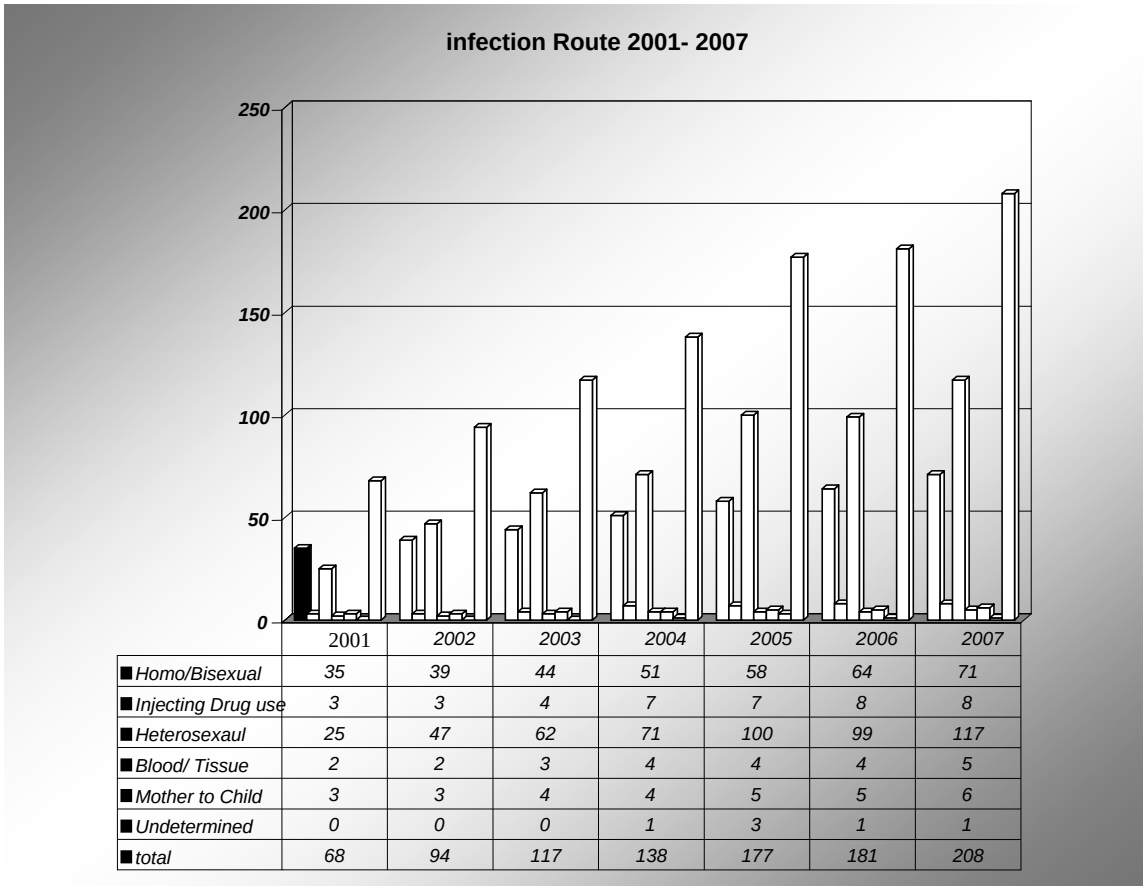
SECTION 2

Bolton - Prevalence of HIV infection, trends, projection of for the next 5 years

- **Bolton HIV statistics**

Greater Manchester has the highest rate of HIV infection outside the London area. By 2007 208 people were identified as HIV positive, although this can be increased by an estimated 25%, to include those who may be infected but have not yet taken a HIV test.
Within Bolton most routes were indicated as heterosexually infected (55.1%) and the remainder were men who had sex with men (35.2%).
55.1 % of all cases are currently asymptomatic. (Cook, P et al, 2006).

Figure 4
Bolton Infection Route 2001-2007



	2001	2002	2003	2004	2005	2006	2007
Homo/Bisexual	35	39	44	51	58	64	71
Injecting Drug use	3	3	4	7	7	8	8
Heterosexaul	25	47	62	71	100	99	117
Blood/ Tissue	2	2	3	4	4	4	5
Mother to Child	3	3	4	4	5	5	6
Undetermined	0	0	0	1	3	1	1
total	68	94	117	138	177	181	208

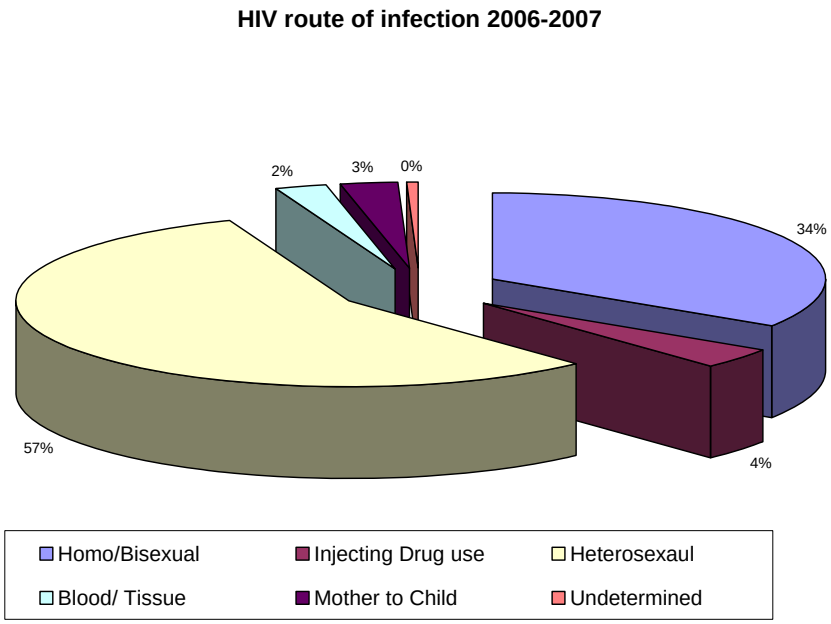
This graph indicates a steady rise year on year with an overall increase over five years of approximately 77%, with an average increase per year of approximately 20% (19.25%).

Projection from 2007 – 2012

Year	Projected numbers of HIV + Bolton Residents
2008	250
2009	300
2010	360
2011	431
2012	518

The biggest growth area for route of infection is within the heterosexual community. This continuing trend can be clearly seen in the graph below for route of infection for the figures available for Bolton during the period 2006-2007.

Figure 5



Year	Mother to Child transmission
2004	4
2005	5
2006	5
2007	6

Figure 6

Infection route split by gender Bolton 2001-2005

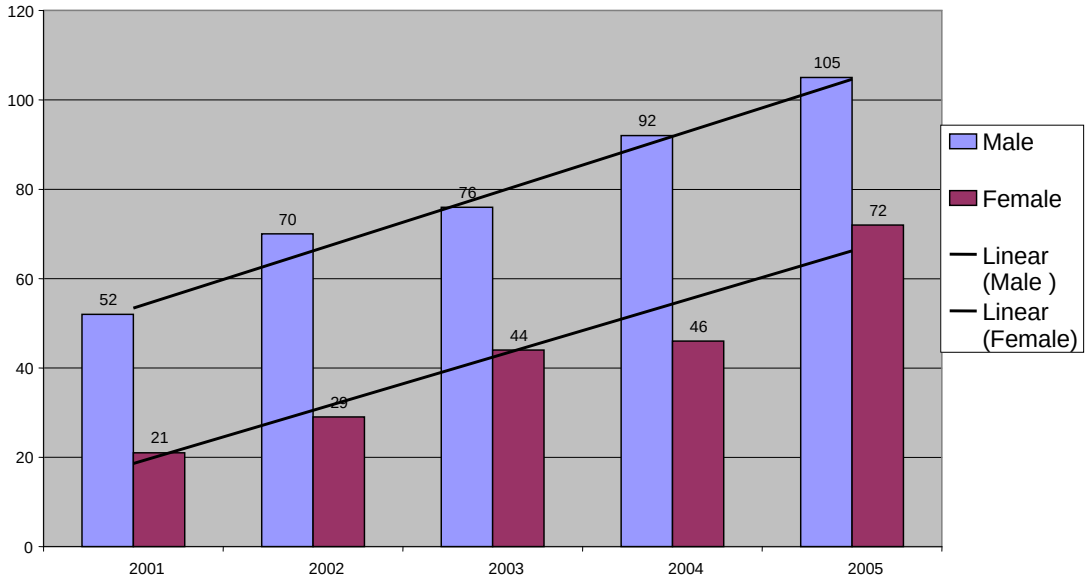
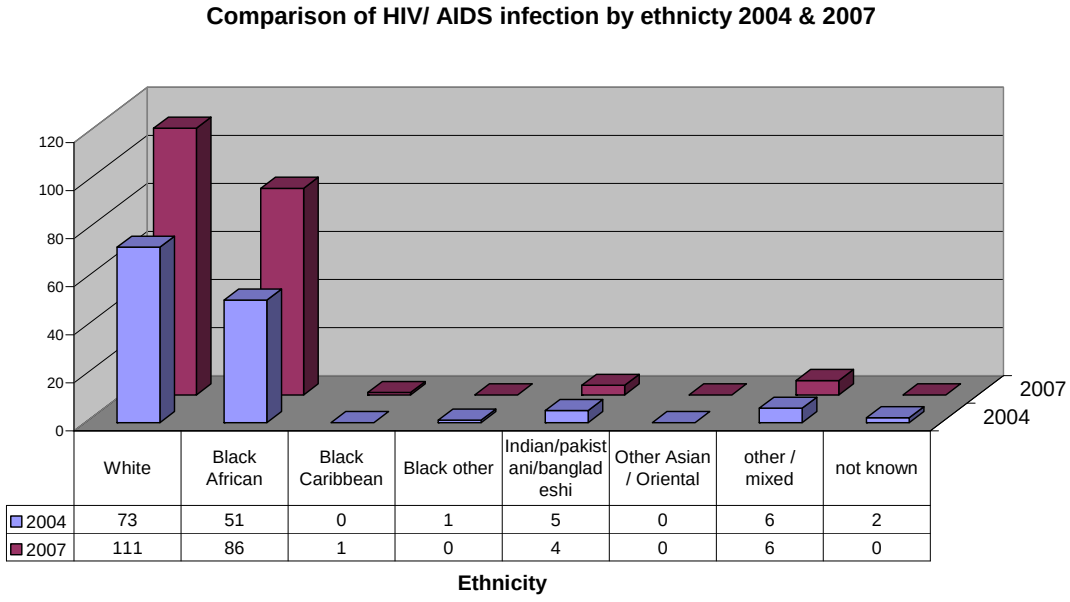


Figure 7



KEY POINTS SECTION 2

These statistics indicates a steady rise year on year with an overall increase over 5 years of approximately 77%

They is an average 20% increase every year, if this trend continues, it is projected that during the next 5 years that the number of people living in Bolton with a HIV+ diagnosis will increase to 518.

Alongside this we would expect a growth in informal carers for people who are positive.

In 2001, 51% of people diagnosed were Men who have sex with men
In 2007 34% of people diagnosed were Men who have sex with men
A decrease by 17%

In 2001 37% of people diagnosed were heterosexual
In 2007 56% of people diagnosed were heterosexual
An increase by 19%

This show a significant increase in heterosexual transmission; given the increase in referrals to Barnardo's during 2007 (see Figure 8 below) this may indicate an increased need to support people with dependant children. Again the 7% increase in female transmission may also indicate that there is a likelihood of greater need or impact on children and families with women as the primary carer.

In 2001, 70% of people diagnosed were Men
In 2007 63% of people diagnosed were Men

Whilst there is an increase in overall infection rate when looking at the split between different ethnic groups the percentage difference between these groups remains relatively static (Figure 7 for two comparison years 2004 & 2007).

EVALUTION OF CURRENT SERVICES AND ACCESS TO THOSE SERVICES

From the information provided by North West HIV / AIDS monitoring unit (Cook, P et al 2007) Figure 8 was drawn up showing new referrals to those services 2000-2007 (not all services contacted are represented).

Figure 8

Barnardo's	Black health agency	BP Cheshire	BP Blackpool	BP north West	GHT	Sahir	Total	year
2	1	0	1	12	34	0	50	2000
0	1	0	0	7	19	0	27	2001
1	1	0	0	5	24	0	31	2002
3	4	0	0	0	37	1	45	2003
2	3	0	0	7	35	1	48	2004
1	3	0	1	11	35	0	51	2005
2	1	0	1	12	34	0	50	2006
13	8	0	0	17	63	0	101	2007

Key Points

New referrals

This information indicates that new referrals to each of the services represented remained relatively static until 2006 with a large increase in 2007; and that the most significant number of referrals was to GHT with the biggest increase in referrals to both GHT and Barnardo's during 2007.

To enable further analysis of current service provision the information provided by each service is detailed below:

Body Positive North West (BPNW)
Body Positive North West is a self-help organisation for anyone affected by HIV the organisation's manifesto states that it exists to 'support people regardless of their gender, race, ethnicity, and sexuality or how they acquired HIV'.

Body Positive North West currently employs around 20 members of staff. They also have a data base of over 30 volunteers to provide services. BPNW states that their 'holistic approach to communities means that they are able to support people affected by HIV through an all-encompassing range of facilities and services'.

These services are listed as follows:

- Confidential helpline
- Advisors at clinics throughout Manchester and the North West
- Discreet drop-in centre
- Dedicated team to help with any health & social care enquiries
- Support groups
- Subsidised meals

During April 2007 to April 2008 the number of people from Bolton who accessed the services provided by BPNW was 24. Statistically BPNW state that each individual has had an average of 4.6 contacts through-out the year.

The breakdown of access to these services during this time is detailed below:

Services	Service used
Baobab – Education / Training	5
Counselling	5
Dinner	1
Drop-in	10
Hardship	1
Helpline	1
Housing	1
Immigration	2
Lunch	7
Newsletter	73
Positive self Management	4
Therapy	1
Total	111

Figure 9

The gender / age breakdown of this group is indicated as:

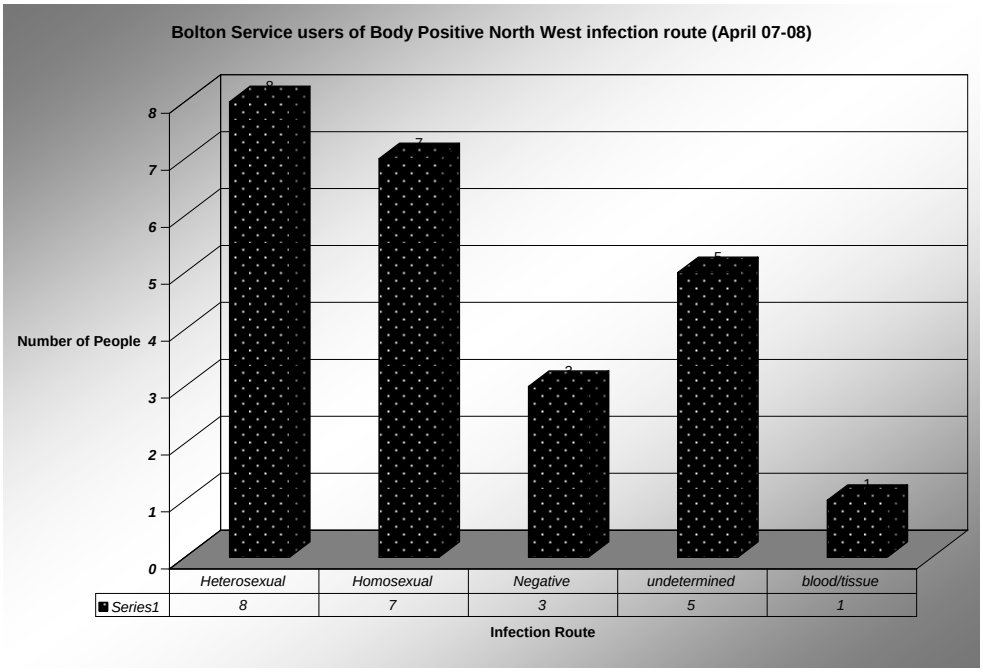
- 13 women 11 men
- The majority of individuals are in the age range 30-49, although there is one 17 year old and two people over 50

BPNW state to have an open access policy and access to this service can be either through self referral or referral by a specialist service.
Ethnicity of service users as identified by BPNW:

17 people identify themselves as white British, 3 are unknown, 1 Black British, 1 Black Other and 1 Black African.

Figure 10

Infection routes for service users as identified by BPNW 2007/2008



Over the three year period April 2005-March 2008 the number of people from Bolton who accessed the services provided by BPNW was 35, below are the services used, statistically each individual has had 30 contacts through-out this time frame.

Figure 11

Services	**Service used**
Advice and Advocacy	29
A & A in house	36
A & A out reach	1
A & A Phone Call	9
Baobab – Education / Training	11
Benefit	1
Counselling	89
Dinner	9
Drop-in	318
Gym	13
Hardship	2
Health Issues	1
Helpline	2
Housing	1
Immigration	3
Information	79
Lunch	180
Massage	2
New Registration	1
Newsletter	137

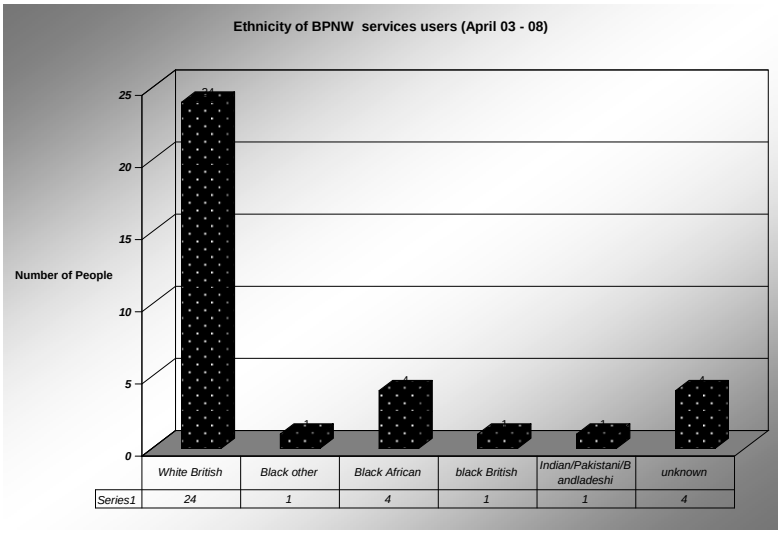
Positive self Management	53
Social services	1
Sunbed	12
Training Course	5
Therapy	55
Total contacts	**1050**

The gender / age breakdown of this group is indicated as:
18 women 17 men
The majority of individuals diagnosed are aged 30-49 years, one 17 year old, two people aged 50+ and one person aged 60+

Ethnicity of service users accessing BPNW 2003/2008:

The majority have United Kingdom residency, 6 people identified themselves as overseas students or Asylum Seekers

Figure 12



Commissioning issues identified by BPNW

- It is anticipated that commissioning changes will occur after March 2009 with the completion of the second 3 year NW HIV sexual Health commissioned SLA.
- Number of people living with HIV has grown and as specialist centres and services are becoming increasingly outstretched it would make strategic sense to identify localised provision. It is clear from the data that clients who live in peripheral areas in the North West are often unable to access specialist provision because of financial difficulties / inequalities.
- As people are living longer with HIV there is a greater need for provision because of earlier disabilities normally associated with ageing. Services may need to shift to area localities with increased generic services to meet identified needs.

- This will fit in with the personalisation agenda such as individual budgets i.e. services following the client will fit more in line with the personalisation of the care agenda.
- Change in awards of benefits and DLA reviews.

The BPNW currently report to Bolton PCT on a quarterly basis providing monitoring figures and a written summary of any changes in service provision / organisational change during each period.

Monies received from Bolton Council and Bolton PCT, pooled budget £4,266.39. Based on the number of people accessing this service from Bolton (24), this was a unit cost of £177.77

Referrals to specialist social worker 2006-2007 = 0 (see figure 26)

Key points

24 People accessed services, in 2007/2008 with an average 4.6 contacts per person

71% of people identified themselves as white British.

1/3 of people identified as heterosexual

29% of people identified as homosexual

12.5% of people identified as Carer's

11.5% of all HIV positive people in Bolton accessed this service.

They were no referrals to the specialist Social Worker

65% were news letter contacts

27% were face to face contacts

Face to Face contacts cost per person £115

From the data provided to date it would appear that there has not been an increased or sustained referral / access to BPNW services during the period indicated.

The Lesbian and Gay Foundation (LGF)

The Lesbian and Gay Foundation offers a range of services alongside community health and support services such as individual counselling, clinical services, telephone helpline and a range of support groups.

The LGF provide information and advice including a range of leaflets and booklets, a monthly magazine - Outnorthwest – alongside regular updates via their online news pages and email newsletters.

Their archive library houses a collection of literature and press and they regularly conduct research and surveys amongst the LGBT population.

Figure 13

Breakdown of numbers of service users accessing LGF services 2007/2008

LGF Services	**Numbers accessing from Bolton 07/08**
LGF sexual health outreach Clinic	11
Face to Face Counselling	1 (12 sessions in total with one individual)
Helpline	28
Group work includes Carousel: a social group for lesbian & bisexual women Stepping stones: A support group for lesbian and bisexual women Married Men's Group: A support group for men, who are on relationships with women, but have feeling for men 40+ Gay Men's Group: A social and support group for gay and bisexual men LGBT Black Group: a support and social group. LGF Art class: a group for lesbian, gay and bisexual people who would like to do some art.	41 *****
Other Resources	
Out North West magazine – Monthly magazine produce by LGF	3200 copies
Info and other resources	3635 copies

*This figure indicates 41 sessions, the LFG are unable to provide data as to whether this is 41 different people or 4 people attending 10 times

The LGF does not monitor service users' HIV status and therefore are unable offer any other data.

Commissioning issues

The LGF were unable to provide any issues related to commissioning for this service user group.

The LGF currently report to Bolton PCT annually, providing monitoring figures and a written summary of any changes in service provision / organisational changes during this period.

Monies Received from Bolton Council and Bolton PCT pooled budget £9,877.70.

Referrals to specialist social worker 2006-2007 = 0 (see figure 24)

Key points

Due to the limited data provided by the LGF and it is hard to therefore determine at what level any service agreement should be set, or indeed what service is currently being provided for the HIV service user population in Bolton.

Barnardo's Services for families living with HIV

Barnardo's offer a range of services to families and young people infected and affected by HIV/AIDS

Services to children and young people

- Therapeutic support and direct work with children and young people
- Group work support provided for children and young people who are aware of HIV in their family
- Group work support for refugee and asylum seeking children who are young carers
- Befriending service linking volunteers with children and young people
- Individual support for asylum seeking/ refugee children
- Group work support and play opportunities for refugee and asylum seeking
- Group work sessions provided for host community children to raise awareness and understanding of asylum and refugee issues

Family Support services

- Families are linked into local support networks
- Financial hardship alleviation
- One to one support for parent and carers to explore HIV and asylum issues
- Parents group provided for families
- Crèche and child care support for under 5's
- Play activities and residential activity holidays for older children
- Fun days and play activities
- Advocacy and networking on behalf of families.

When asked for details of numbers and breakdown Barnardo's provided a detailed breakdown for nine of their current case load. All are families that have at least one child and 7 have issues with immigration. The information provided for each of these families has been transferred into table form below and highlight key areas of case work currently being undertaken.

Figure 14

Details provided from case studies (Barnardo's 2007/2008)

Referred by	Primary client	Carers	contacts April 07-march 08	Services provided
Specialist nurse NMGH	15 yrs young person HIV +	Aunt, 2 sister, 4 cousin	61	One to one and peer support; residential weekend x 2; consultation x 2; attended hospital appointments; benefit support; carer support; financial support
GHT 03/05/07	15 yrs HIV-	Father	6	Assessment; inter-agency liaison
Self referral 26/01/05	HIV+ mother	2 children	16	Liaison with statutory services; financial support; outreach support / visits
GHT 22/09/05	8 yrs child HIV+	Grandparents and sister	29	Liaison with NMGH; solicitor; residential trip for sister; financial assistance
Consultant NMGH 02/02/07	11 yrs child HIV+	Positive parents and brother	41	Peer support; home visits for parent and child; liaison with NMGH; support on admission to hospital; consultation
Consultant NMGH 31/01/07	12month old child HIV+	HIV+ father, (mother died)	21	Assessment; family support and liaison with father; CAB; NMGH; Booth Hall; Bolton Hospital and solicitors; financial support
Specialist nurse 16/05/03	16 year old HIV+	HIV positive parents	49 (42 emails)	One to one sessions; peer support; consultation x 3; summer residential; trips; liaison with NMGH; specialist social worker; GHT; carer support; immigration advice; financial assistance and benefits
GHT 30/0306	Brothers aged 10 and 12 HIV-	HIV+ parents	35	Individual support sessions; office visit by carer; peer support; residential summer camp; liaison with mental health services; safeguarding issues; young carer's project
Consultant 07/05/08	13 yrs HIV+	HIV+ mother and HIV- brother		Assessment on-going.

Number of primary clients =10
Number of carer's = 22
Total = 22

Number of HIV+ children = 6
Number of 'affected' children = 14

Commissioning issues identified by Barnardo's

Of the £1590 received from the AIDS Support Grant £1200 was spent on travel costs of staff visiting Bolton or funding individual travel costs of children attending peer support groups
The service has worked out unit costs of £3059 per family to reflect current level of service provision, indicating a minimum spend of £24000 to continue to fund at this current level.
The reasons given for this significant increase are:
High numbers of HIV+ children in Bolton
Additional costs of travel
Additional need for contract meetings and increased links between services

The most significant issue identified by Barnardo's was:
Increase in HIV+ children living in Bolton and the specialist services they require as they progress through adolescence e.g. non adherence to medication, good sexual health, and prevention of onward transmission of HIV.

Barnardo's currently report to Bolton PCT annually, providing monitoring figures and a written summary of any changes in service provision / organisational changes during the period.

Monies Received from Bolton Council and Bolton PCT pooled budget £1,590. Based on the number of people accessing this service from Bolton, this was a unit cost of £72.27

Referrals to specialist social worker 2006-2007 = 3 (see figure 24)

Key points

In 2007 -2008 Barnardo's were providing services to 6 positive children from Bolton, and 14 children affected by HIV, either a sibling, parent or other close family member , unfortunately they are not any official numbers of 'affected' children, highlighting a possible hidden group.

This is also reflected in the increase in transmission amongst the heterosexual population and the increased need in services for child and families.

Barnardo's are requesting further funding as the numbers of service users accessing Barnardo's has significantly increased during the period 2007/2008.

Barnardo's have made explicit the need for increased contact between voluntary and statutory services, suggesting a gap in service provision from children and families services. This may indicate the need for a clear mapping of care pathways, criteria and appropriateness of services.

Pathways between statutory services, children's services and voluntary services need to be improved to enhance provision for positive children and there families. The request for increased contact between services needs addressing.

George House Trust (GHT)

Bolton Service Users – 2003/2008

George House Trust offers the following services:

- Advice/Advocacy
- One to one support
- Group services (African service, Gay Men's space, Women's service, Saturday space, non-African women's space)
- Financial support (from our own funds and access to other agency funds)
- Events and Courses (Gay Men's residential, Newly Diagnosed Course, African Weekend away)
- Volunteer support (one to one volunteer support/mentoring, driving to appointments)
- Counselling (from qualified volunteer counsellors)
- Information by email and post, including quarterly newsletter
- Taxi costs for people attending hospital appointment unable to travel by public transport
- Crèche facilities at Barnardo's for parents/carers attending individual appointments or group services.

76 people with a Bolton postcode have accessed services in the year April 2007/2008.
121 people with a Bolton postcode have accessed services in the period April 2003/2008.

Figure 15

Breakdown of access by age / year

	03/04	**04/05**	**05/06**	**06/07**	**07/08**	**Total**
0-18	1	2	6	6	6	10
19-30	1	8	12	12	10	18
30-45	16	16	26	30	34	51
45-60	12	21	18	22	23	36
60+	0	5	2	1	3	6
Total number of people	**30**	**52**	**64**	**71**	**76**	**121**

Figure 16

Break down of people accessing service by gender 2005/2007

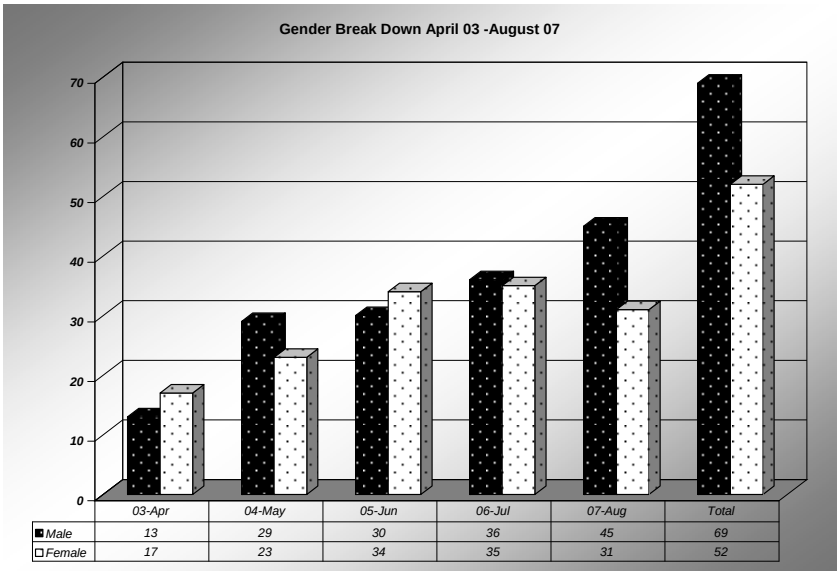


Figure 17

Ethnicity as indicated by GHT

	03/04	04/05	05/06	06/07	07/08	Total
Asian	1	2	1	1	1	2
Black - African	17	19	31	30	32	55
Black - UK	0	1	2	2	3	3
Other	0	2	1	1	0	3
White - Ireland	0	0	1	1	1	1
White - Other	0	2	3	2	3	3
White - UK	12	26	25	34	36	54
Total number of people	**30**	**52**	**64**	**71**	**76**	**121**

Figure 18

Residency status as indicated by GHT

	03/04	04/05	05/06	06/07	07/08	Total
Asylum Seeker	4	4	9	10	10	15
Failed Asylum Seekers	4	4	5	5	6	10
Not known	4	9	5	4	5	16
Other	2	1	3	2	0	5
Other EU National	0	3	2	2	2	4
Refugee/Leave Granted	5	7	11	11	12	17
Student	0	1	2	1	1	2
UK National	11	22	26	35	38	50
Work Visa	0	1	1	1	2	2
Total number of people	**30**	**52**	**64**	**71**	**76**	**121**

Figure 19

Referral route as indicated by GHT

	03/04	04/05	05/06	06/07	07/08	Total
AA Self	0	1	11	17	20	23
Barnardo's Future Matters	0	0	1	1	2	2
Bolton Hospitals Trust	0	0	3	3	2	5
Liverpool Social Work	1	4	4	4	4	4
Manchester Haematology	0	1	0	0	0	1
North Manchester CLT	0	0	0	1	2	2
North Manchester Consultant	0	0	1	1	0	1
North Manchester Counselling	19	28	30	27	25	44
North Manchester Social Work	1	3	2	2	2	3
Not known	4	2	6	6	9	16
Other	0	0	0	1	1	1
Salford NHS	4	7	5	6	7	12
Salford Social Services	0	4	1	1	1	4
Tameside NHS	0	0	0	1	1	1
Test	0	1	0	0	0	1
West Lancs. NHS	1	1	0	0	0	1
Total number of people	**30**	**52**	**64**	**71**	**76**	**121**

Service access varies from once per year up to some individuals accessing services over 100 times in one year, or over 400 times in the 5 year period.

Figure 20

Work undertaken with individuals as indicated by GHT

Type	03/04	04/05	05/06	06/07	07/08	Total
Advice/Advocacy	72	63	165	233	51	584
One-To-One Support	0	42	60	46	208	356
African Service	0	15	41	36	15	107
AGN Support	93	0	0	0	0	93
Carer's Service	0	3	10	3	1	17
Children	0	2	7	0	0	9
Counselling	0	25	30	11	0	66
Crèche	0	0	12	9	0	21
Event/Course	0	13	33	27	31	104
Financial Support	0	0	141	120	77	338
Gay Men's Service	0	32	30	28	26	116
Information - Email	0	0	191	204	446	841
Information – Mail out/Post	0	170	174	145	159	648
Information (Request)	0	8	26	18	27	79
Practical	4	0	0	0	0	4
Taxi	0	0	21	17	8	46
Volunteer Support	1	8	73	88	41	211
Welfare Fund Agency/External	86	119	1	0	0	206
Women's Service	0	6	8	14	7	35
Total	256	506	1023	999	1097	3881

George House Trust currently report to Bolton PCT annually, providing monitoring figures and a written summary of any changes in service provision or in the organisation during the period.

The following are a summary of the issues for commissioning

- Continued increase in number of new service users will have an impact on service availability
- Ageing population of people living with HIV will lead to an increased complexity of need
- Improved health resulting in an increased demand for advice on returning to work (issues of disclosure, discrimination under the DDA, volunteer mentoring)
- Reduced benefit support leading to increased financial hardship and return to work support required
- Increased publicity of our service required due to increase in home testing/testing at locations other than GUM clinics
- A need to develop effective secondary prevention initiatives which give positive people the information, confidence, and sense of well-being to help prevent onward transmission of the virus.

Monies Received from Bolton Council and NHS Bolton £12,799.17

Referrals to specialist social worker 2006-2007 = 7 (see figure 24)

Key points

Year on year figures regarding access to GHT between 2003/2008 would indicate that once referred service users remain within the service allowing for a steady increase in contacts.

The figures for referral by the specialist HIV Bolton social worker during this time do not appear to have been included in the figures provided.

76 People accessed services, in 2007/2008. this increased by 5 people per year 36.5% of all HIV positive people in Bolton accessed this service.

In 2003/2004 56% of people identified themselves as Black African.
In 2003/2004 40% of people identified themselves as White British.

In 2007/2008 42% of people identified themselves as Black African.
In 2007/2008 52% of people identified themselves as White British.

42% were face to face contacts

NAM

NAM is a community based HIV information provider. Their mission is to support people living with HIV to live longer, healthier lives. They believe information enables people to:

- take control of their lives and health care
- understand and adhere to their HIV treatment
- develop better dialogues with their healthcare staff
- live longer, healthier and better quality lives

NAM produce and distribute accurate, up-to-date and evidence-based resources (printed, electronic, audio and online), covering both the medical and social aspects of HIV, to people living with HIV and to those who work to treat, support and care for them.

Resources include website fact sheets, booklets, monthly treatment update newsletters, email bulletins, searchable service listings, daily HIV news, information events, reporting from all major international HIV/AIDS conferences,. Some of our resources are available in French, Spanish, Portuguese and Russian.

Between 1 January and 31 March 2008 take up, by residents or clinics in NHS Bolton, of the services was as follows:

Figure 21

	Total number of visits by area residents	Total visit time, i.e. time usage by area residents (hours)	Total number of hits
aidsmap.com	504	181	8,613
	Total number of subscribers in your area	Number distributed to clinics	
HIV Treatment Update	12	10	
	Number distributed directly by NAM to area residents	Number of NAM booklets distributed to clinics	Number of THT booklets distributed to clinics
Patient Information booklets	-	-	-
	Total number of subscribers in you area		
HIV Weekly	6		
	Number distributed to area residents		
Factsheets	24		

Key points

The services NAM provides are mainly web based and literature information leaflets. This appears to be a well received and accepted method of transmitting information to service users.

HIV Specialist Social Worker Bolton Nov 2005 – March 2008

From November 2005 a specialist social work post was developed, based within Royal Bolton Hospital, funded jointly by Bolton PCT and Bolton Council and offering on going case work support and one off specialist sessions for people diagnosed with HIV. In more detail the service provides care to HIV+ people, their families and carers by ensuring that their needs are assessed and met with respect to welfare, benefits, housing, advocacy and other necessary community based practical support, including designing and purchasing packages of care in line with FACS (Fair Access to Care Service) criteria.

Following the codes of practice for social workers the specialist social worker aims to:
• Protect the rights and promote the interests of service users and carers;

• Strive to establish and maintain the trust and confidence of service users and carers;

• Promote the independence of service users while protecting them as far as possible from danger or harm;

• Respect the rights of service users whilst seeking to ensure that their behaviour does not harm themselves or other people;

• Uphold public trust and confidence in social care services; and

• Be accountable for the quality of their work and take responsibility for maintaining and improving their knowledge and skills.

(GSCC Codes of Practice for social workers)

Figure 23

Breakdown of current service provision:

	11/05-03/06	04/06-03/07	04/07-03/08
Advice/Advocacy	4	7	4
Care package		2	2
Referral to voluntary agencies	2	4	3
Carer's assessments		3	1
Children	3	3	
Professional support	5	2	4
Housing	3	6	
Benefits	3	8	1

Financial Support other grants	3	3	
Human rights Assessments	4	2	4
Information general	1		
Information – specific to HIV	1	3	1
Referral to CAB	1	1	3
Aids / adaptations			2
Debt management	2	3	
Meals on Wheels		1	1
Asylum issues	2	3	4
Refuge issues	1		
Local authority subsistence support	2	1	3
Mental / emotional health	1	4	2

Example: Case study one
Matthew is a 35 year old white British male with significant utility debts and issues with unsuitable accommodation. The service provided to Matthew included a full needs assessment under the Community Care Act and led to advice and advocacy with the utilities companies to work out a payment plan; emotional support through this difficult time with an emphasis on empowering Matthew to seek solutions himself; negotiation with the housing provider to complete repairs and improvements to the property. Matthew is now debt free and has returned to work as a musician and feels he is achieving his goals and ambitions.

The following graph shows a breakdown of total work undertaken by the specialist social worker since 2006 categorised by length of intervention. This clearly indicates that the majority of work is short term, time focused and specific.

Figure 24

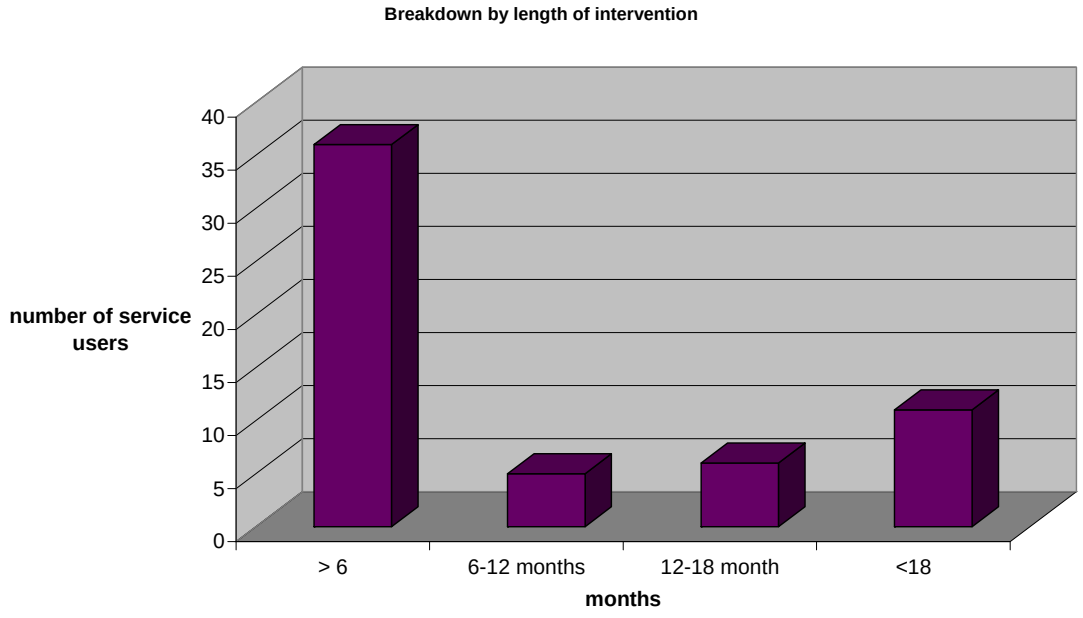


Figure 25

Total HIV and AIDS cases by ethnic group 2007/2008 for people who live in Bolton

White	Black Caribbean	Black African	Black other	Indian/ Pakistani/ Bangladeshi	Asian other	Other Mixed	Unknown	Total
111	1	86		4		6		208
53.4%	0.5%	41.3%		1.9%		2.9%		100%

Current case load of specialist HIV social worker in Bolton

White	Black Caribbean	Black African	Black other	Indian/ Pakistani/ Bangladeshi	Asian other	Other Mixed	Unknown	Total
10	1	16		0	1			28
36%	3.5%	57%		0%	3.5%			100%

Breakdown by age and gender can be seen as:

14 women 16 men
The majority of service users are adults plus two children who are HIV+ and three children living with HIV+ parent / carer

Figure 26

Breakdown of referrals to and from specialist social work service 2007 - 2008:

Referral **from**:	number
Bolton centre for Sexual Health	13
Barnardo's	1
GHT	7
Bolton Racial Equality Council	1
Community Mental Health Team	1
Adult services	3
Hospital Social Work Team	3

Referral **to**	number
Bolton centre for Sexual Health	13
Barnardo's	1
GHT	7
Bolton Racial Equality Council	1
Community Mental Health Team	1
Adult services	3
CAB	3

This specialist post also works with people who are HIV+ and have asylum and immigration issues. This work can include providing assessment under the Human Rights Act (1999) and through this access to services for people who have no recourse to public funding. To date these service users mainly originate from Sub-Saharan African countries including:

- Rwandan
- Cameroon

- South African
- Congo via Germany
- Ethiopian
- Zimbabwe
- Zambia
- Malawi

Figure 27

Breakdown of immigration / asylum work to date

Asylum Seeker	Over-stayed	Refugee Status	Other time limited Visa
6 (Supported by NAM)	4 (Supported by the Local Authority under NNA)	5	4

Example: Case study two
Bally is a 46 year old Black African man from Zimbabwe with a positive diagnosis alongside physical health issues (renal failure). Bally came to Bolton 2 years ago and was being cared for by his cousin who due to financial debt was unable to continue in this caring role. Bally was also struggling with his diagnosis and separation from his family who remain in Zimbabwe. Services for Bally included full assessment under both Community Care Act and the Human Rights Act; significant emotional support; advice and signposting for asylum issues; re-housing and negotiation with Bolton's legal and financial departments. Bally now has a small 3 hour weekly care package that is monitored and reviewed by the specialist social worker, is in settled accommodation and awaiting a Home Office decision re his immigration status.

Figure 28

Number of hospital discharges.

Year	Number of admission in the previous 12months	Number of weeks in hospital	Discharge package	Number of admission after package
2007 NT	1	12	Intermediate care at home and community meals	0
LC	3	14	Care package	0
2008 RS	3	8	Residential home	0

Example: Case study three
Lily is a 54 year old white woman with a positive diagnosis who recently lost her partner and developed physical health problems after a ten week admission to hospital. The services provided include a full needs assessment, using Community Care Act and Mental Capacity Act plus a screen under continuing Health Care. Following these assessments Lily was discharged to residential care. Throughout the specialist social worker co-ordinated the assessments and developed and purchased the care package, ensuring that Lily's needs were met as holistically as possible.

Key Points
45% of all referrals were from Bolton centre for sexual health

24% of all referrals were from George House Trust.

Main areas of work
16% Advice and Advocacy
15.5% Immigration and Asylum Issues
7% Referral to Voluntary Agencies

The majority of interventions are within 'professional support category' which includes housing; advice & advocacy; immigration & asylum; referrals to other agencies; benefits; assessments etc; with a minority being for high end costly packages of care. Working in this way may indicate that timely focused short term work prevents longer term input possibly indicating an overall saving to the service.
In comparison with the Bolton HIV + demographic that services are most commonly used by the black African population (see figure 25), perhaps indicating higher instances of deprivation / social inequalities within this group.

It is also noted that there is a significant difference between lengths of intervention with the vast majority being time limited and specific within a six month period. This is needs of service users who ask for interventions during times of crisis but do not require longer term case work.

<u>Future provision of care by specialist social worker:</u>

When looking at the inverted triangle model it can be seen that the majority of interventions completed by the specialist HIV social worker fall within the middle range, of focused, *targeted* work designed to prevent people moving into crisis and thereby avoiding moving to the *specific* or more costly area of provision. This also fits within the commissioning model, ensuring services can be generalised and less specific and meet the majority of service user needs whilst maintaining graded middle and higher end specialism's for those with most significant needs.
This can also been seen to fit within the personalisation agenda as service users have greater control and input into the care and service they need at times when they request it.

Changes that will impact on service provision

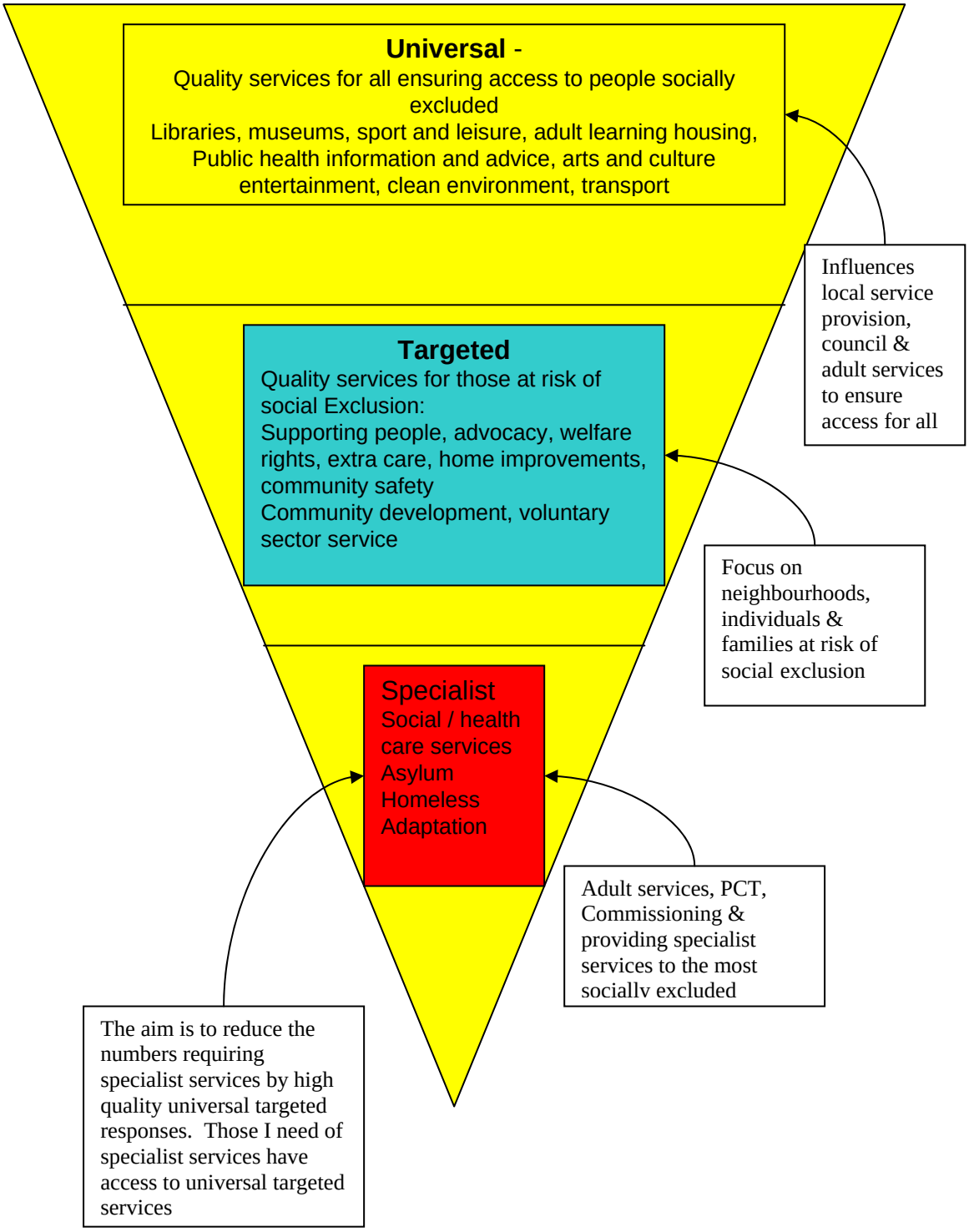
Inverted triangle

Adult and Community Services' role is to improve the quality of life for adults, their families and the communities in which they live by having a whole population focus. They aim to do this by using joint strategic needs assessment to drive future commissioning; recognise all adults as citizens and work towards "narrowing the gap" and building safer, stronger and healthier communities. This is described by the "inverted triangle" of universal, targeted and specialist responses to individuals, families and communities needs.

The main functions are

- Adult & Community Learning.
- Community Safety including Consumer Advice and Trading Standards Services
- Culture and Community Services
    - Public Libraries, Art Galleries and Museums.
    - Sports, Leisure, Arts and Community Development and Facilities
    - The Albert Halls and Civic Catering
- Food Safety & Health
- Safeguarding Adults
- Social Care for Adults and Older Adults
- Supporting People
- Welfare Rights

Figure 22



Outcomes of service provision:

- Healthier
- Safer

- Achieving
- Prosperous
- Stronger
- Cleaner & greener

Commissioning approach

During the next three years Bolton aims to work with partners, moving towards a commissioning model where universal services promote greater citizenship and participation, where targeted services are available for those at risk of social exclusion and integrated multi-disciplinary teams provide specialist services to those in most need. This includes major reviews of key universal services, to ensure that they are more cost-effective, of excellent quality and innovative in a climate where value for money and continued efficiency is maintaining pressure on budgets.

Adult and Community Services are working towards the national agenda of personalisation of services, to promote independence, choice and control through the introduction of Individual Budgets.

A further change is the 'transformation of social care' as signalled in the Adults White Paper, supported by a social care reform grant of £3m over the next 3 years. The main challenges and opportunities facing Adult and Community Services in the next 3 years are:

- To use Universal Services in a targeted way to maximise Health and Wellbeing and prevent Social Exclusion
- To work with partners to build on strong foundations of joint commissioning and delivery in order to deliver a seamless service making best use of available resources
- Co-location and/or integration of services in order to make it easier for the public to receive flexible and tailored services

Personalisation agenda

'Our health, our care, our say' confirmed that people want support when they need it, and they expect it quickly, easily and in a way that fits into their lives. They want adult social care services to consider their needs with a greater focus on preventative approaches to promote independence and wellbeing.

To make this happen, the social care sector needs a shared vision: personalisation, including a strategic shift towards early intervention and prevention, will be the cornerstone of public services

Politically Agenda – Social Care services are high on an agenda, across the political divide. This is broader than social care; it runs through all local authority departments delivering services to all in community not just the current 5 % of service users who receive social care services.

"The way in which services are tailored to the needs and preferences of citizens The vision is that the state should empower citizens to shape their own lives and the services they receive" (Prime Minister Unit 2007)

Key Points

Inverted Triangle of service provision means;

Clearer access and signposting
Access prior to crisis
Speedy and defined pathways back into primary / secondary services
Targeted, focused interventions
Time limited
Accurately commissioned and monitored targeted services

Commissioning model:

Improving health inequalities
Shifting the emphasis from a primary focus on intervention to prevention.
Meeting the increasing demand from demographic changes.
To continue to efficiently commission and provide high quality services
Ensuring universal services offer access to those who are socially excluded.
Implementing the key features of the personalisation agenda.

Personalisation agenda

People are living longer – (85 year olds have increased by a 1/3)
People with disabilities are living longer
HIV+ people increased life expecdencies
Growing number of informal carers
No new monies
Public expectation

Service user consultation

Following a consultation exercise by Krista Lewis with service users in Bolton several key recommendations were made. These have been listed below and a full copy of the report can be found in appendix Y

RECOMMENDATIONS
It is recommended that the following steps are taken to meet the social care needs of people living with HIV in Bolton:

1. At present the need for a Specialist HIV Social Worker still remains.
2. Ensure that people living with HIV have access to welfare rights information and signposting through a variety of service providers
3. The Adult and Community service should consider their role in the establishment of a Bolton peer support group or network for people living with HIV.
4. The Adult and Community Service should investigate ways to enhance their profile of generic and specialist services.
5. There is a need for Bolton Council to conduct a review of their website navigation and content. This information should be used to develop a coherent website that is easily accessible and user friendly.
6. The Adult and Community service should work closely with NHS colleagues working in specialist HIV centres to promote the social care service and establish robust routes of referral.
7. Hospital staff should have a check list for all people living with HIV to include asking the question “Have you any difficulties that a social care service may be able to help and support you with?”
8. The Adult and Community Service should work closely with third sector HIV organisations to ensure that their services are promoted and referrals made as required.
9. The Adult and Community Service should explore accommodation options in which to base the Specialist Social Worker.
10. Procedures must be developed to ensure that during periods when the specialist worker is unavailable clear sign posting enables people living with HIV to get help and support.
11. Adults and Children’s services should examine ways to coordinate the social care needs of families where a member has HIV.
12. Adult and Community Services should ensure that its’ HIV service is inclusive and potential access barriers for service users explored.

Conclusion & Future Recommendations for service provision

The information held within this report indicates that there remains an identified need for services to continue provision to those people infected with or affected by HIV in Bolton. Figures show that year on year there has been a significant increase in the HIV population over the last five years. If this increase continues at the same level then there could be a further predicted rise of over 200% over the next five years.

These figures also show that there has been a decrease within the group men who have sex with men and an increase within the heterosexual group, and linked an increased need to support people with dependent children and a corresponding increase in referrals to Children's services providers. There is also an indicated need for increased services for children infected with HIV as well as those affected, including service links, clearer mapping of care pathway criteria and appropriateness of service

Whilst the figures detail an increase in overall infection rate across all ethnic groups the percentage difference between these groups remain relatively static. It should be noted however that figures from the specialist social work interventions indicate that there is an over-representation from the BME groups compared to the white British population, indicating either an increase level of deprivation within the BME groups or an under exposure / lack of information / need area within the white British population.

The report indicates that there are clear care pathway to and from some of the voluntary service providers and the specialist HIV social worker, but that this could be strengthened to all generic services. This could be promoted through further training.

The provision of a specialist HIV social worker since 2006 has enabled a more direct care pathway to be established from health to social care with the majority of referrals coming from the sexual health clinic. This care pathway needs to be strengthened with clearly defined referral routes, easily accessible information and open access for self referrals. The majority of interventions provided by the social worker also fall within the area of focused, targeted short term work that directly correlates to the inverted triangle model of service provision as well as meeting the expectations of the personalisation agenda.

Due to improvements in treatment options life expectancy within the HIV population has increased bringing a new challenge of increased service provision and complexity as people face the reality of moving towards old age.

Service users who live in Bolton are often unable to access specialist services based in Manchester due to financial difficulties / inequalities. From the service user consultation exercise the need for a peer support group within Bolton has been identified.

As previously discussed to enable current services to be both measured and evaluated the Medical Foundation for Sexual Health (MedFASH) has produced a best practice guide and recommendation for NHS HIV services that includes social care provision. Within the attached appendices these recommendations have been drawn upon to enable a thorough evaluation of current services and where possible to implement measurable targets for future service provision.

These recommendations are detailed below, listed within section 1 of this report as well as within the executive summary.

Recommendations fall under four main headings:

Care pathways

1. Developed care pathways,
2. From this report, the service user feedback and the MedFash recommendations central to all services is the need for clearly defined pathways that enable service user speedy access to the appropriate level of support at the appropriate time.

3. Ensure all agencies have appropriate information and leaflets

4. Improve referral pathway and the profile of the HIV social worker within health settings
5. Specifically there needs to be improved links between health care settings and social care, alongside better defined links with third sector or voluntary agencies.

6. Increase links/ care pathways between paediatric services and HIV specialist social worker
7. Increased level of need for children with HIV indicates a greater need for referral pathways that are accessible and clearly navigated

8. Development of adult and children services working together to support children and there families that are infected and affected.
9. The increased needs of families living with HIV means that greater emphasis should be placed on services to offer joined up, multi-disciplinary action to support these families.

i. Information

10. Information available in common languages and appropriate to different groups.
11. Clearly identified need to ensure access to all population groups within Bolton.
12. Develop improve and simplify the internet and intranet information re HIV/AIDS
13. Improved use of technology to promote services and improve information sharing
14. Increase the profile of all HIV service available to Bolton residents

i. Transparency of service

15. development of recording system and monitoring for people who access HIV social worker in line with local Care first systems
16. Audit the number of people with HIV discharged from hospital who have a planned and documented package of integrated health and social care

17. Re initiate Bolton Sexual health network to over see that outcomes are delivered and to feedback into holistic HIV needs assessment
18. To provide oversight and governance to this area of work and link into the boarder sexual health network.

i. Support

19. Development of services user peer support group
20. Strengthen links with Specialist Social worker across all groups to improve access
21. Voluntary agency have been shown to be beneficial and there has been positive feedback from the services user consultation. It is recommended this continues

Appendices

Appendix 1
Date:01/04/08
Your Ref:COM0308

HIV Social Worker
Royal Bolton Hospital
Bolton Centre for Sexual Health
Minerva Rd
Tel: 01204 390772
Fax: 01204 390755

www.bolton.gov.uk

Dear Service Manager

I am the HIV Social Worker for Bolton Council, we are currently reviewing services to people affected by HIV/AIDS living in Bolton. We want to ensure that we commission and provide patient-centred services in new and innovative ways and we would like to challenge our traditional concepts of service models and delivery.

To carry out our needs assessment and to formulate our plan for the next 3-5 years we will be collecting a range of evidence including public health information with prevalence, incidence, epidemiological and demographic factors. We will also engage with clinicians, services users, and the voluntary sector to develop service models and standards of care to enable integrated, seamless and holistic services to provide requisite care and support in the most appropriate setting to match individual needs.

To enable us to ensure current services are meeting need I would ask that you complete the following for your service:
Questions

1. How many people have accessed your service in the last year (April 2007 / 2008), with a Bolton postcode?
2. How many people have accessed your service in the period (April 2003 / 2008), with a Bolton postcode?
3. Could you provide a breakdown of the above group to include:
    - Gender
    - Age

- Ethnicity
- Residency status
- Number of times the service has been accessed per year by individuals
- How were individuals referred to your service
- Work undertaken with individuals

4. What services do you offer?
5. How do you report / monitor / feedback to Bolton Council ?
6. What issues for commissioning do you see arising for the next 3-5 years with the provision of social care services for individuals accessing your services from Bolton?

I hope the brief outline given is sufficient, however should you have further questions or would like the opportunity to discuss any of the above please do not hesitate to contact me at the above address / number and we can arrange a mutually convenient time to meet / discuss your concerns.

May I take this opportunity to thank you for your time and your continued services to people affected or infected with HIV.

With kindest regards,

Your Name Emma Massey
Your Title HIV Social Work
Direct Line: 01204 390 772

E-mail: emma.massey@bolton.gov.uk

Appendix 2

What is HIV/AIDS and How does it work

HIV - the Human Immunodeficiency Virus - targets the immune system, the very system which would normally defend the body against infections.

The virus attacks a particular type of white blood cells called CD4+ cells. It hijacks the cell, inserts its own genes into the cell's DNA and uses it to manufacture more virus particles. These go on to infect other cells.

The CD4+ host cells eventually die, although scientists do not know exactly how.

The body's ability to fight diseases decreases as the number of CD4+ cells drops, until it reaches a critical point at which the patient is said to have Aids - Acquired Immune Deficiency Syndrome.

HIV is a particular kind of virus – a retrovirus. While simpler than ordinary viruses, retroviruses tend to be harder to defeat.

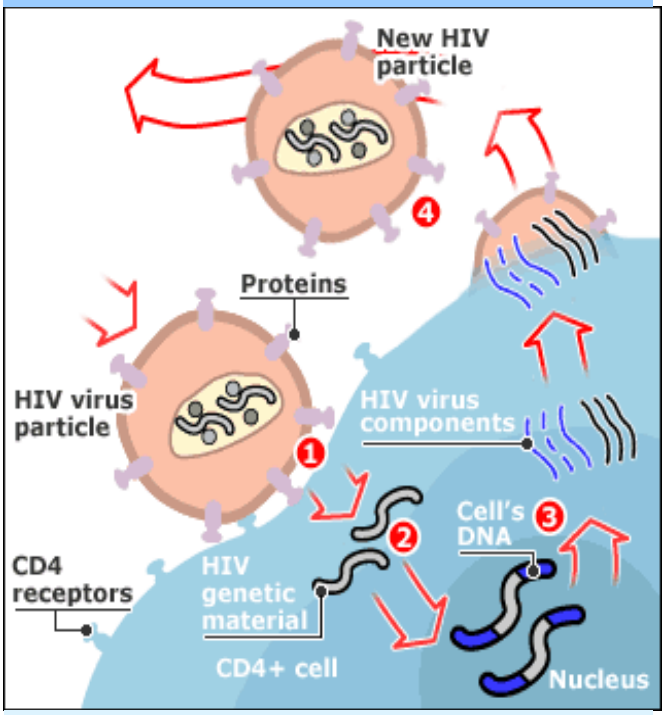
They embed their genes into the DNA of the cells they target, so that any new cells that the host cell produces also contain the virus genes.

Retroviruses also copy their genes into the target cell with a high level of error. In combination with HIV's high replication rate, this means the virus mutates at speed as it spreads.

Furthermore, the "envelope" the HIV virus particle is contained inside is made of the same material as some human cells, making it difficult for the immune system to distinguish between virus particles and healthy cells.

www.bbc.org.uk

HOW HIV REPLICATES



1 **Virus attaches:** Proteins on the HIV virus "dock" with CD4 receptors on the target cell.

2 **Genes copied:** The HIV virus makes a copy of its own genetic material.

3 **Replication:** The virus inserts this copy into the host cell's DNA. When the cell reproduces, it manufactures the parts of the HIV virus.

4 **Release:** The parts are assembled and form a "bud", which breaks off to become a new HIV virus.

Appendix3

Empowering people with HIV - Standard 3

Aim

To facilitate the empowerment of people with HIV to have personal control and choice over the management of their HIV and to enable them to experience the best possible quality of life

Standard 3

All care should take place in a partnership between people with HIV and care providers so that there is joint decision-making and support to adopt and maintain a healthy lifestyle. Services should recognise the impact of HIV infection on an individual and the stigma and social exclusion unique to HIV.

Key interventions	Aims	Current provision	Future recommendations
Culturally appropriate education, information, and peer support can improve knowledge, confidence and psychological wellbeing. This should be multi-lingual where appropriate, tailored to the needs of the individual, and include skills-based approaches.	A local functioning and enabling peer support group Increase the number of services both statutory and voluntary that provide information about the full range of health and social care services. Information / literature available in common languages, relevant to gender, sexuality, minority groups, immigrants	None Leaflet with basic health and social care information, currently available, send to all Health centres and 3rd section agencies, and Bolton centre for sexual health – only in the English language	Development and establishment of services user peer support group Thoroughly developed care pathways, ensure all agencies have appropriate information and leaflets – leaflet available in common languages and appropriate to different groups.

Personal care plans, developed in partnership between themselves and care professionals, can support the empowerment of people with HIV	Robust holistic and self directed care plans	Separate social care plan and medical care plan Joint Care plans with hospital discharges.	Quality audit
Referral pathways which include services to combat social exclusion, as well as directly to tackle health problems, support the individual's ability to self-manage aspects of their condition	Clear pathways which include Local HIV services Regional HIV services (paediatric services) Adult and community services Children Services All specific 3 sectors agencies Local providers (ie housing, disability officers,)	Limited current care pathway.	Implement Robust care pathway to include -Bolton centre for sexual health, -North Manchester general hospital -3rd sector agencies <u>Within Bolton Council</u> Develop clear and simple pathways with referral internet information Redesign of internet and intranet information Increase services user and carers knowledge of all 'Universal Services'

Social care integrated with healthcare for people with HIV - Standard 6

Aim

To maximise the quality of life and value of clinical interventions for people with HIV, by enabling them, their carers and dependants to access a range of social care services which are provided in coordination with healthcare services.

Standard 6

All people with HIV should have access to social care services which are responsive, culturally appropriate and tailored to individual need. All people with HIV requiring multi-agency support should receive integrated health and social care.

Key intervention	Aims	Current Provision	Future Recommendation
• Provision of a range of social care services, responsive to local need, can help people with HIV lead healthier lives and improve their use of healthcare services.	Continue to Monitor funding and commissioning of all services Increase the number of services both statutory and voluntary that provides information about the full range of health and social care services in Bolton including: -Health -social care -3rd sector organisation Information / literature	Quarterly information is provided from all commissioned services excluding HIV social workers post Some information / leaflets available–predominately provided in English.	Development of recording system / monitoring for people who access HIV social worker in line with local council current systems. Provide multi-lingual leaflets / information with details of current services. As above

	available in common languages, relevant to gender, sexuality, minority groups, immigrants		
• Providing health and social care services for people with HIV in an integrated way can improve the effectiveness of both, resulting in better health outcomes.	Provide holistic Care, health and social care service for people with HIV	Co- located health and social care.	Improve referral pathway and the profile of the HIV social worker from health setting
• Single points of access for the full range of health and social care services, as well as single health and social care assessments of individual need, can improve the integration of service provision for people with HIV.	All services need to have a full understanding or easy access to HIV service provision	Some service/ department are very well informed of HIV services – others have a patchy knowledge. Internet and local intranet needs to be updated and the information updated and easy to access	Improvement of referral pathways Increase the profile of all HIV service available to Bolton residents Develop improve and simplify the internet and intranet information re HIV/AIDS
Integrated assessment of health and social care needs at the time of hospital discharge can improve the subsequent uptake of services and quality of care (see also Standard 11).	Joint holistic hospital discharge planning	Current multi disciplinary team care planning on discharge from hospital.	Audit the number of people with HIV discharged from hospital who have a planned and documented package of integrated health and social care

Care of families with HIV - Standard 9

Aim

To enable families affected by HIV to receive coordinated treatment and care services focused on their family needs.

Standard 9

Children, their families and carers should have access to specialist adult and paediatric multidisciplinary care including community care and support.

Key intervention	Aims	Current Provision	Future Recommendation
Provision of multidisciplinary, multi-agency family services can ensure high quality care to meet complex needs in settings which ensure confidentiality for individuals and their families.	To provide holistic services to families who are impacted upon by HIV/AIDS Including health social care and 3rd sector agencies	North Manchester specialist paediatric services. HIV social worker, to support adult family member and Carer Child focused work provided by Barnardo's health through action. Other 3rd sector agencies provide support to adults in family groups	Increase links/ care pathways between paediatric services and HIV specialist social worker Clear links between adult and children services working together to support children and their families that are infected and affected.
Integrating the provision of	Clear and robust care	Provision of specialist HIV	Increase knowledge of current

social care with healthcare, including specialist social services provision within established family clinics, can help meet the multiple needs of families affected by HIV.	pathways referral route from specialist centre's and local provision.	social work post Some service/ department are very well informed of HIV services in Bolton – others have a limited knowledge. Internet and local intranet to be updated with improved updated access	service provision On going audit of Social work provision Develop improve and simplify the internet and intranet information re HIV/AIDS
A life span model of family care, provided by a multidisciplinary team, can respond to changing needs over time and allow transitional care as children move to adolescent and adult services.	A clear progression and transition through appropriate services.	Sporadic use of multi disciplinary team working across adult and children services.	Explore and develop ways in which adults and children services can. Improve working across adult and children's services.

Appendix 4

George House Trust

Additional narrative information required in the Greater Manchester commissioners group monitoring pro-forma.

Quarter 1 – 2008-2009

M	•	Evidence of:
	-	**Partnership Working.** George House Trust continues to work closely with our statutory sector partners across the county and region. This includes participation in the Board of the Sexual Health Network (and all three sector boards and a number of thematic working groups); together with a number of sexual health and HIV joint groups across the area. Between GHT, the Lesbian and Gay Foundation and Barnardo's Health Through Action Project we ensure that the voluntary sector is represented on every working group of the Network. The partnership working on children with and affected by HIV with Barnardo's Health Through Action has continued to bring significant benefits for service users. We are able to offer crèche coverage during appointments at GHT for parents of young children in addition to the regular crèches at our women's and African services. We have worked with a wide variety of partners to develop an appropriate public response to criminalisation of HIV transmission. Discussions have commenced with Sahir House in Liverpool regarding partnership working to deliver newly diagnosed and gay men's residential courses in the Liverpool area. Discussions have commenced with Signposts, a voluntary organisation based in Preston, regarding partnership work in Lancashire. In addition we are already working with the CAB in East Lancashire to improve our service provision in this area.

	-	**Service User involvement. (e.g. how have service users been involved in identifying unmet need, service development/planning?)** During the period, a presentation was given to each of our group services to inform service users of all the options of how to get involved with the organisation. This included participating in focus groups, becoming a member and attending the AGM, and becoming a trustee. We have updated the criteria on becoming a member and this has been published on our website. We worked with Manchester PCT to host a service user consultation on the new sexual health pathway, which had over 40 attendees. This was then followed up with a consultation at our African group which had over 30 attendees. We commenced a service user survey in March 2008. The results of this survey will be published shortly. The Service Monitoring and Review Team (SMART) meet on a monthly basis. The aim of the group is to include a broad representation of service users who then meet to scrutinise service delivery. The meeting is convened by the Director of Services, chaired by the Vice Chair of the Trustees, and findings are reported directly back to the Board of Trustees. Quarterly consultation events continue to be a regular feature at four GHT in-house groups – gay men, women, African and Saturday space. These will feed into future service evaluations and plans. We have a 'Suggestion Box' in reception to encourage feedback and suggestions. In addition we are in the process of reviewing innovative feedback options for example interactive notice boards or weekly survey questions via the website. We continue to be involved in the "Engagement and Involvement" Priority Action Group within the Greater Manchester Sexual Health Network Board.
	-	**Quality Assurance feedback.** There are no specific quality assurance issues to report.

M	•	**Provide details of any problems once services are accessed.** No specific issues to report this quarter.
O	•	**Response Times: Indicate if the agreed response times could not be met during the monitoring period, and what alternative arrangements were made for the service users. (Against service specification)** No issues to report this quarter.
M	•	**Availability of the service: Confirm the days and times the service is available.** **One-to-One support / telephone advice** - Monday 9.00am – 8.00pm; Tuesday – Friday 9.00am – 5.00pm. **One-to-One support and advice (outreach services)** - North Manchester General Hospital (IDU) Fridays 9.30am-12.30pm - Manchester Royal Infirmary Monday 1.30pm – 4.30pm - Salford Hope Hospital Alternate Tuesdays 9.30am-12.30pm **Specialist Advice and Information** – - Welfare Rights 10.00am-12.00pm Thursday and 2.00pm-4pm Monday - Money Advice 10.00am-12.00pm Thursday and 2.00pm-4pm Monday - Immigration Advice (standard office hours above) - treatment advice (standard office hours above) **Volunteer Support** - permanent – evening/weekends/on demand etc **Counselling** - external counsellors 1.00-5.00pm Wednesday and 2.00-4.00 on Thursdays and 10.00-2.00 on Fridays. - internal counsellor (standard office hours above) **In-House Peer Support Groups/Spaces** Gay Men – 4.00-8.00pm Mondays Women – 12.00noon – 3.00pm Alternate Tuesdays (with Creche) African – 12.00noon – 3.00pm Alternate Tuesdays (with Creche) "Saturday Spaces"– 11.00am – 4.00pm once a month on Saturdays **Information** - Insight mailout (quarterly) - Email mailouts c fortnightly. - Web-Site – 24/7 - Information Centre (standard office hours above) - Information in the post (by request) - Information sessions (quarterly – evening) **Financial Support** - emergency payments 9.00am – 5.00pm Mondays – Fridays - standard payments/CRUSAID applications etc – standard office hours above **Events and Courses** occasional as advertised (mostly weekend and evening)

M	•	**Publicity: Report on methods used to publicise the service during the monitoring period.** We are currently working on an updated version of our website to help promote our services. This will be relaunched in August 2008. This is based on service user feedback and research of other websites. In the meantime our website continues to be well used and contains full details of all GHT services and services provided by other agencies (statutory and voluntary). The website includes information on services in French and Spanish. We produced a new volunteer leaflet in the period which will be used to encourage people to volunteer for the organisation. Our 2008 edition of our popular Services Directory, "HIV Services in the North West". This, together with accompanying posters and specific leaflets for gay men and African people have been made available comprehensively across the region at appropriate venues, clinics, CAB offices, housing offices, voluntary organisations and selected GP surgeries. It is also circulated to over 800 people with HIV who we have permission to send mail to. Our quarterly publication "Insight" is distributed extensively across the region and includes updates on our services and information. George House Trust contracts with the Lesbian and Gay Foundation to have three HIV pages in its monthly publication "Out North West" which we use to give information about GHT services and updates on HIV related information topics.
M	•	**Unmet need: Have you been unable to offer services or had to refuse to offer services to any particular user? If yes please provide details.** No specific issues to report in the period.

3. Organisational information:

M	i	**Have there been any significant changes to the organisation (If so give details)** No.
M	ii	**Has there been any changes in the manager(s) of the service (If so give details)** No.
M	iii	**Has there been any changes in the management structure (If so give details)** No.

O	iv	**Have you experienced any problems with receiving payments?** No
M	v	**Provide details of any financial issues you wish to be brought to the service purchaser's attention.** We continue to impress upon commissioners across Greater Manchester the need to move towards a three-year contract approach, as this will deliver benefits to both parties in terms of future service planning and provision.
M	Vi	**Provide a copy of your organisations full income and expenditure accounts (for the previous financial year). (Required in monitoring for the 2nd Quarter)** Provided.
M	vii	**Do you still comply with the insurance requirements set out in the contract relating to the service (State renewal date)** Yes. Insurance renewal is each January.
O	viii	**Give details, including your subsequent actions, of all accidents and incidents relating to users and workers in the monitoring period.** None to report.
O	ix	**Complaints and Compliments: Give details of any complaints / compliments received during the monitoring period and the outcomes (If there has been no complaints please say so).** No significant complaints to report.
M	x	**List of your policy and procedures and the date they were created or last updated. (Required for the first monitoring period)** Equal Opportunities Policy Health and Safety Induction and Training Quality Assurance (Statement) Record Keeping Complaints Financial Standing Orders Involvement with Money Child Protection Vulnerable Adults Volunteer Policy Trustees have recently approved two new policies: HIV Policy Disability Leave Policy

	xi	**Have you got a Child Protection Policy and Procedure?** Yes

4. Workforce Requirements

M	I	**Provide the number of staff including volunteers involved in delivering the service during this monitoring period.** 16 WTE staff 100 + volunteers
M	ii	**Indicate if the agreed staffing level for any service could not be met during the monitoring period and what alternative arrangements were made for the service users.** No issues to report.
M	iii	**Indicate any specific HIV or other training provided for / attended by staff during the monitoring period.**
M	iv	**List of all staff turnover in monitoring period.** None
M	v	**During the monitoring period how have you promoted the protection of children and service users e.g. CRB checks, specialist training etc.** All volunteers and staff who work with children are CRB checked. We work closely with Barnardo's Health Through Action project who advise us on child protection issues and provide information and training as appropriate. We have a policy for CRB checking of volunteers who work with vulnerable adults. All volunteers who have unsupervised access to vulnerable adults (volunteers providing community support and volunteers who are drivers) are taken through a CRB process that we have arranged with a CRB umbrella agency (Manchester Metropolitan Community Church).

Appendix 5
Barnardo's Health Through Action Project
Information for Bolton Council - Barnardo's Service for families living with HIV

Family One - BL2 6E2

Referred on 1.06.04 by North Manchester General Hospital- Ian Nixon- Specialist Nurse.
15 year old HIV+ve young person. Black African. UK resident (no immigration issues)
Parents dead. Living with aunt, 2 sisters and 4 cousins.
During the period April 2007- March 2008 - 61 contacts are on file. This includes :
6 one -to -one sessions for young person with Barnardo's social worker
Attended 6 sessions of peer support group
Attended UK weekend residential in Norfolk for HIV+ve young people. Escorted to and from event by Barnardo's.
Attended Barnardo's summer residential for HIV+ve and affected young people
Attended Alton Towers Consultation event facilitated by Barnardo's (18 +ve young people from North West) met with doctors and commissioners to discuss needs and experiences of treatment centres.
Attended Elton John AIDS Foundation consultation with young people in London. Escorted to and from London by Barnardo's worker.
Barnardo's worker accompanying and being present at 2 hospital appointments at NMGH- on behalf of aunt and with agreement of young person.
Barnardo's worker supported him and escorted him to London to give a presentation at a National Conference 'Alive and Kicking'
Support with DLA forms
Liaison with aunt and young person
Supporting aunt through significant difficulties and her own ill-health.
Financial support of £450 for the family to fund air fare to Africa to enable young person to visit parents' graves and meet grandfather.

Family 2 – BL1 3US

Referred on 3.05.07 by GHT
HIV+ve Black African father living with one child. Refugee status. Financial problems.
During the period April 2007- March 2008 - 6 contacts on file.
This includes carrying out assessment and inter- agency liaision. Other agencies involved include Refugee Action and Emma Massey.
As father is not wanting Barnardo's input on HIV ie does not want son to know, limited services Barnardo's can offer so guidance given to GHT and to father about how to get the support they require.

Family 3 – BL3 4HS

Self- referred on 26.01.05
HIV+ve Black African mother with 2 children. Leave To Remain
Previous very high level of contact however once statutory mental health and children's services become involved, Barnardo's reduced contact.

During the period April 2007- March 2008 - 16 contacts on file.
This includes laision with mental health services, children's services and Dallas Court(reporting centre) and GHT.
Financial support of £150 for freezer and bedding
2 outreach family support visits

Family 4 – BL3 2RU

Referred by George House Trust on 22.09.05
8 year old HIV+ve black African girl living with sister and grandparents. Leave to Remain.
Mother has died.
During the period April 2007- March 2008 - 29 contacts on file.
This includes liaision with solicitor and North Manchester Treatment Centre.
Older sister funded and supported by Barnardo's to attend summer residential holiday run by YHA.
Financial support of £250 from Barnardo's in house funds for clothes and equipment
OIder sister attended 3 sessions of Barnardo's Young Careres group.
Campaigning work by Barnardo's resulted in family gaining leave to remain.

Family 5 – BL5 2SA

Referred on 2.02.07 by Dr Wilkins at North Manchester General Hospital
HIV +ve 11 year old boy of dual heritage (white/African)_living with HIV+ve parents and brother. UK residents. No immigration issues.
During the period April 2007- March 2008 - 41 contacts on file. This includes
Attended 6 sessions of children HIV peer support group
7 Home Visits including support for parents and 1-1 sessions with child
Liaison with North Manchester General Hospital
Support for child and family when admitted to hospital
Contributed to World AIDS Day Display at North Manchester General Hospital
Attended Alton Towers Consultation event facilitated by Barnardo's (18 +ve young people from North West) met with doctors and commissioners to discuss needs and experiences of treatment centres.

Family 6 - BL2 6HB

Referred on 31.01.07 by Dr. Tan at North Manchester General Hospital

HIV+ve child (12 months old) living with HIV+ve father. Black African. Leave to Remain.
Mother died January 2007.
During the period April 2007- March 2008 - 21 contacts on file. Since April 2008 a very high level of input given to family. This includes
Completion of assessment.
Family Support and liaison with father- often at hospital
Liaison with CAB, North Manchester General Hospital, Booth Hall, Bolton Hospital, Immigration Aid (re family reunification as one child still in Africa) GHTetc.
Financial support of £350 from Barnardo's In house funds for baby equipment and clothes following discharge of baby from hospital.

Family 7 – BL1 5TE

Referred on 16.05.03 by Ian Nixon, HIV specialist nurse at North Manchester General Hospital

HIV +ve 16 year old Black African girl living with HIV+ve parents. Now have Leave to Remain.
During the period April 2007- March 2008 - 49 contacts on file. Additionally 42 e- mail contacts with or about this family. This includes
2 one -to -one sessions for young person with Barnardo's social worker
Attended 6 sessions of peer support group
Attended 3 consultation sessions including contributing to clinical research, focus group by UK Coalition on AIDS and Bolton PCT reserach into needs of young people. sessions including contributing to
Attended Barnardo's summer residential for HIV+ve and affected young people
Attended Alton Towers Consultation event facilitated by Barnardo's (18 +ve young people from North West) met with doctors and commissioners to discuss needs and experiences of treatment centres.
Attended Elton John AIDS Foundation consultation with young people in London. Escorted to and from London by Barnardo's worker.
Liaison with North Manchester General Hospital
Liaison with GHT and Emma Massey
Almost weekly e mail correspondence and 11 office visits from parents in connection with lack of benefits, and application for leave to remain. Following leave to remain, focus moved to support with family reunification and transition to refugee status.
Parents contributed case study material for article in Community Care and poverty report re asylum seekers carried out by Barnardo's national research and policy unit.
Parents met with Cherie Blair and Martin Narey (chief executive of Barnardo's) at the project's centre.
Financial support of £250 from Barnardo's in house funds and frequent food parcels to subsidise this family's living costs – while awaiting outcome of application under Human Rights legislation the family was supported by Bolton MBC on vouchers at below poverty levels.

Family 8 – BL4 9RF

Referred on 30.03.06 by George House Trust
HIV+ve white UK parents living with 2 boys aged 10 and 12 years.
During the period April 2007- March 2008 – 35 contacts on file. This includes
2 individual support sessions with the children.
3 office visits by mother
Children attended 4 sessions of children's peer group.
12 year old was financially supported to attend YHA residential holiday.
Liaison with mental health professionals
Management of safeguarding issues
Referral to Baranrdao's Young Carers Project in Bolton.

Family 9 – BL3 6QZ- New Referral

Referred on 7th May 2008 by Dr Toni Tan, North Manchester General Hospital
HIV+ve Black African 13 year old boy living with HIV+ve mother and 10 year old brother.
Family in UK on student visa.
New referral with request to support mother share HIV information with son.
Assessment scheduled to look at needs and plan work.

Financial Issues

During 2007/2008, Barnardo's received £1, 590 from AIDS Support Grant to run this specialist HIV service. £1,200 was spent on the travel costs of staff visiting Bolton or funding the travel costs of children attending peer support groups.

The service has worked out unit costs of £3059 per family to reflect the costs of Barnardo's providing a service. A minimum of £24,000 is needed to support this service.

The actual cost of providing support in Bolton is higher than most other LAs due to the following factors:

- the high numbers of HIV+ve children in Bolton which results in take up of specialist services (peer support, residential holidays, involvement in consultations, liaison with health, support to parents around disclosure and one to one work with children)

- the additional costs of staff travel to Bolton and organising transport for children to attend peer groups and be returned home safely etc.

Question 5

Every year I complete a detailed and time consuming monitoring return to Bolton (Andrew Walton and Paul Hands Griffiths) where I raise issues about lack of financial support and detail the number of contacts we have had per family. No contract meetings or links with children's services exist – however these are welcomed.

Question 6

I think the most significant issue is the increase in HIV+ve children and the specialist services they require as they progress through adolescence e.g. non adherence to medication, good sexual health, prevention of onward transmission of HI

Lesbian Gay Foundation

LGF service	**Number of people accessing from Bolton 07/08**
LGF sexual health outreach clinic	11
Face to Face Counselling	12
Helpline (0845 3 30 30 30)	28
Group work, includes: **Carousel:** A social group for lesbian & bisexual women. First, third and fifth Tuesday. **Stepping Stones:** A support group for lesbian and bisexual women. Second and fourth Tuesday. **Married Men's Group:** A support group for men, who are in relationships with women, but have feelings for men. First and third Tuesday. **40+ Gay Men's Group:** A social and support group for gay and bisexual mean. Every Thursday night. **LGBT Black Group:** A support and social group. Last Thursday every month. **LGF Art Class:** A group for lesbian, gay and bisexual people who would like to do some art. No experience required. All materials provided. Every Friday.	41
Other resources	
Out North West magazine – Monthly magazine produce by LGF	3200 copies
Info and other resources including: • Your Guide to the LGF • A Guide to your Rights • Civil Partnerships • The Good Sexual Health guide – for guys and girls • The F**K Stops With You – Information on HIV • Beating Around the Bush –	3635 copies

Lesbian and bisexual sexual health. • The good Mental Health Guide • LGB Use Safely – Your guide to safer use of drugs and alcohol • LGB Smoke Free – Your guide to a Healthier Lifestyle • LBG Youth Matters – A guide for young people and workers	
Condom and Lube Distribution Scheme (CLDS)	Not funded to provide CLDS

The LGF outreach clinics are held in Manchester city centre and Chorlton. The four locations are:

1. H20 sauna: Under Clone Zone, 36 – 38 Sackville Street. M1 3WA (The Gay village)

2. The Rembrandt: 33 Sackville Street, M1 3LZ (Canal Street)

3. HEAT sauna – 496A Wilbraham Road, Chorlton, M21 9AS

4. Basement sauna: 18 Tariff Street, Northern Quarter, Manchester, M1 2FN

FINDINGS FROM A CONSULTATION EXERCISE HELD WITH BOLTON RESIDENTS LIVING WITH AND AFFECTED BY HIV.

SUMMARY
The social care needs of people living with HIV have changed significantly over the last five to ten years due to improvements in medical interventions. People are generally living longer more healthy lives and the need for intensive social care support has reduced dramatically.

Bolton Adult and Community Services have commissioned this report as part of their Social Care Needs Assessment for people with or affected by HIV/AIDS. The purpose of which is to influence the development and commissioning of service provision to meet individual need for the next three to five years.

This piece of work presents findings from a consultation exercise with service users and potential service users designed to assess their future social care needs. The work included three distinct phases, postal and telephone interviews with people living with HIV, a consultation event held in Bolton and an investigation of ease of access for potential service users into Adult and Community Services and the Specialist HIV Social Worker.

In total 20 people took part equating to 9.6% of the total number of Bolton residents living with HIV.

There are 11 important issues to emerge from this work that require attention. The main finding is that people want a local peer support network to be established.

Key recommendations from the consultation are summarised below:

RECOMMENDATIONS
It is recommended that the following steps are taken to meet the social care needs of people living with HIV in Bolton:

1. The need for a Specialist Social Worker to assess and support the needs of people living with HIV still remains.
2. The Specialist Worker should consider their role in the establishment of a Bolton peer support group or network for people living with HIV.
3. The Adult and Community Service should investigate ways to enhance their profile of generic and specialist services.
4. Bolton Council to need to conduct a review of their website navigation and content and use this information to develop a coherent website that is easily accessible and user friendly.
5. The Specialist Social Worker should work closely with NHS colleagues working in specialist HIV centres to promote the social care service and establish robust routes of referral.
6. Hospital staff should have a check list to include asking the question “Have you any difficulties that a social care service may be able to help and support you with?”
7. The Specialist Social Worker should work closely with third sector HIV organisations to improve referrals and ensure that their service users are aware of the services provided by the Specialist Social worker and Adult and Community Services.

8. Adult and Community Services should explore accommodation options in which to base the Specialist Social Worker.
9. The Specialist Social Worker should establish procedures to ensure that during periods when the worker is unavailable there is clear sign posting to enable people to get help and support.
10. Adults and Children's services should examine ways to coordinate the social care needs of families where a member has HIV.
11 The potential access barriers for service users who have different cultural and language needs should be explored to ensure that the HIV service is inclusive.

CONSULTANCY TASK

To determine the social care needs of people with or affected by HIV in order to inform Bolton's Social Care Needs Assessment which will influence the development and commissioning of future service provision. This piece of work takes the form of direct consultation with Bolton Residents aged 18 and over who have or are affected by HIV/AIDS. This may include parents and carers of children with HIV.